



LifeSpan

Investigating the Mental Health of people
with Intellectual Disability across the LifeSpan

Welcome to the Third Issue of the
LifeSpan Project Newsletter.

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Data Collection Update

No wonder we have been busy. To date, after the three mail outs which have taken in almost all of the southern metropolitan area, we have sent out over 1,800 invitations to participate in the project accompanied with consent letters.

We have received almost 300 consents, all of whom now have the questionnaire booklet to complete. We have nearly 100 returned questionnaire booklets which contain vital and important information. Thank you to everyone who has helped in this process.

The data contained in the booklets will be entered on to the data base at Monash Uni for the Normative study to be completed.

The next area to be incorporated into the LifeSpan process is the Western metropolitan region and you will hear more about that in future editions.

Mental Health of Aboriginal People and Torres Strait Islanders with ID

Aboriginal and Torres Strait Islanders experience higher rates of disabilities and are twice as likely to have profound/severe limitations in their daily living activities. However, due to a distinct lack of research, there is little known about the mental health of Aboriginal and Torres Strait Islanders with an intellectual disability. My research is exploring the prevalence and nature of mental illness of South Australian Aborigines with an intellectual disability.

This involves working closely with the Aboriginal Disability Unit, DSSA Case Managers, SA Aboriginal Disability Network, DECS and Minda in order to develop a more personalised and appropriate method of data collection. I will be exploring the unique cultural factors involved with this population, such as a more holistic view of health/illness, the different perceptions of disability and the possible barriers to service provision.

Phil Flint

The LifeSpan Project newsletter will be a quarterly publication with updates about the progress of our research, useful information relevant to research participants, information about our team members and their extensive experience in the fields of intellectual disability and mental health, and upcoming events.

Why do a 'Normative' study?

All good checklists have 'norms'. These magic numbers mean that one persons situation can be compared to many other people, specifically other people of the same sex, age and level of disability - like comparing apples with apples and oranges with oranges. Not to mention bananas!

You are working with a man in his forties with ID and disturbed behaviour - you assess his behaviour, and want to answer these questions - is this person's behaviour different to another man in his forties with the same level of ID, and if it is different, how much of a difference is there - a little, quite some or a lot?

Only 'norms' will answer these important questions. Where do 'norms' come from? They come from large studies, where hundreds and hundreds of people fill in checklists. These completed checklists are then analyzed and 'crunched', in ways that only experts in statistics really understand, and put into tables.

One day you will be able to turn to the back of a DBC-A Manual and look up the Norm Tables and know that when you filled out a DBC-A for this study you helped put those numbers there for all the world to use!

Caroline Mohr

News Alert.....

The LifeSpan team is giving DBC-A packages to say a big **THANK YOU** to participating agencies and services who have demonstrated extra commitment in assisting with our research. Because if your efforts it may be coming to a team near you!

It pays to get involved!

LifeSpan Events

Expo Displays

On August 2nd the LifeSpan display booth attracted a lot of interest at the Disability Lifestyle Options Expo held at the Wayville showgrounds.

If you missed us you can catch our next display at the Statewide Disability Expo, November 10th at the Morphettville Racecourse, 10am to 4pm. Come along and have a chat and find about how you can get involved or just keep up to date.

Conference Attendance

In May, Phil Flint attended a conference - *Empowering Individuals and Families in the Human Services* - in Melbourne. He also attended a conference "Creating Futures" in Cairns in September.

In October, Barbara Pennington presented her PhD research ideas at an Ageing and Cognition symposium in New Zealand as part of the Australian Psychological Society and New Zealand Psychological Society joint conference.

Industry Partners Meeting

The second Industry Partners Meeting for the year was held on October 20th 2006 at Minda Inc. We will welcome on board Nancy Rogers, Lyn Zeidler and Peter Smith in response to restructure of IDSC to Disability Services SA. This was an opportunity for all the agencies and researchers from Monash and SA to get together, review the past work and plan for the next months together.

Staff Profile: Research Officers

Rafaela Karas and Sharon Stinson are the Research Officers for the project. They are crucial members of our team providing the oil that allows the project to progress smoothly towards its goals. In addition to assisting with numerous administrative tasks they offer the project a wealth of practical knowledge, experience and enthusiasm.

Rafaela is our person "on the spot" at Monash so she provides invaluable assistance with our linkages to other projects and people. She liaises with other researchers and keeps us up to date with the required University processes. Rafaela is a relatively recent graduate of psychology and is keen to continue to develop her clinical knowledge and expertise throughout the project. During October Rafaela will spend a few weeks in France presenting at a conference.

Sharon has more than 18 years experience working with people with an intellectual disability, as a carer, educator and psychologist. In addition to working on the project Sharon works in private practice offering psychology services to people with depressive and anxiety disorders.



Above: Research Officers - Rafaela Karas and Sharon Stinson

Older People with ID

About 3,700 of the Australian Intellectual Disability Population are over 65 years (ABS 2003). The fastest growing section of the population with an ID is the 55-65 year old group.

Life expectancy in 1930 was about 20 years, by 1980's about 60 years. Today a person with mild ID who does not have Down Syndrome may live into their 70's.

People with profound and severe ID still have a reduced life expectancy as a result of neurological deficits and associated disorders. Early/accelerated ageing is most likely associated with undiagnosed and/or untreated conditions.

So our study group (those over 55years) represents the "Healthy Survivors", i.e. people with a mild or moderate degree of ID who have remained relatively healthy.

Older people with ID present with the same issues as the general population but are a more heterogeneous group, therefore age related changes start from widely varying baselines. They (like everyone else) bring into older age their life histories, personalities and pre existing conditions, including mental health problems which may be exacerbated by ageing.

Ageing is an individual and unique experience and process for each of us regardless of ability.

Barbara Pennington



Information and Upcoming Events

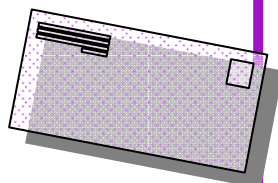
Information Packs - containing information about the project and details about your involvement with the research can be obtained from the address below.

Training - training sessions on the use of the DBC-A and the LifeSpan data collection process will be provided for Disability Services Western Region staff on October 26th at the Western Office. Contact Ann Rymill or Garry Gutteridge for more info.

Mailing list - Let us know if you want to be on our mailing list to receive our newsletters and new information as it becomes available.

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This project is consistent with the Federal Government's National Research priorities and the Third National Mental Health Policy.

Check out our Webpage - www.med.monash.edu/spppm/research/devpsych/lifespan.html and find out more about the project. It will be updated regularly as the research progresses.