

Donald Beasley Institute Newsletter December 2006



From the Director

This year has been just as busy as ever. We have recently welcomed two new part-time researchers, Kelly Tikao and Gina Huakau. Kelly and Gina will provide us with ongoing advice about ensuring that our research is appropriate and responsive to Maori and be actively involved in various research projects. Gina also brings a Pacific perspective to our research.

We applauded the Health Research Council's announcement of Disability Research Scholarships for Masters and PhD students. The Institute recently welcomed three of these scholarship recipients to be placed at the Institute (out of 12 awarded throughout the country). Dr Katrina Varian's PhD research focuses on understanding the experience of falls in people with physical disabilities. Marilyn Raffensberger is undertaking doctoral research into counselling for people with intellectual disabilities. Dr Nina Sawicki is undertaking her Masters in General Practice research into the experiences of parents of children who have had cochlear implants. These three postgraduate researchers bring our Institute total to seven PhD and one Masters students. The Institute's continuing contribution to disability research in New Zealand was recognised this year by two awards I was honoured to receive: An ONZM in the Queen's Birthday honours, and Otago University Students' Association Award for Supervisor of the Year.

Our long term viability rests on our ability to continue to obtain external funding for our research. While our current funding situation is strong, we still have to maintain our annual application to major funding bodies to sustain our research into future years. There is never a

scarcity of ideas for research that needs doing! People with disabilities, families, advocates and service providers provide us with the ideas and motivation to continue our work.

Anne Bray
Director

CURRENT PROJECTS/ ONGOING PROJECTS

Research on the outcomes of resettlement of residents from Kimberley Centre

Kimberley Centre finally closed at the end of October 2006. All Kimberley residents have now been resettled into a range of residential services throughout the North Island. The focus of the research is now on studying the experiences of residents and their families' views on their new lives. The research team is very busy visiting residents in many different locations. They greatly appreciate the welcome and contributions they are receiving from staff in community services. While we have not yet published any formal reports, researchers have made conference presentations at the ASSID Conference in Australia, on some aspects of the research to date. Paul Milner presented a paper on the resiliency of family relationships and Sue Gates' paper related to findings from staff, titled "Institutional closure and resilience of staff".

While the funding for this research ceases in mid 2007, we will be continuing to collect information on all residents 12 months after resettlement, and analysing the enormous amount of detailed information for some time to come yet. We owe this to all the people with intellectual disabilities and Kimberley and community services staff who have been so generous with their time and expertise.

Marsden Project

Jude MacArthur and Michael Gaffney are currently working on the analysis of data from this project, which looks at disabled children's school experiences and their impact on identity. The study is revealing some interesting issues about how children experience "difference" at school, and shows that some children experience difference in negative ways. Their work includes a focus on how schools can support disabled children to be part of the group of "all children" at school. The study concludes this year (2006) although the researchers (Jude, Berni, Michael and Sarah) will be writing up their work in 2007. They are also hoping to work on a book that can be used by teachers.

The Teaching and Learning Research Initiative Project

Dr Nancy Higgins and Dr Jude MacArthur have been working on a project with teachers in a rural school developing teaching approaches to support children who are transient. They have been focussing on the children's sense of belonging at school and assisting teachers to implement teaching initiatives that encourage children to be included in the school and wider community. The study includes some children who have disabilities, and has included children's perspectives on their life at school.

Complex Carers Network Project

In 2006 we repeated the pilot project in Dunedin, as a comparison to our initial study in Waitakere City, and to extend the Network. The information from the Dunedin study is now being analysed and we hope to finish this report by the end of this February, 2007.

Pilot Projects for Families of Children with ASD

These two pilot projects are now completed and evaluations of each of them undertaken by Dr Claire Stewart. The evaluation reports are currently being completed.

Protecting Children – Strengthening Families: When A Parent Has An Intellectual Disability

We have had an extremely busy year working on our Health Research Council funded research in the area of parenting by adults with an intellectual disability. As reported in previous newsletters, this three-year study is designed to capture the experiences of parents who have an intellectual disability. The study has a particular emphasis on determining the features of positive support to such parents, with the parents themselves identifying key supports in their lives. We are currently working with approximately 20 families that include a parent(s) with an intellectual disability and a range of individuals within their support networks. These families are in a range of situations with some participants parenting full time, some who enjoy unsupervised access with their children, and others who see their children in supervised access situations only.

Preliminary findings show quite clearly that parents who have an intellectual disability experience a number of barriers to being able to be good enough parents to their children and, subsequently, experience a high rate of child removal. It is common for parents to be excited about the prospect of having a child but that this excitement can be diminished by the stress and pressure of arranging support and convincing other people that they are competent to parent. It is also difficult for parents to locate and arrange the support that they need to develop competent parenting skills as such support often needs to be high intensity and long-term.

A number of parents participating in the study did not receive any real opportunity to parent their children but continue to express their

desire to develop an on-going relationship with their child(ren). Both mothers and fathers who do not have custody of their children are motivated to maintain a positive relationship with their children as they take a long-term view of this relationship and believe that they may be able to have greater contact with their children as they grow older. However, parents' attempts to stay involved with their children are often perceived by professionals and possibly by foster families as unrealistic and not in the best interests of their child.

It has been common in this study to find that parents do feel as though they have been harshly and unfairly treated by the child protection and legal systems. Furthermore, we have frequently identified that parents are unsure as to why their child(ren) have been removed from their care and/or why they are required to be supervised during access. Both these issues are being explored in greater depth through specific legal research being conducted within the framework of the research.

While this research is currently "in-progress" the importance of this topic has been highlighted by the interest that this study has received over the past year. A report on the study was featured in the Health Research Council Newsletter of this year, and the research has been presented at two international conferences and one national conference during 2006. Two local seminars have been delivered and the study is also being used to inform current policy and service development for parents who have an intellectual disability. The study will be completed in January 2008. Please contact **Brigit Mirfin-Veitch** at the Donald Beasley Institute if you would like any further information about the research.

Peer Abuse In Group Homes For Adults With An Intellectual Disability

The Peer Abuse study is our most recent Health Research Council grant and we are in the very early stages of collecting observation-based data within the group home setting. In New Zealand, approximately 6,700 adults with an intellectual disability live together in groups of four to six unrelated people. This 30-month study has the purpose of exploring the question "What is life really like in group homes for adults with an intellectual disability in terms of friendship and bullying within the home, and how can we understand the multiple factors contributing to these experiences?" The three specific objectives of the research are:

- to learn about intellectually disabled adults' experiences of group living;
- to explore the constructions and understandings of bullying by all of those people involved in residential services;
- to challenge and integrate currently unrelated theoretical and research literature relevant to bullying among adults with an intellectual disability.

The study involves a sample of 10 group homes from a range of disability services and participant observations will be undertaken within those group homes over a period of 12 months. Incident data will also be collected throughout this period. In the second phase of the study individual interviews will be held with people with an intellectual disability, support workers, parents/relatives, and management and governance representatives. The interviews will explore how different stakeholders interpret positive and negative interactions and relationships within the group home setting and will have a particular emphasis on how people perceive their own role in preventing bullying, and promoting non-violence and pro-social, caring behaviours.

CONFERENCES IN 2006

Donald Beasley Institute researchers have had a very busy year attending a range of conferences both nationally and internationally in 2006. Brigit Mirfin-Veitch provided a keynote presentation during the very successful National Residential Intellectual Disability Providers (NRID) Conference in July, along with two research-based workshops at the same event. Brigit also attended and presented at the European Congress of the International Association for the Scientific Study of Intellectual Disability in Maastricht, Netherlands in August. The conference had a strong parenting theme and Brigit valued the opportunity to meet with other researchers working in the area of parenting by people with an intellectual disability. Paul Milner and Sue Gates presented papers relating to their longitudinal Kimberley research project focussing on issues for family and staff respectively. Sue and Paul, along with Nancy Higgins also contributed to the recent New Zealand ASSID Conference held in Wellington. Nancy Higgins and Jude McArthur have contributed to a seminar series hosted by IHC Advocacy in the area of children's advocacy and have participated in a range of other education-focussed forums. Claire Stewart presented on needs assessment and service coordination evaluation research at the Needs Assessment and Service Coordination Association Conference in Hamilton during October.

Research Applications in Submission.

We currently have two research applications submitted to the Health Research Council of New Zealand. Prepared by Dr Nancy Higgins, the two projects are:

Growing up kapo Maori: Whanau, identity, cultural well-being and health.

This study aims to explore how the impairment of blindness affects Maori and how health and education services impact on the identity, cultural well-being and health of kapo.

and

Working in intellectual disability services: Staff retention and turnover.

This study will identify the general demographics and turnover levels of this workforce, the perceived workplace issues, and the factors affecting job satisfaction, stress and burnout.

DBI Lunchtime Seminar Series

During 2006 the staff at the Institute have held a series of lunch time seminars to present their research. The seminars have been well attended and feedback from people attending has been positive.

The 2006 programme is listed below:

Sarah Sharp
Cultural issues and disability research.

Brigit Mirfin-Veitch
Issues in the provision of intimate and personal care for people with disabilities.

Paul Milner
People with disabilities finding their place: The Community Participation Project.

Nancy Higgins
Using the arts to create affirming communities of disabled and nondisabled people" The "Coastal Mappings" and "Macbeth" projects.

Sue Gates
Paid employment for people with intellectual disability? The repeal of the Disabled Persons Employment Promotion Act.

Jude MacArthur
Inclusive education in New Zealand schools – what does the research tell us about where we need to go? The Enhancing Effective Practice in Special Education Project.

Brigit Mirfin-Veitch
Protecting children, strengthening families: supporting the experiences of parents who have an intellectual disability.

Ros McKechnie
What does the research tell us about death, dying and palliative care for people with intellectual disabilities?

Sue Gates & Paul Milner
The impact of institutional closure on long-term staff: The Kimberley Resettlement Project.

Brigit Mirfin-Veitch
Adult siblings talk about their brothers and sisters with an intellectual disability: The Templeton Project.

We invite people to make any suggestions for topics for the seminar programme during 2007.

The Donald Beasley Institute Library

Listed below are some of the new additions to our library this year. A reminder that people can borrow these resources by completing and returning a library enrolment form which can be downloaded from our website. Books are on loan for a period of 2 weeks, with a maximum of 4 resources at any given time. If you would like more information about our library and information service please feel free

to contact me at the following email address or you can give me a call 03 4792162. My hours are Monday to Friday, 9am until 2pm.

Thank you.

Krissy Wright
Information Officer
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NEW BOOKS TO THE LIBRARY

- **A lot to say! A guide for social workers, personal advisors and others working with disabled children and young people with communication impairments**
- **Adults with Down syndrome**
- **Adventures in the mainstream. Coming of age with Down syndrome**
- **Are you listening? What disabled children and young people in Wales think about the services they use. A consultation to inform the children and young people's National Service Framework**
- **Babies and young children in care. Life pathways, decision-making and practice**
- **Brothers and sisters. A special part of exceptional families**
- **Caught between stories: Special education in New Zealand**
- **Challenging behavior and developmental disability**
- **Children taken seriously. In theory, policy and practice**
- **Children, youth and adults with Asperger syndrome**
- **Disabled parents and schools. Barriers to parental involvement in children's education**
- **Eating gluten-free with Emily**
- **Just schools. A whole school approach to restorative justice**
- **Moving on without parents. Planning, transitions and sources of support for middle-aged and older adults with intellectual disability**
- **Palliative care for people with learning disabilities**
- **Parenting with positive behavior support. A practical guide to resolving your child's difficult behavior**

- Special brothers and sisters. Stories and tips for siblings of children with a disability or serious illness
- Special siblings. Growing up with someone with a disability
- The best worst brother
- The birth of an adoptive, foster and stepmother. Beyond biological mothering attachments
- Tools for transition in early childhood. A step-by-step guide for agencies, teachers, and families
- Two-way street. Communicating with disabled children and young people.
- Voices from the spectrum. Parents, grandparents, siblings, people with autism and the professionals share their wisdom
- When I'm away from home
- Your values, my values. Multicultural services in developmental disabilities

Thank you.

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Staff

Associate Professor Anne Bray – Director
Roz Cavanagh – Administrative Secretary
Sue Gates – Senior Researcher
Dr Nancy Higgins – Senior Researcher
Philip Lomas - Library Assistant
Dr Jude MacArthur - Senior Researcher
Roz McKechnie – Administrative Assistant

Dr Brigit Mirfin-Veitch –Assistant Director
Paul Milner - Researcher
Richard Parkinson – Research Coordinator
Sarah Sharp – Research Assistant
Dr Claire Stewart – Senior Researcher
Krissy Wright - Information Officer

Trustees

Mr Peter Cartwright - Chairperson
Mr John Bell
Dr John Clarkson
Mr John Forman

Professor Robyn Munford
Ms Lynne Renouf
Mr Tony Shaw
Ms Suzanne Win

Objectives & Goals

- ◆ To identify critical issues affecting the lives of people with intellectual disabilities in New Zealand.
- ◆ To disseminate relevant research evidence on critical issues.
- ◆ To undertake and disseminate research which contributes to an understanding of the critical issues.
- ◆ To deliver evidence-based information, consultancy services, education and training.