

# LifeSpan

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

Welcome to the Eighth Issue of the  
LifeSpan Project Newsletter.

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## DATA COLLECTION UPDATE

The active data collection process has come to an end with a current return rate of completed questionnaires of approximately 73% from the targeted areas. There are still some questionnaires coming in and we are more than happy to continue to receive these.

The team has been busy finalising data collection and entering data. Over 1600 questionnaires have been processed. The next step is to check this information for missing data (such as date of birth and postcodes) and adjust accordingly so you may be contacted to help fill in some gaps.

The team has also completed an error rate check on a selection of questionnaires, in particular for the DBC-A, to ensure that the data has been entered correctly. A 10% error rate is considered acceptable but we have managed to obtain an error rate of only 0.2% so we are very pleased.

The next stage of the project is to start the analysis process. In addition to establishing norms for the DBC-A, Barbara and Phil are starting to look at the data of their respective cohorts: Older People with ID and Aboriginal and Torres Strait Islanders people with ID.

The LifeSpan team would like to sincerely thank the many individuals with an intellectual disability, their families and staff from the numerous agencies who participated in the project.

**We would like to make a special mention of the work undertaken by both Minda Inc and Strathmont who through their support and hard work managed an overall return rate of 81% and 79% respectively. This is a truly fantastic effort, WELL DONE to everyone involved.**

*The LifeSpan Project newsletter is 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.*

## Resource Review

Dementia Screening Questionnaire for Individuals with ID (DSQIID) (Deb, Hare, Prior, & Bhaumik, 2007)

**The DSQIID is the most recent instrument developed to screen for dementia in people with an intellectual disability.**

The questionnaire was developed using a qualitative "bottom-up" approach. Carers of people with Down syndrome and dementia were interviewed and the items for the questionnaire were derived from these interviews. This 3 part scale considers change from the person's "normal" level of functioning. It contains 53 items which are rated by familiar carers.

The DSQIID is easy to use, (taking 10-15 minutes to complete) and to score, each response indicative of change or a new symptom being scored as 1 and others 0. A total score cut off of 20 indicates the person may have a dementing condition. Although the DSQIID was developed using data from adults with Down syndrome the author confirms that it can be used with adults who have intellectual disability who do not have Down syndrome.

The DSQIID was chosen for use in the Lifespan study of older adults as it has robust psychometric properties, is easy and quick to use and to score and is suitable for use to screen for dementia in people with intellectual disabilities.

**It can be recommended as a useful clinical tool to allow early detection and ongoing monitoring of dementia in older adults with ID.**

Deb, S., Hare, M., Prior, L., & Bhaumik, S. (2007). Dementia Screening Questionnaire for Individuals with Intellectual Disabilities. *British Journal of Psychiatry*, 190, 440-444.

## LifeSpan Events

### Conference Presentations

The team presented papers/information sessions at the following:

- an update on the progress of the project to the Parent Association at Minda on June 24<sup>th</sup>. Members of the Board, parents and family members, and staff attended. Prof Bruce Tonge presented an overview of the LifeSpan project, and some preliminary findings. Following the presentation many approached us asking questions and commenting on the importance of the research.

### Upcoming Conference Presentations

The team will be presenting a number of papers during the latter part of 2008 including:

- IASSID Conference in Capetown Sth Africa, Aug 2008
- Disability Expo, October 24<sup>th</sup> 2008
- The ASSID Conference in Melbourne, November 2008.
- Disability SA & NGO Conference in Adelaide, November 2008

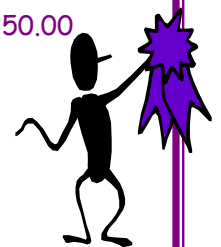
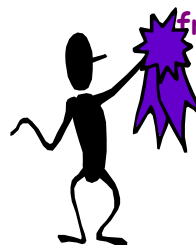
### Winners of the 'Lucky Draw'

By just providing their consent to participate in LifeSpan 2 people from Minda Inc and 2 from Strathmont Centre were the lucky winners of a Woolworth's gift voucher to the value of \$50.00

#### Congratulations to:

Ross Adamson and  
Anna Volkoff,  
from Strathmont Centre

Tracy Malycha and  
Wolfgang Wilhelm  
from Minda Inc



### INTER-RATER RELIABILITY

Part of the research regarding the DBC-A was to investigate the inter-rater reliability of the test. With assistance from both Leveda and Orana DBC-A's were completed for almost 50 individuals by 2 staff members who knew the people well in the same context. Each of these had to be completed within a short time frame of not more than a week

The analysis of this data has indicated that there is an inter-rater reliability of .7 which is high and very pleasing for the designers of the instrument.

### STAFF PROFILE: Debbie

#### Collins (Research Asst- Adelaide)

Debbie has a degree in Disability Studies and is currently studying for a Bachelor of Psychology.

Debbie has worked in the disability field for the past 26 years as a support worker, accommodation service manager and skills trainer/developmental educator.

Debbie has a strong interest in the mental health of people with an intellectual disability.

When not working, studying and spending time with her family Debbie enjoys playing soccer and netball.



### BARBARA'S REPORT



Data collection is now completed and I would like to sincerely thank all who assisted .

We have information for 322 people 55 years and over. In our initial analysis we have found the following:

- 58% are males and 42% females aged between 55 and 86 yrs, (75% of whom are between 55 & 65 yrs)
- 12% have Down syndrome
- 30.4% are living in small CLUs, 24% are in aged care nursing homes and 28% are in large residential facilities. The remainder are living with family, friends or in their own accommodation.
- 29% have a diagnosed mental illness but 37% take medication for behavioural/emotional disturbance
- 5% have been diagnosed with Dementia (70% of these of whom do not have Down Syndrome)
- 77% have chronic medical/ health problems.

### PHIL'S REPORT

Well, the data collection stage of the research project has drawn to an end, and I wish to thank all the people who have been involved in assisting with this process.

We have received 160 completed questionnaires out of 192 clients who were both eligible and able to be contacted - that's over a 83% return rate.

Each region in SA and the NT has at least a 70% return rate and this would not have been possible without the assistance of the Service Coordinators within each region - Thanks to all (and apologies for all the 'humberging'). Particular thanks needs to go to the team who were part of the Aboriginal Disability Unit and are now Service Coordinators in the various regions. Without their ongoing assistance, the return rates would have been much lower.

Thanks also to Danny and the Marla team and the staff in the Aged and Disability Unit in Alice Springs.

Now, its time for all this data to be analysed, written up and presented back. More news to follow.

## 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.

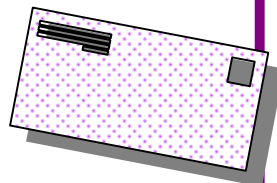
**Mailing list** - Let us know if you want to be on our mailing list to receive our newsletters and new information via email as it becomes available (contact details below).

**Industry Partners Meeting (IPM)** - the last IPM was held on June 2<sup>nd</sup> with some discussion around the increased questionnaire return rate and the process of following-up missing data.

The next IPM is scheduled for October 27<sup>th</sup> at the Child and Youth Specialist Services office (formerly SISS) at Regency Park, 9.30 - 11.30AM.

## Contact Details

Ann Rymill  
LifeSpan Project  
PO Box 34  
Ferryden Park SA 5010  
Ph: 83486500 Fax: 83486599  
[ann.rymill@med.monash.edu.au](mailto:ann.rymill@med.monash.edu.au)



## Research Team

### CHIEF INVESTIGATORS

- ❖ Professor Bruce Tonge
- ❖ Professor Stewart Einfeld
- ❖ Dr Caroline Mohr

Centre for Developmental Psychiatry and Psychology, Monash University

### RESEARCH TEAM

#### Project Manager

- ❖ Ann Rymill  
[ann.rymill@med.monash.edu.au](mailto:ann.rymill@med.monash.edu.au)

#### Higher Degree Research Students

- ❖ Barbara Pennington  
[barbara.pennington@med.monash.edu.au](mailto:barbara.pennington@med.monash.edu.au)
- ❖ Phil Flint  
[phil.flint@med.monash.edu.au](mailto:phil.flint@med.monash.edu.au)

#### Research Officers

- ❖ Debbie Collins (Adelaide)  
[debra.collins@med.monash.edu.au](mailto:debra.collins@med.monash.edu.au)
- ❖ Caroline Keating (Melbourne)  
[caroline.keating@med.monash.edu.au](mailto:caroline.keating@med.monash.edu.au)

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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](http://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.