# Speaker Profiles and Abstracts

Abstracts are listed in chronological order.

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

*Outcomes for specialist mental health service users with intellectual disability and autism*

Background: Previous research has found that many people with autism have poor quality of life and that lower IQ or functioning significantly predicts poorer adult outcome. However, few studies have focussed specifically on adults with low-functioning autism or directly compared adults who have intellectual disability with and without autism.

Method: A cross-sectional study included 98 participants from a community-based, specialist mental health service for adults with intellectual disability in London, UK. The presence/absence of autism was confirmed using the Autism Diagnostic Observation Schedule.

Results: Participants with intellectual disability and autism had lower levels of specialist mental health service use over 12 months despite have higher levels of need, poorer mental health and poorer social outcomes compared to those without autism. A range of other socio-demographic and clinical variables were taken into account using regression analyses. The results indicated that service use, needs and social outcome were significantly predicted by severity of intellectual disability and not the presence of autism. The assessments carried out for the study provided evidence that a high proportion of specialist mental health service users with intellectual disability have undiagnosed autism or unrecognised autistic behaviours.

Conclusion: Previous findings from non-clinical samples of adults with autism appear to hold true for adults with intellectual disability who receive specialist mental health services. However, this study provided evidence that intellectual functioning may be a more important predictor of adult outcome than autism itself. More research is needed to determine whether this is the case across the spectrum of autism disorders.

*Health and well-being across the lifespan, Research / academic, Paper*
*Thursday 8 November, 10:15am - 10:45am, Main Auditorium*

**Espiner Deborah** (University of Auckland, d.espiner@auckland.ac.nz), **O' Brien, Patricia** (Centre for Disability Studies, University of Sydney)
Non-presenting authors: John Kubiak, Tutor, National Institute for Intellectual Disability, Trinity College Dublin; Barrie O' Connor, Formerly Associate Professor, Griffith University, Australia (Former Marie Curie Research Fellow, NIID, TCD)

*The three C's of inclusion within university settings: Choice, Commitment and Capacity*

Background: The United Nations Convention for the Rights of Persons with Disabilities (2006), specifies that all persons with disabilities have the right to an inclusive education system at all levels. Whilst increasingly students with disabilities are receiving an inclusive education in early childhood, primary and secondary educational settings they are still under-represented in third level or tertiary settings. Enrolments of students with disabilities in post-secondary settings are still considerably lower than enrolment amongst the general population (Wehman, 2001). Aim: The purpose of this study is to explore the perceptions of students, lecturers, and mentors who participated in a project that saw the inclusion of students with intellectual disability across a range of classes within an undergraduate degree programme at Trinity College Dublin. In exploring such participation the study aimed to identify the drivers and barriers of such inclusion. Method: An interpretative approach was taken that saw a range of tools being used that included focus groups, questionnaires, and

participant observation. All three participant groups were probed on their personal experience of being involved in the undergraduate classes. Findings: The three major themes that emerged were Choice, Commitment and Capacity. The multi-faceted nature of these themes reflecting the weaving of perceptions of all three participant groups will be exemplified. Discussion: An interdependent framework of inclusion will be proposed as a means of ensuring that students with intellectual disabilities experience university with required levels of support. Drivers and barriers of the model will also be outlined.

Easy English Abstract:

This paper will describe what it was like for a group of students who attended a university course in Dublin, Ireland. The students were supported by mentors to help them with their learning. We will discuss what the students, the mentors and lecturers reported about attending class.

*Values into practice, Research / academic, Paper*
*Thursday 8 November, 10:15am - 10:45am, Civic 1*

**Bigby, Christine** (LaTrobe University, Living with Disability Research Group, c.bigby@latrobe.edu.au)
Non-presenting authors: Dr Julie Beadle-Brown, Tizard Centre, University of Kent & LaTrobe University; Dr Emma Bould, LaTrobe University

*Implementing Active Support with people with more severe intellectual disability. Findings from a longitudinal Victorian Study*

Aims: Three decades research has found two factors that explain the quality of life of people with intellectual disability: the level of ability of the person and whether staff enable them to be engaged in meaningful activities and relationships. Active support has been adopted by various organisations in Victoria but there is little evidence about its implementation. Methods: This paper presents data at two points, 12 months apart on the characteristics, quality of life and quality of support experienced by 138 people with intellectual disabilities supported in shared accommodation provided by six organisations. Data were collected using observational methods and staff rated questionnaires. Findings: On average little significant change occurred in the quality of support or resident engagement between Times 1 and 2. Staff contact, assistance and active support remained weak particularly for people with more severe disability. Slight improvement occurred in two organisations across a range of measures. Average time that residents were engaged increased from 61% to 66%, was greatest for those with less severe disabilities and occurred without increased staff assistance. In the organisation where active support was highest there were no differences in engagement between residents of different ability levels, and a different pattern of engagement was observed. Conclusions: The findings suggest in two organisations opportunities has increased for residents with less severe levels of disability to be engaged but staff and organisations continue to struggle to implement active support for people with more severe levels of disability. The paper will discuss the possible reasons for these findings that relate to staff attitudes and organisational factors

*Values into practice, Research / academic, Paper*
*Thursday 8 November, 10:15am - 10:45am, Civic 2*

**Attwell, Ally** (Voice Thru Your Hands Charitable Trust, ally@voicethruyourhands.org.nz), **Rickard, Debbie** (Voice Thru Your Hands Charitable Trust; Education Advisor, debbie.rickard03@gmail.com)

*Tarryn - Our Guiding Light*

Tarryn is a year 8 student with Down syndrome who is hearing but has difficulty with speech. She is fully mainstreamed at her local school, attends a number of community activities, and has a strong friendship group. None of this would have been possible without communication. Using Maslow's hierarchy of needs we will demonstrate how Tarryn has overcome her communication barriers through the use of New Zealand Sign Language (NZSL) to engage meaningfully in her community. Through Tarryn's successful journey towards independence the non-profit organisation Voice Thru Your Hands (VTYH) was born. VTYH promotes the importance of Visual Communication and New Zealand Sign Language (NZSL) for children. NZSL became an official language of New Zealand on 6th April 2006 and is the language of the Deaf community. VTYH is of the view that it also benefits hearing children who have difficulty with speech - like Angelman syndrome, Down syndrome, Autism and many more.
As the organisation's ambassador, Tarryn demonstrates to others what is possible.
Easy English Abstract:
Tarryn is a year 8 student with Down syndrome who can hear but has difficulty with speech. She is fully mainstreamed at her local school, attends a number of community activities, and has a strong friendship group. None of this would have been possible without communication. Using Maslow's hierarchy of needs we will demonstrate how Tarryn has overcome her communication barriers through the use of New Zealand Sign Language (NZSL) to engage meaningfully in her community. Because of Tarryn, a new organisation started, called Voice Thru Your Hands (VTYH.) VTYH promotes the importance of Visual Communication and New Zealand Sign Language (NZSL) for children. NZSL became an official language of New Zealand on 6th April 2006 and is the language of the Deaf community. VTYH believes i also helps hearing children who have difficulty with speech.
As the organisation's ambassador, Tarryn demonstrates to others what is possible.
*Values into practice, Lived experience (self advocate, family), Paper*
*Thursday 8 November, 10:15am - 10:45am, Civic 3*

**Toth, Anne** (Canadian Association of the Deaf, DrAnneToth@rogers.com)

*Bridge of Signs: Can sign language empower non-deaf children to triumph over their communication disabilities?*

This pilot research project examined the use of sign language as a communication bridge for non-deaf children between the ages of 0–6 years who had been diagnosed with, or whose communication difficulties suggested, the presence of such disorders as Autism, Down Syndrome, Fetal Alcohol Spectrum Disorder (FASD), and/or learning disabilities. Teaching staff, speech language therapists and parents noted that hearing children who used the Bridge of Signs model experienced language development with sign language and, in some cases, went on to use that foundation as a bridge to speaking the oral language of their caretakers. Though deaf children who used the model were more likely to have been exposed to sign language and its use, they still showed improvement in vocabulary acquisition and production. Future development and application of this model will benefit from quantitative and longitudinal study.
*Values into practice, Practice, Paper*
*Thursday 8 November, 10:15am - 10:45am, Square Affair*

# asid

# Let's talk -
# Self Advocacy Forum

10.30am – 4.10pm

Hosted by leaders of People First New Zealand Inc. Nga Tangata Tuatahi

Leaders are: Caroline Quick, Alex Snedden, Kayla Le Gros, Michael Aldridge, Robert Martin, Hamish Taverner

**Let's talk** is a great opportunity for **people with intellectual/learning disability** to talk with each other about topics that are important to them. The participants will discuss topics and create key messages and challenges which will then be presented to the main audience of the conference.
Topics covered will include:

- The United Nations Convention
- What does a good life mean to me?
- Friends and relationships
- Making my decisions
- Real work, real pay
- Being in community
- My money
- The right support

**Key message and challenges will be presented by the leaders to the main conference participants in the main auditorium at 4.10pm**

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**Oxnam, Paul** (Queensland Forensic Disability Service, paul.oxnam@gmail.com), **Gardner, Emma** (Clinical Psychologist, emma_willcock@yahoo.com), **Turish, Teresa** (Capital & Coast DHB, teresa.turish@ccdhb.org.nz), **Watson, Jared** (Capital & Coast DHB, Jared.watson@ccdhb.org.nz), **Malcolm, Sandra** (Capital & Coast DHB, sandra.malcolm@ccdhb.org.nz)

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

**Attendance for this sold out workshop is via pre-conference registration only.**
Developed by Paul Oxnam and his colleagues at Te Korowai Whariki – the Central Region Forensic Mental Health, Rehabilitation and Intellectual Disability Service, Stepping Stones is a 42-week emotion regulation, communication and social skills group therapy programme specifically designed for people with an intellectual disability.

Since its inception in 2008, Stepping Stones has evolved to meet the requirements of forensic and non-forensic clients in community and inpatient settings in New Zealand and Australia. Clients engaged in Stepping Stones complete a series of 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.

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. 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. Ref: Oxnam, P. and Gardner, E. (2012). Stepping Stones – A group therapy programme for the treatment of emotion regulation difficulties in offenders with an intellectual disability. *Journal of Learning Disabilities and Offending Behaviour*, 2, (4), 146-151.

This highly practical four-hour workshop would suit clinicians working with groups of forensic and non-forensic clients who reside in both inpatient and community settings. Attendees will be provided with the knowledge and resources required to implement and facilitate Stepping Stones in their own services. Following the workshop, attendees will receive access to the programme manuals and remote support to negotiate the logistical challenges and therapeutic trepidations associated with setting up a group treatment programme.

Easy Read Abstract:
Developed by Paul Oxnam and his workmates at Te Korowai Whariki – the Central Region Forensic Mental Health, Rehabilitation and Intellectual Disability Service, Stepping Stones is a 42-week group therapy programme for people with an intellectual disability who have trouble managing feelings like anger, sadness and worry.

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.

Clients who have completed Stepping Stones don't go off as often as they used to. This means that they feel better about themselves, get on better with care staff, and get to do more 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 cope with problems that might come up in the future.

This four-hour workshop is for staff who work with groups of clients who live in hospital or in the community. People who attend the workshop will learn how to set up and run Stepping Stones

programmes in their own services. Attendees will get copies of the Stepping Stones manuals and support from the facilitators to work through some the hard parts of setting up a group treatment programme.
*Thursday 8 November, 10:15am – 4:05pm, Renouf 1*

**Marlow, Sue** (WelTec, sue.marlow@weltec.ac.nz)
Non-presenting author: Denise Walsh, Te Omanga Hopsice, Home Care Co-ordinator, Denise.Walsh@teomanga.org.nz

***Win – win - win: Strengthening collaboration between Te Omanga Hospice and intellectual disability support services through research based practice development***

This presentation will focus on the provision of equitable access to person-centered palliative care services for individuals who have an intellectual disability and are dying.
A brief overview will be given of a research project which revealed the lived experiences of people who had supported a family member with an intellectual disability when they had been dying in a community setting. The guiding principles of palliative care and the Te Omanga Hospice home care delivery model will then be introduced.
The presenters will show how the experiences shared by participants in the research project led to practice development recommendations. Examples of how resulting initiatives have continued to evolve based on the subsequent dialogue of those receiving and delivering collaborative care from the hospice and intellectual disability support services will also be outlined.
The presentation will conclude with a discussion of how the enactment of specific initiatives has enhanced the wellbeing of individuals with intellectual disabilities who have been on the Te Omanga Hospice homecare programmes while continuing to live in their own supported care environment. Benefits gained by the whanau, friends and support workers who have been involved will also be described.
Easy English Abstract:
Win – win - win: The nurses at a Hospice have found ways to work closely with support workers. This has created a strong team which can give good care at home to people who have an intellectual disability and are dying.
The speakers will talk about the right of people with intellectual disabilities to get good care and support if they are dying. They will describe to you what some people said it had been like caring for someone in their family with an intellectual disability when they were dying.
You will be told how the nurses at the Hospice learnt to work more closely with support workers. This has given people with intellectual disabilities who are dying better hospice care at home. Their partners, family, flatmates and the staff who support them at their houses liked knowing more about how to help.
*Health and well-being across the lifespan, Practice, Paper*
*Thursday 8 November, 10:50am – 11:20am, Main Auditorium*

**Peden, Susan** (Disability Services Commission WA, Susan.Peden@dsc.wa.gov.au)
Non-presenting author: Jacki Hollick

***A process of innovation and cultural change across Western Australia in supporting people with challenging behaviour***

Background: A sector wide strategy, the Positive Behaviour Framework responds to the needs of people with disability with challenging behaviour, their families/carers and support workers.
It aims to extend the reach of services in a coordinated and consistent way through extensive cultural and organisational change.

Method: A change process was adopted to influence change, which reflects the 'scaling up' approach referred to in Eric Emerson's and Stewart Einfeld's book "Challenging Behaviour", third edition. This includes:

Innovation: A Statewide Positive Behaviour Framework translating evidence into practice

Resource team: Sector wide representation on a Guiding Committee guiding the process of change focusing on partnerships.

Adopting organisations: Involving key disability sector organisations in pilot projects demonstrating local evidence

Scaling up strategy: Long term planning for demonstration of local evidence across the disability sector.

Results: This paper provides an overview of cultural and organisational change across the sector demonstrating outcomes through projects, policy, guidelines and data. In particular, voluntary engagement in the elimination of restrictive practices is demonstrated across several organisations with promising data for change.

Implications: The Framework is informed by ongoing monitoring and evaluation ensuring dynamic and contemporary evidence based practice and provides crucial information for a partnership approach to improved service design.

This model of change has implications for future innovations. Elements of the approach have been incorporated into Western Australia's strategic approach to health issues for people with disability.

Easy English Abstract:

The Positive Behaviour Framework is about finding ways to work together to help people with a disability who have challenging behaviour.

To improve people's lives we have to change how we think about things and do things differently. This paper is about how lots of organisations in WA have worked together to change the way things are done to help people with challenging behaviour.

Everyone worked together and agreed to try new ideas and ways to provide better support and services. The new ideas were closely tested to see what worked best so that everyone can get better at what they do.

This way of working together to change things helps all services to improve and the way it was done can also be used for other types of services.

*Values into practice, Practice, Paper*
*Thursday 8 November, 10:50am - 11:20am, Civic 1*

**Thompson, Tessa** (Workforce Strategy, Disability, Department of Human Services, Victoria Public Service, Australia, Tessa.Thompson@dhs.vic.gov.au)

***Considering how to nurture an effective direct-support workforce for truly client-driven disability accommodation and support services: Reflections from a policy practitioner 'flung in the deep end'***

There are inherent tensions between the perspectives of the support workforce and support service-users. The workforce systems that manage these tensions need more consideration if we are to achieve our common purpose.

We do now have a good common sense of what we want to achieve with future disability services. People with disabilities and their families want a fair chance to have the ordinary kind of control and choices in their lives that most people expect to have. We also know that, for people using disability accommodation support, the way that the support workforce do their job is mission critical.

We are not so clear about the workforce systems that enable direct-support staff to do their job well. What does the transition away from a service-centred approach mean for recruitment, rostering, performance management, remuneration and accountability arrangements?

This question covers territory which is emotional, sensitive, political and potentially expensive. So it is not surprising that policy practitioners often shy away from directly addressing the complexity of workforce systems when outlining disability service policy.

This paper will intrepidly explore workforce system challenges and opportunities found in the power-shifts that sit at the heart of a transition to client-driven services. Industrial relations experience and discourse will inform a proposed change strategy which nurtures and acknowledges the support workforce as lead explorers in a transformative journey towards better services and an inclusive world.

Easy English Abstract:

Disability support workers need some help to do their job well.

People with disabilities and their families want a good life.

Disability support workers help people who live in group homes to have a good life.

We have questions about disability support workers. How can we make sure we have support workers in the right place, when we need them? How can we help them do the best job they can?

Answering these questions is hard and can be uncomfortable for people who are disability support workers. It can also be uncomfortable for the government, and for people with disabilities and their families.

This paper will try and answer the questions carefully. It will talk about how workers make changes to what they do at work and how they are told what to do. It will also talk about how to look after disability support workers so they can best help people with disabilities and their families have a good life.

*Values into practice, Practice, Paper*
*Thursday 8 November, 10:50am - 11:20am, Civic 2*

**Johnson, Hillary** (La Trobe University/Scope, h.johnson@latrobe.edu.au)
Non-presenting authors: Assoc. Prof. Jacinta Douglas, Dept of Human Communication Disorders, LaTrobe University; Prof. Christine Bigby, School of Social work and Social policy LaTrobe University; Prof. Teresa Iacono, La Trobe Rural Health School, La Trobe University

***Social interaction for adults with severe intellectual disability: Sharing enjoyable time together***

Adults with severe intellectual disability have limited communication skills and few opportunities for social interaction. Social interactions are key to developing relationships and hence enhance possibilities for social inclusion. The aim of this presentation is to describe the types of social interaction that occur between adults with severe intellectual disabilities and those with whom they have positive relationships.

There were six participants with severe intellectual disabilities and 57 people with whom they had positive relationships, comprising family members, paid workers and people with an intellectual disability. Data were drawn from field notes, transcriptions of interviews, the first author's journal and relevant published literature. The data were analysed using the grounded theory method.

Results: Social interactions comprised a process termed sharing the moment, in which participants derived pleasure from having fun together and hanging out. Having fun together was routine or comedic in nature. Hanging out involved less intense interactions that involved contact or just being in someone presence. Relationships that involve mutual satisfaction occur between people with severe intellectual disability and some of their network members. Spending enjoyable time together in specific types of social interactions may supplement paid worker job satisfaction and increase opportunities for social inclusion by people with severe intellectual disability.

*Values into practice, Research / academic, Paper*
*Thursday 8 November, 10:50am - 11:20am, Civic 3*

**Webber, Lynne** (Department of Human Services, Victoria, Australia, Lynne.webber@dhs.vic.gov.au)
Non-presenting authors: Dr Ben Richardson, Deakin University, Melbourne, Victoria; Dr Frank Lambrick, Office of the Senior Practitioner, Melbourne, Victoria

### The use of seclusion in disability services: Individual and organizational risk factors

Seclusion is a restrictive intervention that results in some form of containment and social isolation of a person from others. It is used by disability and mental health services in Australia and most other developed countries to control behaviours that are perceived to be harmful to others. The use continues despite a lack of evidence showing effectiveness. Furthermore, it has been argued that the practice can lead to physical and mental health problems and places both staff and people with a disability into unsafe situations. In this study we examined the use of seclusion in disability services in Victoria, Australia over a three-year period. Specifically, we focused on the characteristics of individuals who were secluded in disability services and some of the characteristics of organisations that reported using seclusion. When compared to those who were never reported to be secluded, two individual characteristics put people at risk of being secluded: a diagnosis of Autism and/or a psychiatric diagnosis. A relatively small number of services reported that they secluded people. People in shared supported accommodation and congregate care facilities were at greatest risk of being secluded. Some individual services reported using seclusion for several people for two or more of the three years. These findings are consistent with previous research, but add to this literature by showing that certain organisations or parts of these organisations may have a culture where seclusion is deemed to be a useful way to control people who show behaviours of concern.
*Bioethics, Research / academic, Paper*
*Thursday 8 November, 10:50am - 11:20am, Square Affair*

**Talve, Riia** (Riia Talve, Drivenr@hotmail.com)

### A life through images

My name is Riia Talve and I live in Vancouver Canada. I am an artist, public speaker, and self advocate for people with learning disabilities and mental health issues. My Skype presentation is centered upon my personal life experiences. I was born premature with a brain haemorrhage. In Elementary School I was placed in learning disabilities resource rooms, and struggled with mental illness in a psychiatric ward. I received therapy and counselling that helped with my Obsessive Compulsive Disorder. From there I attended Emily Carr University of Art and Design, where I learned to express my emotions through my art. Currently my art has been shown as far away as Aberdeen Scotland. While I had, and have, struggles and challenges in my life, I am also successful. My message is one of hope. Perceived disabilities do not mean you cannot be successful. My presentation will include images of my artwork to enhance the story and encourage hope.
I have been an invited guest speaker at a range of functions, including the Australian Society of Intellectual disabilities Conference in 2010.
*Health and well-being across the lifespan, Lived experience (self advocate, family), Paper*
*Thursday 8 November, 11:25am - 11:55am, Main Auditorium*
Please note that this will be presented via Skype.

**Lewis, Lesley** (University of Sydney, lesley.lewis@sydney.edu.au)

*Geographies of disability, resilience and social justice: An inclusive research project*

This paper presents a discussion of the inclusive research project 'Geographies of Disability, Resilience and Social Justice', which is at the leading edge of an emerging literature of geographies of disability and inclusive research practice.

The project has as its focus an investigation of the way notions of urban space are experienced, created, regulated and transgressed by people with disability living in an urban environment; by the various professional 'gatekeepers' with whom they interact; and at a wider level, by urban planners and policy makers, in terms of the impact of planning and policy on the lifeworlds of people with disability. Embracing geographies of exclusion/inclusion and matters of social justice, the project makes reference to the United Nations Convention on the Rights of Persons with Disability, and offers a transformative geography of disability, created not 'for' but 'with' urban dwellers with disability.

The enactment of values into practice operates on two levels:

1.  engaging directly with a panel of experts - a group of people with disability who have informed opinions; the wisdom of lived experience as urban dwellers and the wish to be involved in this inclusive research project with a view to developing into a collaborative team - the project is challenging and transforming the inclusive research paradigm
2.  it is anticipated that an outcome of the project will be the development of an accessible, useful and practical knowledge base that will be used for planning and policy-making around provision of services for people with disability in the urban context.

Easy English Abstract:

This paper will discuss a research project that explores geographies of disability, social justice and inclusive research.

The project involves people with disability as a panel of experts who will meet with the researcher to talk about their ideas and experiences of living in the city.

The research is being done 'with' and not just 'about' people with a disability, and this is in line with 'Nothing About Us, Without Us'.

We want to learn from you about what is good, and what is not good, about living in the city. We would like to hear what you think needs to change to make living in the city better for people with a disability.

There will be four main themes and questions we will be using as starting points for the discussions:

1.  how does having a disability affect your access to people, services, places and activities?
2.  what do you think needs to change in the city structures, and in the way people with disability are viewed, to make a better life for people with disability who live in the city?
3.  how can we work together to make sure that the voices and opinions of people with disability are heard by city planners and by the community?
4.  how can we make sure that your opinions and ideas are presented so that more people can understand the good and the difficult things you experience in living in the city?

*Values into practice, Research / academic, Paper*
*Thursday 8 November, 11:25am - 11:55am, Civic 1*

**Degrave, Julie** (The Argo Trust, argo.trust@xtra.co.nz), **Atkinson, Dayna** (Argo Trust Manager, argo.trust@xtra.co.nz); **Serrao, Giuliano** (Argo Trust Training and Development Manager, qualitycoordinator@xtra.co.nz)

*A New Vision - supporting people with profound disabilities*

Eighteen years ago a group of parents who had children with disabilities had a vision for a unique high quality service. They fought hard to establish a small trust with funding agencies and over the

years, Argo Trust has developed & progressed into a leading service provider.

We set up a purpose built home in central Wellington and started a vocational and residential service. We negotiated funding contracts with relevant ministries and found the right management and staff.

The board (parents of each child) recognised that getting the right staff actually created a progressive environment where people with profound disabilities were out in the community doing things family never thought possible.

We found that we had set up a vocational programme that was putting our values actually into practice. This was not about the degree of disability, but more about our attitude to it. We looked at individual planning and meaningful goal setting that involved fun, development, therapies and community involvement.

What it means:

That it is possible to promote a new way of supporting people who have disabilities – where new practices can emerge.

Wanting to pave way for more innovative and high quality services, with residents' (and staff's) lives enriched as a result.

That its incredibly good for people with disabilities and the community; challenges all of us and our perception & misconceptions of profound disability.

*Values into practice, Practice, Paper*

*Thursday 8 November, 11:25am - 11:55am, Civic 2*

**Garrett, Tania** (IDEA Services, tania.garrett@idea.org.nz), **Boot, Bridget** (IDEA Services, bridget.boot@idea.org.nz)

### *Next Generation Project: Designing services for the 'Next Generation' that meet the needs of those accessing our services*

Traditional service models offered by IDEA Services were recognized as not meeting the needs of the next generation of young people and their families who need modern and flexible supports at key life stages of their journey, and into the future.

Idea Services wanted to understand the hopes, concerns and aspirations of the young people and their families as they move towards adulthood. We undertook consultation with young people and their families in 5 key locations in New Zealand and with an online survey. This consultation was held with young people and their families on what these services could look like to support them into the future. The findings of this consultation were documented in a report.

Five key themes were identified from this consultation:

- Belonging and Connecting
- Strengthening- Family resilience
- Changing- a whole of life process
- Engaging- building on life skills and community engagement
- Knowing- knowledge and information

From this report and the underlying principles a strategy was developed to shape new practises and develop new services.

This paper will discuss the process of consultation, the key findings of the consultation with young people and their families, the design of the strategy to shape new services, the way forward for Idea Services and the people that will use our services, and practical issues and the challenges faced by the organisation to make this happen for the next generation.

*Values into practice, Practice, Paper*

*Thursday 8 November, 11:25am - 11:55am, Civic 3*

**Adams, Bernadette** (Focus, bernadette@focuslife.com.au), **Sipthorpe, Annette** (Focus, Quality Coordinator)

*Dementia diagnosis and accessing aged care services for people with Down syndrome*

During 2009 Focus staff became concerned about the decline in living skills of some of the residential clients with Down syndrome. Staff then experienced difficulty when attempting to quantify the changes, obtain a diagnosis and plan for ongoing needs.

A search of resources available in Victoria and interstate led to adoption of the Broad Screen Checklist of Observed Changes developed by MINDA in South Australia. This tool offers a standardised way to measure living skill change. A standardised approach was required because many different staff support these people and the staff all have different perceptions of reported changes.

This assessment is administered to clients with Down syndrome as a baseline and repeated as required. Completed assessments are scored. Referrals, when required are made to GP's, CADMS (Confusion and Dementia Memory Service), ACAS (Aged Care Assessment Service), and RDNS (Royal District Nursing Service).

An official diagnosis of dementia enables the client, family and support workers to develop a person centred plan that details specific support requirements, apply for appropriate funding, and give guidance to the people involved when planning future supports. These may include moving from a disability service to a residential aged care facility.

An official diagnosis may also assist the organisation when requesting assessment and services from aged care related services.

Access to these services has perhaps been the biggest barrier because people with Down syndrome who develop dementia are usually younger than sixty years. The inclusion of a community nurse to liaise with these services is assisting in breaking down this significant barrier.

Easy English Abstract:

During 2009 people working for Focus worried about people with Down syndrome who were losing their life skills.

They wanted to find a way to measure peoples life skill abilities so that if they change, the doctor could see what is changing.

Focus started using the Broad Screen Checklist of Observed Changes from MINDA. The checklist is a way to measure life skill changes. We did the assessment with people living with Down syndrome who live in our community houses.

If there were a lot of changes we made referrals to doctors and health professionals.

If the doctor says a person with Down syndrome has dementia, the person with Down syndrome and their families and support workers can make a plan about how to help them manage the changes.

Some of the health professionals would not help because the people with Down syndrome were younger than 60 years and they only help people older than 60.

The community nurse is now helping so that the health professionals will help people with Down syndrome and dementia.

*Cultural and social contexts, Practice, Paper*
*Thursday 8 November, 11:25am - 11:55am, Square Affair*

**Quinlan, Cassandra** (Focus Individual Support Service, quinlanc@focuslife.com.au)

*Uniting with families to achieve Outcomes - A Training Package using 'Circles of Support' to achieve this*

It was identified that families were having trouble with the introduction of the Disability Act 2006 (Australia). We needed to find an approach where we could support people with a disability and their families, through self directed approaches; whilst providing an opportunity for enhanced outcomes as a result of pursuing a range of options.

It was identified that we needed to collaborate with all parties involved in the person's life, to be able to implement unity across all areas of their life, and most importantly show the rich diversity of the individual with an integrated approach.

Focus decided that the 'Circle of Support' concept would be a good option for achieving the outcomes we were looking for. We identified Holly as someone who would benefit from a 'Circle of Support' as she had indicated that she wasn't achieving the life she wanted. The 'Circle of Support' concept has empowered Holly to have greater control of her life.

This was the first of many successful 'Circles of Support' Focus was to implement over the years. We are pleased with the positive results and felt it was a natural step to develop a training package to benefit others.

The goal of this presentation is to promote the DVD and training package. The training package is a competency based package to be used by organisations to train staff and can be used to encourage families to embrace this concept. The 'Circle of Support' leads to a whole of life integrated approach to the individual.

Easy English Abstract:

Some families were having trouble with the new laws in Victoria Australia.

We needed to help people with a disability, families and friends understand what was possible with the new laws.

We needed to find something that would bring everyone together as a group. That included the person with disability, families, friends, and staff. To look at what an individual person wanted and how we are going to help them achieve it.

A 'Circle of Support' was started for a lady named Holly. Holly's Circle was a group of family, friends and staff who were able to empower Holly and give her greater control of her life.

People who come to this presentation will learn about how Holly's 'Circle of Support' worked for her. We will be showing the DVD and talking about training package that people can buy for staff training. The DVD can be used to encourage families to look at 'Circles of Support.'

*Values into practice, Practice, Poster*

*Thursday 8 November, 12:15pm – 12:45pm, West Court*

**Girdler, Sonya** (Edith Cowan University, s.girdler@ecu.edu.au)

Non-presenting authors: Peter Jacoby, Telethon Institute for Child Health Research, Centre for Child Health Research, University of Western Australia, Perth, Australia; Dr Sonya Girdler, Department of Occupational Therapy, School of Exercise and Health Sciences, Edith Cowan University, Perth; Dr Jenny Downs, Telethon Institute for Child Health Research, Centre for Child Health Research, University of Western Australia, Perth, Australia; Dr Helen Leonard, Telethon Institute for Child Health Research, Centre for Child Health Research, University of Western Australia, Perth, Australia

***Family quality of life of young adults with Down syndrome participating in open employment***

Aim: Describe family quality of young adults with Down syndrome transitioning from school to post-school and explore the relationships with young person's post-school day occupation.

Method: Questionnaires (n=197) were collected from families of young adults with Down syndrome aged 15-29 years. Information about the young adult functioning and day occupations, and other person and environment characteristics were collected. The Beach Centre Family Quality of Life Scale was used to measure family quality of life.

Results: Young adults were still at school (n=30) or attending post school day occupations (150); open employment (n=38), training (n=16), sheltered employment (n=59) or attending an alternatives to employment activity (ATE)(n=37). Better family quality of life was reported by families of those young adults attending open employment (107.15 SD 13.62) or training (102.91 SD 18.85) compared

to those attending sheltered employment (94.91 SD 16.01) or an ATE activities (93.23 SD 22.56) (p=0.0017). The final model adjusting for behaviour, function and family characteristics, where the baseline was those in open employment, showed families of those attending sheltered employment reported lower overall family quality of life (Coef -5.94, 95% CI -12.98, 1.11).

Conclusion: Preliminary analysis has revealed that families of young adults attending open employment or training report a higher quality of life than families of young adults in sheltered employment or ATE, even when adjusting for confounding variables.

*Health and well-being across the lifespan, Research / academic, Poster*
*Thursday 8 November, 12:15pm – 12:45pm, West Court*

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

*Healthy and loving it – a complicated science or common sense simplicity?*

Keeping good general health is dependent on a number of factors, including having a good diet and exercising regularly. Poor nutrition and lack of exercise are contributing to the increasing rates of obesity for people who have intellectual disability (at a higher rate than in the rest of the population). This presentation will discuss work undertaken by IHC NZ and IDEA Services focused on improving the activity levels and nutrition of middle aged people with intellectual disability, with the intent that a focus on good health in the middle years will lead to improved health as people age. The strategies trialled and evaluated were simple and effective, and provide a promising framework for broader implementation across services.

Easy English Abstract:

It is important to be eat well and get enough exercise. We helped people find ways to do this. We will talk about what we did. This will help other people to get healthy and fit too.

*Health and well-being across the lifespan, Practice, Poster*
*Thursday 8 November, 12:15pm – 12:45pm, West Court*

**Whatnell, Dina** (MidCentral Health DHB, dina.cole@midcentraldhb.govt.nz)

*Health Promotion Health Awareness Education Programme: Developing Self Awareness for People with Intellectual Disabilities*

Many people with intellectual disabilities have ongoing and complex health needs that are often unrecognised. In many circumstances it can be difficult for people with intellectual disabilities to identify their own health needs and take appropriate action.

The Health Promotion - Health Awareness education programme has been developed from many years experience combining a passion to empower and improve the long-term health of people with intellectual disabilities. The aim of the pack is to empower and motivate people with intellectual disabilities to take a lead and ownership of their own health.

This programme can be divided into individual workshops each focusing on a different area of health (including the Yearly Health Check) or run as a complete programme. The workshops can vary in length from 15 – 30 minutes depending of the needs of the participants. Resources for the workshops include: PowerPoint presentation, facilitators handbook, visual aids – posters (prompts for further displays), games and activity sheets, easy read information leaflets, health diaries. The easy read leaflets have also being developed so they can be used individually in health establishments to ensure that timely and accessible information is available for people with intellectual disabilities. Subjects include: what to do when I feel sick? what is consent? what is blood pressure?

I will also discuss feedback that has been received so far from participants that have taken part on the programme and future plans for development.

Easy English Abstract:
Health is very important. It is very important that you know about your own health and how to keep yourself well.
The Health Promotion - Health Awareness education resource pack has been made to help you learn more about your health. The aim of the programme is to teach you how to keep well and also what to do if you are not well.
You can just go to some of the classes in the programme or you can decide to go to all of them. Each class will last between 15 and 30 minutes.
There have been some resources made for the programme: a handbook for the teacher; PowerPoint presentations; posters; games; information leaflets for you to read and look at and some health diaries for you to fill in.
Some of the things that you can learn are: what to do when I feel sick? what is consent? what is blood Pressure?
I will talk about what the programme does, what the people think about the programme and what we hope to do in the future.
*Health and well-being across the lifespan, Practice, Poster*
*Thursday 8 November, 12:15pm – 12:45pm, West Court*

**Matthews, Martyn** (Timata Hou, IDEA, martyn.matthews@timatahou.org.nz)

***ASD Plus: Flexible delivery of an ASD-specific parent training programme in New Zealand***

ASD Plus is a parent training programme for families of pre-school children with a recent ASD diagnosis. It was developed by and is delivered by IDEA Specialist Services in New Zealand and is jointly funded by the Ministries of Health and Education.
As New Zealand has a highly dispersed rural population who find it difficult to access services, the programme was designed to have a high degree of flexibility in method of delivery, including group, individual family and distance learning options. Development of the programme drew strongly on evidence from the domains of both ASD early intervention and adult education. Following its first year of operation, the programme was subject to an external evaluation commissioned by the funding ministries which was undertaken by Litmus, a health and social research and evaluation organisation. This poster will describe the content of the ASD Plus programme, methods of delivery, the challenges of meeting the needs of dispersed populations and the results of the external evaluation.
External evaluation has identified the following outcomes:
- The tailored and individualized approach is a major strength of the programme
- The programme has provided tangible short term benefits for participating families
- Management and monitoring systems are comprehensive, efficient and well designed
*Health and well-being across the lifespan, Practice, Poster*
*Thursday 8 November, 12:15pm – 12:45pm, West Court*

**Buchanan, Angus** (Curtin University, a.buchanan@curtin.edu.au)
Non-presenting author: Ms Vesna Milasinovic

***Reliability of the Revised Irrabeena Core Skills Assessment (RICSA) used in formal accommodation services and implications for adults with intellectual disability***

Background: Increasing functional skills for adults with intellectual disability is important for community living, and can promote opportunities to express self-determination, support social inclusion and enhance quality of life. The Revised Irrabeena Core Skills Assessment (RICSA) is a tool used in formal accommodation services that evaluates the functional skills of adults with intellectual

disability. The results of the assessment are used to inform training for skills development. This study focused on establishing evidence for inter-rater reliability of the RICSA and identifying potential issues that may affect the reliability.
Method: The RICSA was completed by 101 staff members on a sample of 30 adults with intellectual disability living in group homes managed by an accommodation service provider. Interviews were conducted with nine staff members in order to identify potential issues that may affect the reliability of the assessment. Inter-rater reliability was analysed using the Intra-class Correlation Coefficient (ICC) and thematic analysis was conducted from the interview data.
Results: The ICC values ranged from 0.63 to 0.73 across the five main domains of the RICSA. The interview data identified six themes, with the most frequent being related to the attributes of the assessment form.
Conclusions: The results of the study suggest that the moderate agreement found between staff members may be regarded as unsatisfactory when considering that the use of the RICSA is to inform skills training for people with intellectual disability. The findings suggest that unreliable assessments may negatively impact on skills development, successful community living, and quality of life.
*Health and well-being across the lifespan, Research / academic, Paper*
*Thursday 8 November, 2:00pm - 2:30pm, Main Auditorium*

**Burke, Felicity** (Ageing Disability and Home Care NSW, Department of Family and Community Services, Felicity.Burke@FACS.nsw.gov.au)

***Sync or Swim? Trials of iTechnology in our agency***

Consumers want to use iPads, iPods and iOS generally for communication systems. Government systems and services often prevent staff access to these devices and applications. Drive is outpacing research. It's hard to know what clinical advice to give regarding new devices, new applications and new options for users.
In 2011 an "iProject" was undertaken by speech pathologists in Ageing Disability and Home Care in NSW. Approval was granted for supply of an iMac Pro lap top, iPad (version2), iPod touch and orbital speaker to each of the six regions of ADHC in NSW. All devices were loaded with 37 pre-chosen applications. All regions were set up with an iTunes account and money available to purchase and trial other additional applications.
A package was produced with information, guidelines and data forms for collection. The basic data collected was:
• Information on frequency of use for either professional development or client trial; request frequency; geographic areas of request for the devices in the iProject.
• Time spent and resources used for self directed learning in this area by the speech pathologists concerned
• A summary of client trials and outcomes on specific iDevices and apps
• Ratings of iDevices for each trial
• Ratings of apps for each trial
• Other apps chosen- reasons and rationales for choices
The process and outcomes of this project raises many interesting questions.
Gosnell's (2011) recent work on feature selection chart to compliment a clinical framework may help inform future decisions on iDevices/app purchases.
Easy English Abstract:
Many people want to use iPads and iPods to communicate. There is not much research in this area yet.
People with intellectual disability wanted to try using iPads and iPods to communicate.
The Speech Pathologists in Ageing Disability and Home Care did not have any iPads or iPods for people to try.

So we got an iMac, iPad and iPod touch for each or our six regions in Ageing Disability and Home Care in New South Wales. We did this so that people with intellectual disability could try them out and also let the speech pathologists try them out.

There are lots of applications you can use for communication on iPads and iPods. It is hard to know which ones are best.

We tried 37 communication applications and we had money to buy others on iTunes accounts.

We found out about:

- How much the iPads and iPod touches were used and what they were used for
- how the speech pathologists learnt about using these machines and applications
- good and bad things about using the iPad and iPod touch from speech pathologists and people with intellectual disabilities
- good and bad things about using the applications from speech pathologists and people with a disability
- what other applications were used and why they were used

There are still a lot of questions to answer. We now have some ideas about choosing applications and devices for communication and are looking at other people's work in this area.

*Values into practice, Practice, Paper*
*Thursday 8 November, 2:00pm – 2:30pm, Civic 1*

**McGinn, Valerie** (Alcohol Healthwatch, vmcginn@ihug.co.nz)

***Providing Fair and Equal Justice to Offenders with a Fetal Alcohol Spectrum Disorder (FASD).***

Persons with FASD disability are over represented in the criminal justice system. They have poor capacity to link their behaviour to consequences and to learn from their mistakes. As a result of their brain- based disability they often behave inappropriately in the community. FASD brain impairment provides significant disadvantage at all stages of legal proceedings from arrest to trial and sentencing. Issues such as deterrence, culpability, FASD as a mitigating factor and effective sentencing are important considerations in the dispensing of fair justice to FASD affected defendants. Without specialist FASD assessments provided to the Court identifying the nature of the disability and how this may have impacted on the offence, there is a risk of the justice system criminalising FASD disability and responding ineffectively to reduce recidivism.

In 2010 the Canadian Bar Association passed a resolution urging their government to avoid the criminalization of people with FASD and develop policies relating to FASD as an access to justice issue. New Zealand is beginning to develop capacity in the recognition of FASD within the criminal justice system. The workshop will present international research and case law pertaining to FASD and offending. A proposed study to diagnose FASD in the Auckland Youth Court to establish the prevalence and special requirements of this vulnerable group of young offenders will be presented. Participants will be asked to consider how we may better identify and meet the needs of individuals who due to brain impairment may break the law and behave dangerously in the community.

*Legal issues and developments in forensics, Practice, Workshop*
*Thursday 8 November, 2:00pm - 4:05pm, Civic 2*

**Craig, Jocelyn** (ASLaRC Aged Services Unit, Southern Cross University, jocelyn.craig@scu.edu.au)
Non-presenting authors: Professor Colleen Cartwright, ASLaRC Aged Services Unit, Southern Cross University; Dr Kelly Shaw, ASLaRC Aged Services Unit, Southern Cross University.

***Future planning for older carers of adults with disabilities***

This project aimed to empower carers of adults with intellectual disabilities to plan ahead for a future time when they may not be able to continue to provide the level of care required, because of death or incapacity of the carer.

The first 2 phases of a 3-phase project will be briefly presented, followed by detailed findings from Phase 3.
The 1st Phase was to develop a model suitable for use by government, service providers and carers.
The 2nd Phase tested the model by expanding the project to a wider range of carers.
During Phase 3 of the project the research team worked with employees with intellectual disabilities, their families and staff of a supported employment organisation to explore future housing needs and support options for people with intellectual disabilities. Participants in the study expressed a strong desire for housing and support options that will help them to maintain and enhance their social networks with peers as they grow older and require assistance with the transition to formal housing and support services. Although the supported employees in this study were ageing and becoming less able to continue to work, they and their families had not considered or planned for their future retirement.
In Phase 3 individual Futures Plans were developed in conjunction with planning for the future housing and support for the group as a whole. The project provided the participating carers with the information, guidance and assistance that they needed to overcome the challenges they were facing.
*Values into practice, Research / academic, Paper*
*Thursday 8 November, 2:00pm – 2:30pm, Civic 3*

**Ford, John** (Tautoko Services/Massey University, johnford@tautoko.org.nz)

***Finding practical solutions to an ethical dilemma; supporting people who have Prader Willi Syndrome in residential services***

Prader Willi Syndrome (PWS) usually results in Intellectual Disability. It also leads to a condition that has been described as a 'disorder of satiation'; the marked reduction of the sense of satiety after eating. Common consequences are a chronic drive to seek food leading to hyperphagia and obesity that often becomes life threatening unless access to calories is limited.
This presents those who support people who have PWS with a high-stakes ethical dilemma that could be characterised as a clash of values: autonomy verses safety.
Interviews were conducted with a group of first level managers who work within residential services that support people who have PWS. The managers were asked how they had sought to resolve this dilemma. Themes that emerged from their answers will be presented in this paper. We'll also consider the international consensus as represented by the recently published International Best Practice Guidelines for the Support of Adults who have PWS (2011).
If time permits we will conclude with a round table discussion seeking insights from the experiences of staff who support people who have PWS into the wider issue of defining the ethical responsibilities faced by professional caregivers when those we support make choices that are not against the law but that appear to be dangerous.
Easy English Abstract:
People who have Prader Willli Syndrome usually have Intellectual Disability. They also have a difference in their brain that means that they are almost always hungry, even after eating.
This is a problem for people who have Prader Willi Syndrome because they put on a lot of weight very quickly. Being so overweight seriously harms their health. It also presents a problem for staff who support them. Staff usually want to support their clients who have Prader Willi Syndrome to make their own choices but they also know that it is often dangerous for a person with Prader Willi Syndrome to have free access to food.
I interviewed some managers who support people who have Prader Willi Syndrome. I asked them how they had tried to solve these problems. I will present their answers in this paper. I will also present the ideas of staff from around the world who have published guidelines for supporting people who have Prader Willi Syndrome.

If we have enough time we will also have a discussion about what staff should do when the people they support choose to do something that seems to be dangerous.
*Values into practice, Practice, Paper*
*Thursday 8 November, 2:00pm - 2:30pm, Square Affair*

**Garriock, Judy** (Spectrum Care Trust Board, judy.garriock@spectrumcare.org.nz)

***Implementation of an evidence-based comprehensive health assessment tool: A disability support provider's strategy to provide higher-quality health outcomes for people with ID and other cognitive disabilities***

Spectrum Care is an independent charitable trust providing services for children, young people and adults with disabilities and their families in New Zealand.
Due to growing concerns about poor health outcomes for people with disabilities accessing its services, Spectrum Care reviewed its health tools and processes. This review identified that many the poor outcomes were linked to breakdowns in primary health supports through:
•   Unrecognised or poorly-managed health conditions and diseases
•   Inadequate or non-existent health screening
•   Ineffective communication between the individual, their supports and General Practitioners (GPs) /healthcare professionals
Through its research, Spectrum Care discovered the Comprehensive Health Assessment Programme (CHAP), which is an evidence-based health assessment tool for GPs. The CHAP was developed in 1999 by Professor Nick Lennox – an Australian GP with New Zealand experience. Professor Lennox is the Director of the Queensland Centre for Intellectual and Developmental Disability, School of Medicine, University of Queensland.
In 2010, Spectrum Care introduced the CHAP tool for an initial group of approximately 300 people with disabilities across 70 of Spectrum Care's residential houses. Training in the application of the tool has been provided for in excess of 300 staff, and more than 100 GPs have provided input, feedback and support for the pilot programme.
An overview of the initiative, analysis of the data collected and recommended pathways for other providers seeking to adopt a similar approach will be presented at the conference, with involvement and contributions (via video footage and interviews) from people with disabilities and their support staff.
Easy English Abstract:
This presentation describes how a service provider introduced looks at the methodology and outcomes of a disability support provider's implementation of the CHAP, a health assessment tool, as a pathway to improve the health for people with intellectual disability accessing their residential services.
Spectrum Care has introduced the CHAP tool for approximately 300 people across residential services. More than 300 staff, and more than 100 GPs have provided input, feedback and support for the pilot programme.
Overall outcomes:
1.   People were examined more thoroughly during their annual health assessments using the CHAP
2.   People and their supports were involved in health action planning
3.   Health problems were spotted with use of the CHAP, which would have been missed at previous annual assessments
4.   GP costs for annual assessments using the CHAP ranged from $35 to $175
*Health and well-being across the lifespan, Practice, Paper*
*Thursday 8 November, 2:35pm - 3:05pm, Main Auditorium*

**Williams, Robbi** (Julia Farr Association Inc, aliciaf@juliafarr.org.au), **Fidock, Alicia** (Julia Farr Association Inc, Research Officer, aliciaf@juliafarr.org.au)

*Small money, big changes? An evaluation of a two-agency Individualised Funding pilot in South Australia*

The Service Transformation initiative is a partnership project between the Community Accommodation and Respite Agency (from the disability sector) and ACH Group (from the aged care sector) funded by the Australian Government Home and Community Care (HACC) program.
The initiative seeks to transform HACC funded respite packages into individualised funding packages which are portable and support individuals living with disability, older persons and their families to have control and choice over how they purchase their support needs.
JFA Purple Orange was approached by Community Accommodation Respite Agency and ACH Group to undertake an independent evaluation of their Service Transformation project to identify, among other things, the extent people are engaged and empowered to redesign and transform their HACC funded packages.
The paper:
• Outlines the basic features of the individualised funding initiative JFA Purple Orange was asked to evaluate
• Outlines the evaluation approach JFA Purple Orange undertook
• Highlights what the evaluation told us about people's experiences with individualised funding packages
• Examines the extent to which personal control over small sums of public funding can make a difference
• Examines what might be required to strengthen outcomes and sustainability for participants, and associated implications for the proposed National Disability Insurance Scheme in Australia.
This is a companion paper to the poster by Frauke Husner on 'Service Transformation – Implementation of Individualised Funding at Cara' on Wednesday 7 November, 12:35pm - 1:05.
Easy English Abstract:
Our talk is about a project in Adelaide that is helping people make their own choices.
The project name is Service Transformation.
The project is looking at what happens when a person's family needs to take a break from helping the person.
The project wants to know if good things happen when people get more choice about how they get help.
We are a group of people called JFA Purple Orange and we talked to the people on the project to find out if the project was helping them.
We will share what they told us. We will say what we think needs to happen in the future so that people have more say in what happens to them, and can get the best help.
*Values into practice, Research / academic, Paper*
*Thursday 8 November, 2:35pm - 3:05pm, Civic 1*

**Smith, Peter** (Praxis Disability Consulting, petersmith1@westnet.com.au)

*Employment and Self Determination. Moving from looking for a job to career planning*

It's common practice for disability employment service providers to attempt to try a "best fit" approach when looking for employment opportunities for clients with a disability, based on the persons needs, skills and vocational interests.

Cobigo, Lachapelle & Morin (2010) noted that inappropriate matching could result in withdrawal, absenteeism and turnover, along with decreased productivity (Crossley & Highhouse, 2005; Kristof, 1996).

In light of this possibility and increasing evidence that real client choice is being sacrificed in order to meet service provider organisational goals, in part driven by government imperatives, it's time that governments & disability employment service providers placed greater emphasis on the client and their long term employment or career aspirations.

Self determination is one key ingredient to successful long term employment for individuals, whether they have a disability or not. It's critical for control over one's life.

This presentation seeks to examine the principles of self determination and the methodology that disability employment service providers could use to improve disability client success rates and place more focus on career planning rather than just finding a client a job. This may increase the possibility that clients will have long term employment success, increasing the level of social inclusion.

*Values into practice, Practice, Paper*
*Thursday 8 November, 2:35pm - 3:05pm, Civic 3*


**Versteegh, Sean** (Explore, sean.versteegh@explore.org.nz)

*Challenging Behaviourism*

Behavioural theory was heavily influenced by the results of laboratory experiments carried out by psychologists on caged animals. Unlike most other populations to which psychological therapy is currently applied behavioural theory continues to dominate the practises we employ in our work with people with ID. While acknowledging the contributions that behavioural theory has made to this field I want to take a critical look at its influence and effect. I will review a range of studies from the past 50 years that have criticised behavioural theory and its application to people with intellectual disabilities. My central criticism will focus on what I consider to be a failure in applied behavioural theory to appreciate the impact that interpersonal relationships have in the creation of behavioural change. I will conclude by discussing theoretical approaches and practises I believe can be used to redress this issue.

*Values into practice, Practice, Paper*
*Thursday 8 November, 2:35pm - 3:05pm, Square Affair*


**Mirfin-Veitch, Brigit** (Donald Beasley Institute, bmirfin-veitch@donaldbeasley.org.nz), **Milner, Paul** (Donald Beasley Institute, pmilner@donaldbeasley.org.nz)

*On the margins of good health: An ongoing analysis of the health of New Zealand Special Olympic athletes*

International research has identified people with intellectual disability (ID) as experiencing poorer health outcomes than the general population. They are at risk for a range of specific health conditions and having difficulty accessing population-based health promotion. In New Zealand, the Ministry of Health recently compared a selection of health status and health utilisation indicators for New Zealanders with and without ID. It found that people with ID receive three times the amount of government funded primary healthcare than the general population. This high level of health funding does not appear to be contributing to a commensurate improvement in the health status of this group.

Special Olympics New Zealand (SONZ) has been working to improve the health status of Special Olympic (SO) athletes for over seven years using Health Athletes Screening (HAS), a programme

that offers targeted health screening to athletes with ID. This presentation will detail an on-going research collaboration between SONZ and the Donald Beasley Institute and will present the results of two recent studies using HAS data to explore the health status of SO athletes, and people with ID who are not involved in SO.

This ongoing research has the potential to contribute important health information across the health and disability sectors and will, in the future, enable a more comprehensive understanding of the relative health status of New Zealand athletes, change over time in the presentation of conditions, and the identification of other factors that may impact on the health trajectory of people with ID.

Easy English Abstract:

Overseas researchers say that people with intellectual disability often have more health problems than other people. It also says that people with intellectual disability sometimes miss out on opportunities to learn about how to look after their own health. In New Zealand, the Ministry of Health have said that they spend three times more money on the healthcare needs of people with ID than people without ID. Even though the government seems to be spending a lot of money, people with ID are still having a lot of health problems.

Special Olympics New Zealand has been working with the Donald Beasley Institute on some health research. This presentation will talk about two studies that have looked at the health of people with intellectual disability who are Special Olympic athletes. In one of the studies, health information was also collected from people who were not involved in Special Olympics. The research helped us to find out quite a lot about the health needs of New Zealanders with intellectual disability.

This research is important because it can help us to answer questions like:
* What are the big health problems for people with intellectual disabilities?
* How does the health of people with ID change as they get older?
* What health services are needed for people with intellectual disabilities in the future?
* What do health professionals need to learn so that they can work well with people with intellectual disabilities?

*Health and well-being across the lifespan, Research / academic, Paper*
*Thursday 8 November, 3:35pm - 4:05pm, Main Auditorium*

**Dikian, Jack** (Ageing Disability and Home Care, Department of Family and Community Services, jdikian@me.com)
Non-presenting author: Lauren Gaudry, Behaviour Support Practitioner

***The Behaviour Support System Review: A personal reflection***

Understanding the factors that impact on behaviour support service provision for people with an intellectual disability is an important component of overall quality improvement and maintenance. This is a personal reflection of the work undertaken over a 5 year period, developing methods to better understand and explore service-related themes within service systems. This work culminated in the development the Behaviour Support Systems Review Practice Guide.

During this period a number of other important initiatives were being progressed by Statewide Behaviour Intervention Service (SBIS), a specialist clinical service within the Office of the Senior Practitioner. These contributed significantly to the approach as a practitioner undertaking service reviews.

This presentation describes the background, context, goals and objectives that were set. Personal reflections and insights will be shared, including important questions that shaped this work and ideas for future directions [Schon, 1983]. Questions explored included: What really is a behaviour support system, is there even broad consensus, what factors contribute to the provision of sound behaviour support? The challenges experienced when undertaking these reviews and what was learnt during this period will be presented.

Through this reflective approach questions were addressed and new ones explored. Findings included:
- Ways to improve the review outcome by placing emphasis on scope definition, expectations, approach, and role definitions.
- The value of collaboration throughout the review process using specific strategies.
- Identified service and systemic factors were good predictors of the health of the service system.
- The value of reflective practice by the practitioner in order to maintain neutrality, objectivity and transparency.

The outcomes of this work confirm the importance of the identified service and systemic factors and their impact on behaviour support. It also highlights the value of reflective practice when undertaking this work and provides additional directions in what is a dynamic and evolving approach.

Schon D., (1983). The Reflective Practitioner. New York: Basic Books.

*Values into practice, Research / academic, Paper*
*Thursday 8 November, 3:35pm - 4:05pm, Civic 1*


**Becker, Wendy** (Gracelands Group of Services, wendy.becker@gracelands.org.nz), **Bowman, Chris** (Manuka Health New Zealand Limited, chris@manukahealth.co.nz)
Non-presenting author: Stella Bowman-Hall

***Ingredients that made a partnership between a place of employment and a disability organisation successful achieving real employment outcomes for people with disabilities***

In 2009, an idea turned into an opportunity for Gracelands to partner with a local employer, Manuka Health. Manuka needed a workforce to help with a short term work task, and a Gracelands staff member raised the possibility of people with disabilities taking on that work. This was such a success, that three years later, Manuka Health employs two people in permanent employment and eight other individuals who work between three and six hours per week. There is also a small group of people supported by Gracelands, who are gaining real work skills and experience at Manuka Health, to assist them to gain paid employment in other workplaces. The work and the training is undertaken at the business premises – and all who enter those premises are bound by the organisation's health and safety policies and practices.

This presentation will explore the ingredients that made this a successful partnership that achieves real employment outcomes with people with disabilities. It will outline what the employees and work experience students believe they have gained from an inclusive work environment, and what the challenges have been. The partnership between Gracelands and Manuka Health has added value to both organisations and it has enabled real employment and inclusion in the community. Is it repeatable? With the right relationships – and the right attitudes, absolutely! We look forward to sharing our insights with you.

Easy English Abstract:

We will tell people about how Gracelands and Manuka Health helped people with disabilities to develop work skills and get paid jobs. All the work practice and paid work happens at the Manuka Health business, alongside other employees. We will talk about what helped make this arrangement successful, in getting people with disabilities into employment.

*Values into practice, Practice, Paper*
*Thursday 8 November, 3:35pm - 4:05pm, Civic 3*

**Higgins, Sue** (IDEA Services, sue.higgins@idea.org.nz)
*Consumer Perspectives vs Service Ethics and Philosophy*

***How do we meet consumer wants and needs when they do not meet organisations philosophy and values?***

This paper explores the challenges that services face when organisational philosophies and values do not meet the needs, wants, and values of individuals. It also explores the ethical dilemmas that must be considered when an individual's voice needs to be interpreted by their actions.
This paper centres on my work with a young woman whose support needs and complex features of Autism significantly challenged her support services. She has spent the larger part of her life learning to communicate her needs through challenging behaviour.
Through a detailed assessment process and functional analysis a number of hypotheses have been developed and tested around what she thinks and wants. We explore the services ability to respond within its specifications, and how this has evolved through a restraint minimisation policy frame work. We follow the history of successful intervention and how the more progressive the service became in improving her quality of life and interpreting the link between her behaviour and sensory and communicative needs the more apparent and difficult the ethical dilemmas seemed relating to safety and duty of care.
This paper may not be able to answer many of the questions it poses but it will certainly broaden the thinking associated to supporting those with complex needs.
*Values into practice, Practice, Paper*
*Thursday 8 November, 3:35pm - 4:05pm, Square Affair*