

RISK FACTOR IDENTIFICATION AND
ASSESSMENT OF ALZHEIMER'S
DISEASE IN ADULTS WITH DOWN
SYNDROME
&
DEPRESSION IN PEOPLE WITH AN
INTELLECTUAL DISABILITY

focus' INDIVIDUALISED SUPPORT
SERVICES

ANNETTE SIPTHORPE
JULIE DUNN
RON HYDER

THE PARTNERSHIPS

STUDY ONE

The partner for the Disability and Dementia (Down Syndrome) study - Centre for Developmental Disability and Health and the Department of Pharmacology, both divisions of Monash University funded by Monash University Faculty Fund.

STUDY TWO

The partner for the Intellectual Disability and Depression study -Deakin University and funded by the Beyond Blue organisation.

THE PASSION

'focus' current strategic plan prioritises collaboration with researchers to enhance knowledge and improve practice in the provision of service to people who have a disability.

STUDY ONE

Risk Factor Identification
and Assessment of
Alzheimer's Disease in
Adults with Down
Syndrome.

- In 2006, CDDHV approached disability services to participate in the study.
- *'focus'* was aware of the current research indicating dementia occurs more frequently and with an earlier onset than the general population, in adults with Down Syndrome.
- *'focus'* was able to identify eligible people that met the criteria.

- The study commenced in July 2007 with CCDHV providing the assessment tools.
- A “referral for service” pre-appointment questionnaire was required to assess the general health of the participants and to establish the personal history of the individuals.
- Researchers specifically requested a staff member who was familiar to the participant, for a period of at least twelve months, support the person during the assessment.
- The questionnaire was reviewed and signed off by the person’s General Practitioner.

- The study was conducted over the course of three two day sessions at '*focus*' Red Hill property.
- Two clinicians assessed the participants.
- On one occasion the clinicians conducting study one chose to remain in the area overnight in nearby accommodation.

- Testing of Language: A set of pre-determined questions were asked and the answers recorded then analysed.
- Testing of Cognitive Skills: A pictorial analysis was shown to the participants and the responses recorded.
- Blood tests were performed to screen for factors that are generally associated with Alzheimer's in the wider population- for example, high cholesterol.
- Participants utilised the pathology services of their choice for the blood collection.
- It was not compulsory to consent to all tests identified to be included in the study

- Individual reports and recommendations were detailed for the person.
- *'focus'* is currently implementing some of the information gathered during the study.

STUDY TWO

Depression and Intellectual Disability.

- The organisation was contacted to participate in the study by the research fellow.
- The Coordinators collaborated with the research fellow to conduct the study.
- Interested staff members from across the organisation were asked to volunteer to participate as facilitators.
- Specific training for 10 members of staff was conducted over two days.

- The Coordinators asked for staff to identify people within the accommodation services who presented with symptoms that may be attributed to depression.
- The “checklist” used by staff to identify suitable people was provided by the clinician.
- Thirteen people were nominated and subsequently interviewed by the researcher.
- Eight people were selected to participate in the study by the researcher.
- Five people chose not to participate or were deemed unsuitable for a variety of reasons.

- The study was conducted over the period of five days between the hours of 9.30am and 3.00pm.
- Participants were transported to the venue and were supported by familiar staff.
- Short breaks were provided throughout the day, 10 minutes for morning and afternoon tea and 45 minutes for lunch.

- Training was delivered in a group situation with all 8 people and 5 support staff.
- Over the five days of the training course, the researcher's tool was used to assist participants to identify the link between thoughts, feelings and behaviors.

I THINK

I FEEL

I ACT

- At the conclusion of the training, the participants were re-interviewed by the researcher three times over a twelve month period.
- The final report is due in December 2009.
- *'focus'* Individualised Support Services recognised the staff's commitment to the study through remuneration.

THE POWER

- Further research associated with Study Two will be delivered in a modified manner.
- Feedback from research clinicians was extremely positive towards '*focus*' as an organisation.

'focus' recognises that ongoing education and training are necessary to ensure that knowledge and skills are current and relevant to needs of the individuals they support.

THE POWER
THE PASSION
THE PARTNERSHIPS



Presenter: Annette Siphthorpe.
siphthorpea@focuslife.com.au
0409 021 656

Julie Dunn.
julied@focuslife.com.au
0409 403 529