Emotional and behavioural problems in Indigenous adults with intellectual disability

Submitted by

Philip James Flint

B.App.Sc. (Disability Studies), Flinders University 1996

School of Psychology and Psychiatry
Faculty of Medicine, Nursing and Health Sciences
Monash University
Melbourne, Australia

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ABSTRACT

Indigenous people experience higher levels of intellectual disability (ID) than the general population. Individuals with intellectual disability also experience higher levels of psychopathology than members of the general population. There is limited data on intellectual disability and the prevalence and nature of psychopathology among Indigenous adults with intellectual disability.

This research aimed to provide a profile of Indigenous adults with intellectual disability and investigate the prevalence and nature of psychopathology in Indigenous adults with intellectual disability living in urban, regional and remote communities of South Australia. It also explored the support needs of Indigenous people with intellectual disability and their carers.

This research project used the Developmental Behaviour Checklist for Adults (DBC-A), a carer-completed checklist, to investigate the prevalence and nature of psychopathology in Indigenous adults with intellectual disability living in South Australia and the Northern Territory.

A further aim was to compare the rates, patterns and differences in the psychopathology of the population of Indigenous adults with intellectual disability to a large community cohort of non-Indigenous Australian adults with an intellectual disability and to better understand the social, cultural, environmental and developmental contexts of disturbed behaviours in Indigenous adults with intellectual disability.

The final aim of the research project was to describe the usefulness and limitations of this carer completed checklist (the DBC-A) in the assessment of psychopathology in Indigenous adults with intellectual disability. Carer-completed screening checklists

have been shown to be effective instruments with which to assess the mental health of

people with intellectual disability and the DBC-A has been proven to be a valid and

reliable tool, extensively used within mainstream Australian populations of adults with

intellectual disability.

In addition qualitative information was collected to further explore various aspects of

intellectual disability and psychopathology in the Indigenous Australian population in

order to increase understanding of how intellectual disability and psychopathology are

perceived by the Indigenous community now, and how that might differ from a

traditional perspective.

Data was collected from carers who knew the adult with an intellectual disability well

using the Lifespan Questionnaire Booklet, which contained the DBC-A and other

questions about a range of demographic information about the individual. Potential

participants for this study were identified from the South Australian Department of

Family and Community Disability Services register. All clients aged 16 years or older

who were identified as an Aboriginal and/or Torres Strait Islander on the register were

eligible to participate. This information was compared to results from a representative

cohort of non-Indigenous Australian adults with intellectual disability. Of a possible

198 adults, 161 participated (an 81% participation rate), thus ensuring confidence in

the representativeness of the findings.

The results show that 29% of Indigenous adults with intellectual disability experience

mental illness which is 40% higher than the non-Indigenous population of adults in

South Australia with intellectual disability. These levels of mental health problems

decreased over the lifespan for both Indigenous and non-Indigenous participants and

were more prevalent in young adult Indigenous males. The research found levels of

mental health problems increased the further people lived from major cities and were the highest in remote communities.

Considering the findings about the higher levels of psychopathology in the Indigenous cohort, it is surprising that when variables such as age and level of intellectual disability were controlled for, this research showed little difference in the rates of psychopathology between Indigenous and non-Indigenous groups. This is possibly further evidence that it is the presence of intellectual disability that is the main determining factor for the higher rates of mental health needs.

While the literature suggests that there are no unique words in Indigenous languages to describe intellectual disability and mental illness, this research found that there were. Further findings suggested that it is traditional understandings and perceptions of intellectual disability and mental health which influences acceptance, care and seeking of services for those with intellectual disability.

Indigenous people with intellectual disability and/or mental health problems can experience similar stigma and marginalisation from their community as occurs in the broader Australian population but often Indigenous carers expressed concern and distress about their family member with a disability being taken away from them and placed in accommodation services a long way from home, which disrupts and fragments family based care, personal identity and creates further mental health problems.

The DBC-A has a potentially useful role in the assessment and management of mental health problems in Indigenous adults with intellectual disability. It is also likely to be a useful research tool, for example, in service planning and epidemiological studies of psychopathology as long as due attention is paid to the context and environment in which it is administered. A personalised interactive process, undertaken by an

assessor who has cultural sensitivity and understanding, or is supported by someone

with these qualities, is required for valid results to be obtained.

STATEMENT OF AUTHORSHIP

I certify that this thesis contains no material that has contributed to the award of another degree or diploma. No information published or written by another person has been included without appropriate citations and acknowledgements in the main text. All research reported in this thesis was approved by the Monash University's Standing Committee on Ethics in Research Involving Humans, Clayton, Victoria, Australia.

Candidate's Name: Philip James Flint

Candidate's Signature:

Date:

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CHAPTER 1

1.1 INTRODUCTION

The health and wellbeing of Indigenous people is an issue of international importance as Indigenous people suffer a higher burden of illness and significantly lower life expectancy (Glasson, Sullivan, Hussain, & Bittles, 2005, p. 74). Improving the health of Indigenous people is a stated priority in many countries including Australia, Canada, New Zealand and the US (Sanson-Fisher, Campbell, Perkins, Blunden, & Davis, 2006).

In Australia, Indigenous people with a disability are often referred to as being doubly disadvantaged (NSW Law Reform Commission, 1996) or multiply disadvantaged (Australian Human Rights Commission, 2008) because they may face more discrimination and marginalisation, jurisdictional barriers and lack of access to culturally appropriate supports than Indigenous people without a disability.

As with many other aspects of Indigenous life very little is known about intellectual disability, particularly prior to colonisation (O'Neill, Kirov, & Thomson, 2004). There is still very little known about this issue today as there has been a distinct lack of research into intellectual disability and related psychopathology within the Indigenous population in Australia. Many reports highlight the urgent need for further research into the prevalence, patterns, and causes of intellectual disability in this population group (Evans, Hunter, Thompson, & Ramsay, 1985).

This thesis will provide a comprehensive profile of Indigenous adults with intellectual disability in South Australia and explore the issue of their mental health. Today, Indigenous people are located in both urban and regional towns and cities as well as in remote areas and traditional communities and homelands. It is important to recognise and appreciate that there are many Indigenous cultures in Australia which each have

their own unique lifestyle, social, cultural, educational, geographical and family background (Brown, 2001).

There are dangers in generalising from the literature and applying this information to specific individuals and communities as much literature found on this subject within Australia is limited to specific groups, communities and regions (Mokak, 1997). What is true of one Indigenous group in Australia is not necessarily true of another person's or group's individual or collective values or lifestyle.

Little is known about the prevalence and nature of psychopathology in Indigenous adults with intellectual disability. The Lifespan research project provided a unique opportunity to specifically study Indigenous adults with intellectual disability and increase our understanding of the nature and prevalence of emotional and behavioural problems in these Indigenous adults with intellectual disability in South Australia. It also provided the opportunity to observe and further explore other aspects of Indigenous disability and psychopathology. For example, Indigenous perceptions and understanding of intellectual disability are explored, together with issues relating to disability support needs and service provision.

The main measure of psychopathology was the Developmental Behaviour Checklist for Adults (DBC-A) (Mohr, Tonge, & Einfeld, 2005), a carer completed questionnaire. The DBC-A has been proven to be a valid and reliable tool in accurately assessing psychopathology within Australian populations of adults with intellectual disability (Einfeld, et al., 2006). The DBC-A was used in a large companion study of the mental health of non-Indigenous people with intellectual disability in South Australia, therefore comparison data was available. One of the subsidiary purposes of this study was to explore if the DBC-A is a practical, reliable and culturally appropriate tool to use with Indigenous adults with intellectual disability. The research was undertaken with a commitment to culturally appropriate and sensitive research methods.

1.2 USE OF TERM INDIGENOUS

The word *Aboriginal* comes from the Latin term *ab origine* which means *from the beginning* and refers to the original inhabitants of a particular place (Moore, 1997). Whilst some researchers may refer to *Indigenous Australians* and others use the term *Aboriginal people* or *Aboriginal and Torres Strait Islanders* when referring to the original inhabitants of Australia pre-colonisation, throughout this paper the term *Indigenous* will be used when referring to people of Aboriginal and/or Torres Strait Islander descent and will encompass the meaning and definition of both Australian Aborigines and Torres Strait Islanders. The term Indigenous is considered to be the politically and academically accepted term in mainstream Australia.

Aboriginal and Torres Strait Islander identification is in accordance with the accepted working definition proposed in the Constitutional Section of the Department of Aboriginal Affairs Report on a review of the administration of the working definition of Aboriginal and Torres Strait Islanders (Department of Aboriginal Affairs Constitutional Section, 1981). The section offered the following definition:

> An Aboriginal or Torres Strait Islander is a person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander and is accepted as such by the community in which he or she lives (Department of Aboriginal Affairs Constitutional Section, 1981, p. 1).

This definition of Aboriginality recognises that Aboriginality is not determined by blood quantum. It is also important to recognise that many Aboriginal people consider that their identity is one of the most important features of their lives.

It is most common for Indigenous people to refer to and identify themselves according to the appropriate local terms. For example, people living in and from the greater Adelaide metropolitan area will refer to themselves as *Nungas,* whereas people from

the north-western areas of South Australia (Anangu Pitjantjatjara (AP) Lands), will likely refer to themselves as *Anangu*. It is also common for individuals to refer to themselves in relation to the particular Indigenous language groups that they identify with, for example, Pitjantjatjara (in far north South Australia), or Ngarrindjeri (the River Murray, Coorong and lower lakes area in South Australia).

Considering that this research will be mainly related to Indigenous people in South Australia, and there are various terms used for self-identity of Indigenous people within South Australia, the appropriate term will be used depending on the situation. For example, if there is information reported on Indigenous people from a specific area such as the Port Augusta region, the term used would be *Yuras,* as opposed to *Aboriginal*, or *Indigenous*. Reporting on a group of people by using specific local terms will only be used when it is clearly appropriate and has been confirmed as the preferred term by the Indigenous people involved in such report.

CHAPTER 2

INTELLECTUAL DISABILITY AND

PSYCHOPATHOLOGY

This chapter provides definitions for the various terms that are related to intellectual disability and psychopathology. A review of assessment, classification and diagnosis issues is included and further information on psychopathology screening instruments for adults with intellectual disability is also included in this chapter.

2.1 DEFINITIONS

2.1.1 MENTAL DISORDER/ ILLNESS

The Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000) defines mental disorder as "a clinically significant behavioural or psychological syndrome or pattern that occurs in an individual and that is associated with present distress (e.g. a painful symptom) or disability (e.g. impairment in one or more important functioning area) or with significant increased risk of suffering, death, pain or disability" (p.xxxi). Examples of a mental disorder as defined here are Schizophrenia and Bipolar Affective Disorder. Although intellectual disability is part of the psychiatric classification system, it is not classified as an axis I mental illness (Deb, Thomas, & Bright, 2001a), but is classified in the DSM-IV-TR under axis II and specified with four degrees of severity (American Psychiatric Association, 2000, pp. 41-49). Psychiatry is primarily concerned with the treatment of mental disorders that adversely affect an individuals mental health and ability to function and maintain an acceptable

quality of life (Holland, 1999). The practice of psychiatry has made rapid progress following the development of agreed diagnostic criteria for specific mental disorders, as described in the American Psychiatric Association Diagnostic and Statistical Manual, 4th Edition (DSM-IV-TR) (American Psychiatric Association, 2000) and the International Classification of Diseases, 10th Edition (ICD-10) (World Health Organization, 1992).

2.1.2 PSYCHOPATHOLOGY

Psychopathology can refer to either the study of mental illness, or the manifestation of behaviours and experiences which may be indicative of maladaptive behaviour or psychological impairment (Oyebode, 2008). The Australian Concise Oxford Dictionary (Moore, 1997, p. 1085) defines psychopathology as a "mentally or behaviourally disordered state, however there is considerable debate in the psychological literature about the definition of psychopathology (Bergner, 1997). Bergner (1997) states that this lack of clarity and agreement about a definition has hampered efforts to study and treat psychopathology.

The definition used in this thesis of psychopathology in relation to adults with intellectual disability is: "Behaviours and emotions which are abnormal by virtue of their qualitative or quantitative deviancy and cannot be explained on the basis of intellectual disability alone, cause significant distress to the person, carers or the community, as well as significant added impairment" (Einfeld & Tonge, 1992, p. xii). This definition was used by Einfeld and Tonge (1992) in the studies of children and adolescents with intellectual disability which led to the development of the Developmental Behaviour Checklist (Einfeld & Tonge, 1992). They adapted it from Reid et al (1978) who derived it from the work of Graham & Rutter (1970).

2.1.3 INTELLECTUAL DISABILITY

Whilst there is no universally adopted term to describe deficits in cognitive functioning and adaptive behaviour beginning in the developmental period, intellectual disability (ID) is the accepted term within Australia and is the term that will be used in this thesis. Efforts by the Association of the Australian Society for the Study of Intellectual Disability (ASSID) have led to acceptance of the term intellectual disability by all Australian government departments and non-government service organisations.

The National Community Services Data Dictionary (Australian Institute of Health and Welfare, 2004b), defines intellectual disability as:

> Intellectual disability applies to conditions appearing in the developmental
> period (0-18 years) associated with impairment of mental functions, difficulties
> in learning and performing certain daily life skills and limitations of adaptive
> skills in the context of community environments compared to others of the
> same age (Australian Institute of Health and Welfare, 2004b, p. 69).

Other accepted terms in current usage internationally are mental retardation (the term preferred throughout most of the USA), developmental disability and learning disability (used in the UK). Other terms such as mental sub-normality, mental handicap and learning difficulty have been used in the past, and are still in use in some contexts today (Priest & Gibbs, 2004).

2.1.4 MENTAL RETARDATION

Mental Retardation, a term synonymous with Intellectual Disability, is used in DSM-IV-TR (American Psychiatric Association, 2000) and ICD-10 (World Health Organization, 1992). The DSM-IV-TR defines mental retardation as a disorder with

an onset before 18 years, characterized by "significantly sub-average intellectual functioning" and "concurrent deficits or impairments in present adaptive functioning in at least two of the following skill areas: Communication, self-care, home living, social/interpersonal skills, use of community resources, self direction, functional academic skills, work, leisure, health and safety" (American Psychiatric Association, 2000, p. 49).

2.1.5 DEVELOPMENTAL DISABILITY

Developmental Disability is a related but different term, defined by the presence of functional limitation in three or more major areas of major life activity originating before the age of 22 and likely to continue throughout one's life (Larson, et al., 2001). Some examples of developmental disabilities are pervasive developmental disorders and cerebral palsy.

2.1.6 LEARNING DISABILITY

The term *learning disability* is used in the United Kingdom interchangeably with intellectual disability and mental retardation, and is based on the same three core criteria of the definition of intellectual disability (significant impairments of intellectual functioning and adaptive/social functioning and onset before adulthood) (British Psychological Society, 2001).

However, in the USA, learning disability is considered to be different from intellectual disability in that it refers to a discrepancy between an individual's apparent capacity to learn and his or her level of achievement.

The National Joint Committee on Learning Disabilities defined learning disabilities as:

"A heterogeneous group of disorders manifested by significant difficulties in the acquisition and use of listening, speaking, reading, writing, reasoning or

mathematical abilities. These disorders are intrinsic to the individual, presumed to be due to central nervous system dysfunction, and may occur across the lifespan. Although learning disabilities may occur concomitantly with other disabling conditions (e.g., sensory impairment, serious emotional disturbance) or with extrinsic influences such as cultural differences, insufficient or inappropriate instruction, they are not the result of those conditions or influences" (National Joint Committee on Learning Disabilities, 1991, p. 19).

2.1.7 DUAL DIAGNOSIS

Dual Diagnosis is a term adopted by American clinicians and researchers to refer to a group of individuals who have two co-morbid conditions, one of them being a psychiatric disorder. The term arose out of a need to make administrative distinctions because funding came from different sources (Russell, 1997). Confusingly this term is now used to refer to two groups of people with co-morbidity, firstly psychiatric disorder and intellectual disability, and secondly psychiatric disorder and substance abuse disorders. Both groups present to psychiatric services with diagnostic and treatment challenges.

In some states in Australia, such as South Australia, the term Dual Disability which refers to the co-existence of intellectual disability and a psychiatric disorder, has been adopted. As the presence of a psychiatric disorder does not necessarily equate with the long-term acquisition of any additional disability, this term will not be used here.

2.1.8 CHALLENGING BEHAVIOUR

In Australia, intellectual disability service systems often describe some disturbed behaviour of people with intellectual disability as 'challenging'. This term was first

defined and used by Emerson (Emerson, Toogood, & Mansell, 1987) in the United

Kingdom.

Severely challenging behaviour refers to behaviour of such intensity, frequency or

duration that the physical safety of the person or others is likely to be placed in serious

jeopardy, or behaviour which is likely to seriously limit or delay access to and use of

ordinary community facilities (Emerson, et al., 1987, p. 166).

Challenging behaviour is not a clinical diagnosis and will not be used here to describe

the behaviour exhibited by people with intellectual disability. In a study by Allen and

Kerr (1994) (cited in Russell, 1997), no significant differences were found between

those people with intellectual disability referred to two separate services, one

providing treatment for challenging behaviour and the other treatment for psychiatric

disorders.

2.2 CLASSIFICATION

As one of the member states of the World Health Organisation, Australia has an obligation to report mortality and morbidity statistics at an international level using the ICD-10 (Janca, 2001). Although the ICD-10 was originally developed as an instrument to classify the causes of mortality as recorded at the registration of death, it has developed over the years to include diagnoses of morbidity and has become the international standard diagnostic classification for all general epidemiological purposes (Janca, 2001).

The Fourth Version of the Diagnostic and Statistical Manual of Mental Disorders, Text Revision (DSM-IV-TR) (American Psychiatric Association, 2000) sub-classification by IQ level into mild, moderate, severe and profound intellectual disability also appears in ICD-10, however ICD-10 provides a more definite delineation for research purposes, in contrast to clinical purposes where flexibility is more desirable. For example in DSM-IV-TR the IQ range for mild intellectual disability is 50-55 to 70, whereas in ICD-10 it is 50-69. The DSM-IV-TR also matches DSM-IV-TR with ICD-10 diagnostic criteria and can be used as a 'cross walk' algorithm for ICD-10 coding purposes (Janca, 2001).

There is a need to improve the consistency of intellectual disability concepts and definitions and to increase the comparability of data collections for different purposes (Wen, 1997).

2.3 PREVALENCE

Intellectual disability affects approximately 1-2% of all Australians (Krahn, Hammond, & Turner, 2006; Wen, 1997). People with intellectual disability have poorer general health and restricted health care opportunities with resultant reductions in their life expectancy (Eastgate & Lennox, 2003; Evenhuis, Henderson, Beange, Lennox, & Chicoine, 2001). However, survival rates have increased dramatically over the last 50 years demonstrated in studies by Bittles et al (2004; 2002) using a state-wide database that spanned 50 years.

The table below presents international estimates of the prevalence of intellectual disability from different data sources, methods and operational definitions adopted from Wen (1997, p.x).

Table 1

Comparison of estimates of intellectual disability (Wen, 1997, p. x)

Estimates of prevalence (%)	Regions	Data sources and methods	Definitions
0.4 – 0.5	Australian States	1983 Agency records	Adapted definitions of AAMR
0.42	Australia	1989-90 national health survey (excluded people in institutions). Mental retardation/specific delays in development as a long-term condition	Adapted ICD-9 classification
0.65	Australia	1993 ABS disability survey. 'Intellectual' as a primary disabling condition. Identified before age 18	Adapted ICIDH concepts and ICD-9 classifications. AIHW groupings
0.73.	Australia	1993 ABS disability survey. 'Intellectual' as a primary disabling condition	Adapted ICIDH concepts and ICD-9 classifications. AIHW groupings
1 – 1.5	World	1992 US Epidemiological studies	AAMR/ICD etc.
1.7	Australia	1993 ABS disability survey, based on screening question of 'slow at learning or understanding'	All people reporting positively to the screening question of 'slow at learning or understanding'
1.86	Australia	1993 ABS disability survey 'Intellectual disability' including all relevant disabling conditions and disorders	Adapted ICIDH concepts and ICD-9 classifications. AIHW groupings
3.0	United States	1970 US President's Panel on Mental Retardation	This theoretical prevalence rate is an extrapolation from statistical models based on IQ scores

2.4 HISTORICAL PERSPECTIVE

2.4.1 PEOPLE WITH INTELLECTUAL DISABILITY

People with intellectual disability have historically been treated by other people in a society as outcasts. Beginning with Hippocrates, Plato and Aristotle, people with intellectual disability have been labelled as 'deviant other' and controlled through laws and policies which both took away the responsibilities of citizenship and the rights that were conferred on people without a disability. People with disabilities were considered to be either of divine (a gift from God) or demonic (arising from the devil) origin, and therefore either protected by their family and the state or murdered or allowed to die in the name of the safety of the larger community (Winzer, 1997).

People with intellectual disability have been referred to, often unkindly, as 'idiots' and 'defectives' and have been feared, rejected and treated with ambivalence (Biasini, Grupe, Huffmann, & Bray, 1999; Parmenter, 2001). The oldest term still in current usage that is used to refer to people with an intellectual disability is 'idiocy', which can be traced back to the 13th century (Patton, Payne, & Beirne-Smith, 1990). Although this word is now in common use as an insult, it stems from the Greek word 'idiotes' which refers to a person who does not take part in public life (Liddell & Scott, 1940). It was replaced by 'feeble-mindedness' in the late 19th century, a term included in the name of the first professional organisation concerned with intellectual disability, formed in 1872, the *Association of Medical Officers of American Institutions for Idiots and Feebleminded Persons*. This association was to become the *Association for Mental Deficiency*, then renamed as the *American Association for Mental Retardation* and as of the 1st January 2007, is now known as the *American Association on Intellectual and Developmental Disabilities* (AAIDD).

Prior to industrialisation, in many cultures a person with an intellectual disability would have been either cared for at home or placed in the care of the state or church and confined to an institution. These large congregate care settings usually also accommodated people with a mental illness and/or violent offenders and were therefore often very unpleasant and dangerous places (Melling & Forsythe, 1999). People with less severe intellectual disability were often able to contribute to family businesses or local work. After the industrial revolution of the 19th century, which resulted in a greater separation of the workplace and home, more people with intellectual disability were marginalised and played a much smaller part in the production of wealth (Rockhold, 2006).

It is only in the last 50 years that the model of accommodating people with intellectual disability in large residential institutions has been replaced by community based accommodation services as alternatives to institutionalised care (Mansell, 2006). This has been one of the most important changes in service delivery policy towards people with intellectual disability up to the present (Mansell & Ericsson, 1996). The principles of deinstitutionalisation were first articulated by Wolfensberger and was termed the 'normalisation' approach to providing services to people with intellectual disability (Kugel & Wolfensberger, 1969). More recently, the term 'social role valorisation' has replaced the term for the principle of normalisation (Wolfensberger, 1983). This 'social model' of disability has given rise to a 'rights based' movement, advocating for people with a disability (Mansell, 2006).

2.4.2 MENTAL HEALTH AND INTELLECTUAL DISABILITY

Although the idea that people with intellectual disability can, and do, experience the full range of mental health problems has received significant attention from researchers for over 20 years (Priest & Gibbs, 2004) distinctions have been drawn

between mental illness and intellectual disability for centuries (Reid, 1989).

Descriptions of co-occurrence of intellectual disability and mental health disorder appeared in the medical literature in the 19th century (Shapiro, 1979). The formal distinction of the two groups only occurred in the UK in 1886 with the Idiots Act, and, in 1913 with the Mental Deficiency Act.

When working with people with intellectual disability, doctors began to write about their observations of disturbed behaviour in their patients which they characterised in psychiatric terms. For example, Wells wrote in 1845 (cited in Reid, 1989, p. 364) about mania and suicidal behaviour in people whose cognitive functioning had been lowered by a goitre condition. In 1866, psychoses in "idiot children" were divided into hyperkinetic and hypokinetic subgroups by Seguin (cited in Reid, 1989, p. 364). Recorded observations of cases of manic depressive psychosis, made by Gordon in 1918 (cited in Reid, 1989, p. 364) in people with intellectual disability highlighted that their delusions lacked "depth and elaboration", and in manic states they lacked "speed in comprehension, wit or humour". These findings are consistent with contemporary comments (Sovner & Pary, 1993).

Throughout the 20th century, there were varied views on the susceptibility of people with intellectual disability to mental health disorders (Wright, 1982). Myerson (1941), (cited in Wright, 1982, p. 498), contended that with increasing intelligence there was a diminishing incidence of mental disease.

Although difficulties in diagnosis were acknowledged (Heaton-Ward, 1977), Penrose (1938) an experienced psychiatrist working and publishing in Britain in the early 1900s claimed that "the problems of separating the effects of low intelligence from those of mental illness were not insoluble" (Heaton-Ward, 1977, p. 525).

Reid (1989, p. 365) reports that by the 1960s "surveys were beginning to suggest a very significant relationship between mental retardation and mental illness". Since then there have been major advances in research and practice, including the proliferation of books and conferences on this subject. In response to the growing awareness of mental health issues with people with intellectual disability, the National Association for the Dually Diagnosed (NADD) was established in America in the early 1980s, and Sovner and Hurley (1982) began their influential *Psychiatric Aspects of Mental Retardation* Newsletter in 1982.

The DSM-IV and ICD-10 have been designed primarily for use with people of normal intelligence, and the clinical features which must present to confirm a diagnosis of mental disorder may be difficult to detect in a person with an intellectual disability, particularly when language skills are absent (Sovner, 1986). This does not mean that the principles inherent in the use of diagnostic criteria do not apply. The concept that psychiatric disorders form discrete syndromes with characteristic emotional features and specific behaviours is equally relevant to individuals with intellectual disabilities (Sovner & Hurley, 1986) and has led to the development of diagnostic classification criteria specific for use in people with intellectual disability, such as the Diagnostic Manual – Intellectual Disability (Fletcher, Loschen, Stavrakaki, & First, 2007).

2.5 COGNITIVE AND FUNCTIONAL ASSESSMENT

The principal method for assessment of intellectual functioning is an individually administered standard cognitive psychological assessment based on the normal distribution of general intelligence, with the presence of an intellectual disability being confirmed when the test performance results in a score of more than two standard deviations below the population mean.

2.5.1 INTELLIGENCE TESTS

The two most widely used intelligence tests are the Wechsler Intelligence Scales, which includes the Wechsler Adult Intelligence Scale (WAIS-III) (Wechsler, 1997a) for use with adults, and the Wechsler Intelligence Scale for Children (WISC-IV) (Wechsler, 2004) for use with children, and the Stanford-Binet Intelligence Scale (SB5) (Roid & Barram, 2004), currently in its fifth edition.

The WAIS-III measures scores across three areas; vocabulary, arithmetic and visual-spatial capabilities and takes into account general knowledge, social awareness and short term memory as well. This is the preferred assessment scale of clinicians to diagnose level of mental retardation in their adult patients (Kaufman & Lichtenberger, 1999).

The Stanford-Binet scale measures intelligence across four areas: Verbal reasoning, quantitative reasoning, abstract/visual reasoning, and short-term memory. Scores are based on the number of items answered, and are converted into a standard age score corresponding to age group, similar to an IQ measure.

2.5.2 ADAPTIVE BEHAVIOUR ASSESSMENT

Despite challenges in defining adaptive behaviour, there exists a variety of scales purporting to measure it. These are usually completed by direct observation and/or in conjunction with at least one informant who knows the person well such as a parent, carer or friend.

The use of adaptive behaviour measurement tools allows the standardised assessment of the level of functioning in daily tasks such as are required in the home, community, and work place. Two main tools are used by professionals:

- The Vineland Adaptive Behavior Scales-Second Edition (VABS-II) (Sparrow, Cicchetti, & Balla, 2005) is a measure of personal and social skills needed for everyday life. Domains assessed include Communication, Daily Living, Motor Skills, and Socialization

- The Adaptive Behaviour Assessment System II (ABAS-II) (Harrison & Oakland, 2003) uses a behaviour rating format to assess adaptive behaviour and related skills for individuals 0 through 89 years of age and provides a number of scales for use with individuals of infant and preschool age, school age and adults. The scale used for adults is The Adaptive Behaviour Assessment System II for Adults (Ages 16-89) (ABAS-II Adult) (see Appendix A). The Adult form includes 239 items, with 20 to 27 items per skill area assessed. Information on children may be provided by parents and/or teachers; information on adults may be provided by significant others, care providers, supervisors, and/or the client. The ABAS-II measures a person's general adaptive behaviour as well as his or her functioning in 10 related adaptive skill areas: Communication, community use, functional academics, school/home living, health and safety, leisure, self-care, self-direction, social, and work (Harrison & Oakland, 2003). It provides a comprehensive, norm-referenced assessment of adaptive skills for individuals aged from birth to 89 years (Harrison & Oakland, 2003).

2.6 MENTAL HEALTH ASSESSMENT

There are many complexities in providing accurate assessments of mental health in people with intellectual disability. For example, symptoms such as self biting or spitting that might indicate the presence of a mental health problem such as an affective disorder in a person with an intellectual disability may not correlate well with

the DSM-IV or ICD-10 diagnostic criteria (White, Chant, Edwards, Townsend, &

Waghorn, 2005).

Sovner and Hurley (1986), highlight other factors that can also compound the

challenges for accurate assessment of mental health issues in adults with intellectual

disability. These include:

- Intellectual distortion: Concrete thinking and impaired communication skills

  effecting the ability to self-report

- Cognitive disintegration: Stress-induced disruption of information processing

  presenting as bizarre behaviour and psychotic symptoms

- Psychosocial masking: Reduced social skills and life experiences leading to

  unsophisticated presentation

- Baseline exaggeration: Pre-existing cognitive deficits and maladaptive behaviours

  that distort symptoms and make interpretation difficult

- Overshadowing: Where the existence of the intellectual disability is regarded as

  sufficient explanation for all behavioural problems (Sovner, 1986).

In addition, phenomena such as talking to oneself and having imaginary friends can be

mistaken for psychopathology in a person with an intellectual disability when it is

appropriate or normal for the developmental age level (Sturmey, 1998). Behaviours of

concern might be due to a number of factors such as in response to an organic,

psychiatric, or environmental causes, or a combination and interaction of these factors

(Borthwick-Duffy, 1994).

2.6.1 DIAGNOSTIC TOOLS

2.6.1.1 DIAGNOSTIC CLASSIFICATION CRITERIA

In order to facilitate a more accurate psychiatric diagnosis of people with intellectual disability, The National Association for the Dually Diagnosed (NADD), in association with the American Psychiatric Association (APA) developed a manual which adapted the DSM-IV-TR, and is called the Diagnostic Manual – Intellectual Disability (DM-ID) (Fletcher, et al., 2007) .

In addition to including the DSM-IV-TR diagnostic criteria with adaptations for the population of people with intellectual disability, this manual provides a description of each disorder, a literature review and discussion of the aetiology and pathogenesis of the various disorders.

An additional diagnostic tool developed for improved psychiatric diagnosis of people with intellectual disability is the Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/ Mental Retardation (DC-LD) (Royal College of Psychiatrists, 2001). This tool has recently been developed by the Royal College of Psychiatrists and is aimed at improving diagnosis, clinical practices and assisting research activities related to adults with an intellectual disability (Royal College of Psychiatrists, 2001).

This classification system is intended to be used with adults with moderate to profound disabilities, although it can be useful with adults with mild or low average intelligence (Cooper, Melville, & Einfeld, 2003).

2.6.1.2 PSYCHOPATHOLOGY RATING SCALES

There is a range of tools currently used for assessment of psychopathology in people with intellectual disability. In relation to adults, there are six comprehensive checklists for psychopathology that have been well researched.

These are the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson, 1988), the Diagnostic Assessment Schedule for Severely Handicapped (DASH-II) (Matson, Coe, Gardner, & Sovner, 1991), the Reiss Screen for Maladaptive Behavior (RSMB) (Reiss, 1988), the Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist (PAS-ADD Checklist) (Moss, et al., 1998) and the Aberrant Behavior Checklist (ABC) (Aman, Singh, Stewart, & Field, 1985).

These checklists all have various psychometric, practical or theoretic limitations (Mohr & Costello, 2007). The sixth checklist, and the one used in this research project, is the Developmental Behaviour Checklist for Adults (DBC-A) (Mohr, et al., 2005). The DBC-A was based on the existing Developmental Behaviour Checklist (DBC) for children and adolescents with intellectual disability (Einfeld & Tonge, 1992, 1995; 2002) and was developed because of the need to have an additional checklist which could be used with adults with intellectual disability. The DBC checklists are further discussed below. These checklists for psychopathology in adults with intellectual disability can generally be categorised into either clinician administered scales, or scales that are completed by the individual with an intellectual disability, a caregiver, or someone who knows the individual with an intellectual disability well.

There are two main psychopathology scales which are required to be administered by a clinician:

1. Diagnostic Assessment for the Severely Handicapped –II (DASH-II) (Matson, 1995)

2. Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson, Kazdin, & Senatore, 1984).

There are four main psychopathology scales which are carer-completed, or self-report scales:

1. Assessment for Dual Diagnosis (ADD) (Matson & Bamburg, 1998)

2. Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD) (Moss, et al., 1998)

3. Reiss Screen for Maladaptive Behavior (RSMB) (Reiss, 1988)

4. Anxiety Depression and Mood Scale (ADAMS) (Esbensen, Rojahn, Aman, & Ruedrich, 2003).

Depression in people with intellectual disability may not be accurately diagnosed and treated (Einfeld & Tonge, 1996b; Evans, Cotton, Einfeld, & Florio, 1999). A variety of scales have been designed to specifically assess depression in people with intellectual disability. These include:

1. The Self Report Depression Questionnaire (SRDQ) (Reynolds & Baker, 1988) which was designed to assess depression in people with mild to moderate intellectual disability, as opposed to those with a severe or profound intellectual disability

2. The affective disorder subscale of the Psychopathology Instrument for Mentally Retarded Adults (PIMRA) (Matson, 1988), which was based on the DSM-III criteria

3. The Reiss Screen for Maladaptive Behavior (RSMB) (Reiss, 1988) includes subscales for depression (behavioural signs) and depression (physical signs) and can be used for people with all ranges of intellectual disability.

2.7 DEVELOPMENT OF THE DEVELOPMENTAL BEHAVIOUR CHECKLISTS

The Developmental Behaviour Checklist (DBC), (Einfeld & Tonge, 1992, 1995; 2002) is a reliable and valid, widely used 96 item carer-completed rating scale for the comprehensive survey of a broad range of behavioural and emotional disturbances in young people (aged 4-18 years old) with intellectual disability. It is completed by parents or other primary carers or teachers, reporting problems over a six month period. The DBC shares the structure of the Child Behaviour Checklist (Achenbach & Edelbrock, 1983) with each behavioural description being scored on a 0, 1, 2 rating (where 0= not true as far as you know, 1= somewhat or sometimes true, and 2 = very true or often true). The items were independently derived from a study of the descriptions of behavioural and emotional disturbances in the medical files of 7000 children with intellectual disability seen in a developmental assessment clinic.

2.7.1 DIFFERENT VERSIONS OF THE DEVELOPMENTAL BEHAVIOUR CHECKLISTS

2.7.1.1 DBC FOR 4 – 18 YEAR OLD YOUNG PEOPLE

There are two versions of the DBC for use with young people (aged 4-18 years old), the DBC – P (Primary Carer Version), (Einfeld and Tonge 1992) and the DBC-T (Teacher Version) (Einfeld & Tonge, 1992, 2002). The DBC-P has been translated into other languages, namely Arabic, Chinese, Croatian, Dutch, Finnish, French,

German, Greek, Hindi, Japanese, Norwegian, Portuguese, Portuguese (Brazil),

Spanish, Swedish, Turkish and Vietnamese.

Scoring is done at three levels:

1. *The Total Behaviour Problem Score (TBPS)* is an overall measure of emotional and

behavioural problems. The DBC can also detect clinically significant levels of overall

emotional and behavioural disturbance (a cut-off score of 46 or greater).

2. *Five subscales (derived from factor analysis)* - scores give a measure of disturbance

across five sub-scales: Disruptive/Anti-social Behaviour, Self-absorbed,

Communication Disturbance, Anxiety and Social Relating.

3. *Individual behaviour items* – indicates the prevalence and severity of individual

items.

The DBC–Early Screen (DBC-ES)(Gray & Tonge, 2005) consists of a 17 item

screening algorithm within the DBC-P which have been shown to be effective screens

for Autism in young children (aged 4-18 years) with a developmental disability (Gray,

Tonge, Sweeney, & Einfeld, 2007).

An additional algorithm, the DBC-ASA was developed from the DBC by selecting a

29 item scale as a screening tool for autism in children (aged 4-18 years old) and has

been shown to be a reliable and valid Autism screening tool (Brereton, Tonge,

Mackinnon, & Einfeld, 2002).

2.7.1.2 DBC-A

The Developmental Behaviour Checklist for Adults (DBC-A) (Mohr, et al., 2005) was

developed for use with adults with intellectual disability (aged 18 years or older) and

is completed by the carer of the individual with an intellectual disability (somebody who knows the individual well).

It has 107 items and employs the same three-point rating scale as the DBC-P. It utilises six subscales derived from factor analysis (Disruptive, Self-absorbed, Psychological Disturbance, Antisocial, Social Relating and Depressive) as well as a total behaviour problem score (TBPS) which is worked out by calculating the total score of all of the items.

2.7.1.3 DEVELOPMENT OF THE DEVELOPMENTAL BEHAVIOUR CHECKLIST FOR ADULTS

The DBC-A was developed by changing, adding and deleting items from the DBC-P and has been shown in studies to be a reliable and valid tool with satisfactory psychometric properties to be described later (Mohr, et al., 2005).

The selection of items for the DBC-A utilised the same process of checklist construction that was used by Einfeld and Tonge for the DBC-P (1992). The process of adaption began with a file review of 605 files of clinical descriptions of emotional and behavioural disturbances in adults with intellectual disability made available from the Centre for Developmental Disability Health Victoria (CDDHV). The files contained clinical information recorded by CDDHV clinicians and reports from parents, teachers, intellectual disability service workers, psychologists, psychiatrists and other health specialists.

Graham and Rutter's (1970) definition of disturbed behaviour and emotion was then employed to guide item selection:

> Where behaviours and emotions are abnormal by virtue of their qualitative or quantitative deviancy and cannot be explained on the basis of developmental delay alone, and cause significant distress to the person, carers or the

community, as well as significant added impairment, then they will be

regarded as disordered (Einfeld & Tonge, 1992; p. xii).

In addition, those behaviours that could be explained solely on the grounds of

developmental delay or attributable solely to physical disorder were excluded from the

descriptions of disordered behaviour.

This definition of disturbed behaviour (Graham & Rutter, 1970), used in the

development of the DBC differs from the definitions of mental disorder employed in

the International Classification of Diseases – Tenth Revision (ICD-10) and the

Diagnostic and Statistical Manual of Mental Disorders – Fourth Edition (DSM-4).

The differences recognise that the individual will already be somewhat impaired "in

one or more functioning areas" (American Psychiatric Association, 1994, p. xxi)

because of their intellectual disability, and that it may not be the person affected who

is able to report on their distress and suffering.

The resulting descriptions of behavioural and emotional disturbances were matched

with items from the DBC-P, synonymous terms reduced to single terms, and existing

DBC-P items were reviewed to ensure appropriate wording for adults.

These methods of item selection resulted in the deletion of one DBC-P item, changes

to the wording of seven DBC-P items and the inclusion of an additional 12 new items

to construct the DBC-A.

2.7.2 PSYCHOMETRIC PROPERTIES

2.7.2.1 RELIABILITY

Test-retest and inter-rater reliability studies were undertaken in the development of the

DBC-A with separate groups of paid carers and family carers.

The test-retest reliability study with paid carers investigated the relationship between the Total Behaviour Problem Scores (TBPS) of two DBC-As that were completed by the paid carer with a two week break in between the times of completing each one. This relationship was investigated using the Intraclass Correlation Coefficient (ICC) and found a strong positive correlation between the two scores (ICC = 0.75, n = 34, 95% CI 0.55- 0.86).

The same method was used with family carers and found a similar strong correlation between the two scores (ICC = 0.85, n = 52, 95% CI 0.75 – 0.91) indicating high levels of test-retest reliability. There was not a significant difference between the two mean DBC-A TBPSs from rating time one to rating time two (see Table 2 below). An inter-rater reliability study was conducted with paid carers (*N*=38, ICC= .70, 95% CI .54 - .86) and family carers (*N*=27, ICC= .72, 95% CI .48- .86).

Table 2

DBC-A reliability results

		N	ICC	95% CI	t	df	Sig. (2-tailed)
Test-retest reliability	Paid carers	34	.75	.55 - .86	3.88	33	.000
	Family carers	52	.85	.75 - .91	.25	51	.81
Inter-rater reliability	Paid carers	38	.70	.54 - .86			
	Family carers	27	.72	.48 - .86			

2.7.2.2 VALIDITY

There is a high correlation between the total score on the DBC-A and two other measures of behavioural and emotional disturbance in Adults with intellectual disability, the Aberrant Behaviour Checklist (ABC) (Aman, et al., 1985) and the Psychiatric Assessment Schedule for Adults with Developmental Disability Checklist (PAS-ADD) (Moss, et al., 1998).

The relationship between the TBPS on the ABC and the DBC-A was investigated using Pearson Product Moment correlation coefficient and found that there was a strong positive correlation between the two variables ($r = 0.63$, $n = 77$, $P < 0.001$), with high scores on the ABC associated with high scores on the DBC-A.

The relationship between total scores on the PAS-ADD Checklist and the DBC-A was investigated using Pearson Product Moment correlation coefficient and found that there was a strong positive correlation between the two variables ($r = 0.61$, $n = 70$, $P < 0.01$), with high total scores on the PAS-ADD associated with high total scores on the DBC-A.

The total score on the DBC-A also correlates with clinician ratings of the presence and severity of psychopathology using Rutter's (1970) definition. The scale has high criterion group validity in distinguishing psychiatric cases from non-cases

2.7.2.3 READABILITY OF THE DBC-A

The readability of items in the DBC-A was determined by computing the Flesch Grade Level using Microsoft Word, with a result of a Flesch Grade Level of 6.4.

This finding compares favourably with the same statistic computed for DBC-P (Flesch Grade Level = 7.3), demonstrating that changes and additions to the DBC-P have not produced a new checklist that is more difficult for carers with a primary level of education to read, understand and complete.

2.7.2.4 FACTOR STRUCTURE

The internal structure of the DBC-A was ascertained by an analysis of the principal components on a matrix of polychoric correlations. Using the factor analysis program Mplus (Muthén & Muthén, 1998), an oblique rotation (Promax) was performed on the resulting 5 and 6 factor solutions.

Internal consistency was calculated using SPSS 10 (SPSS, 1999) and the effect on internal consistency of removing any single item was tested. Cronbach's alpha was not significantly increased by the exclusion of any item (range = .9462 - .9477). The factor structure, variance and internal consistency of the six subscales of the DBC-A are described in Table 3 below.

Table 3

Factor structure, variance and internal consistency

Factors and highest loading items*	% of variance	Internal consistency (Cronbach's α)
Disruptive (tantrums, irritable, whines, kicks, impatient, mood)	11.6	.91
Psychological Disturbance (talks to self, thoughts, echo, repeats, talks fast, pronouns)	9.9	.86
Self-Absorption (hums, danger, soils, urinates, flicks, laughs)	7.6	.84
Antisocial (steals, lies, manipulates, hides, easily led, impulsive)	6.9	.85
Depressive (withdrawn, lost enjoyment, communicating, lost self-care, sleeps much, appetite)	6.7	.80
Social Relating (on own, affection, cuddled, eye contact, feelings, aloof)	4.5	.77
Total scale	47.2	.84

* Abbreviated item descriptions

2.8 LIMITING FACTORS IN THE USE OF CHECKLISTS

There are limitations in using checklists and rating scales to assess behavioural and emotional disturbances in adults with intellectual disability. In relation to the DBC-A these include:

1.   Checklists and rating scales used in clinical practice should only form part of a comprehensive assessment of the mental health of a person with an intellectual

disability, and should never be relied upon solely to provide a diagnosis (Einfeld & Tonge, 2002). A comprehensive mental health assessment of a person with an intellectual disability should include, wherever possible, an interview of the person, opportunities to observe the person in a home or work setting, interviews with carers, an appropriate medical review, tests and investigations and the selective use of a range of assessment instruments. This process may take longer to complete than mental health assessments of people without disabilities. A checklist such as the DBC-A used for screening of emotional and behavioural disorders should be followed, where indicated, by assessment with a specialist in the area. Conversely the specialist can use the DBC to complement the diagnostic assessment.

2.   When a carer completes a checklist they are providing information that may be a biased or incomplete picture of what may be a complex situation. Some checklist developers recommend that a checklist should be completed by two carers separately, and the results compared. (e.g. Reiss, 1988). In situations where different raters are unavailable, the ratings of one carer who knows the person well is acceptable because the DBC-A has satisfactory levels of inter-rater agreement.

3.   Carer-completed checklists and rating scales are not able to make a diagnosis of a specific psychiatric disorder. Even when a cluster of items is selected by a carer which appears to point to a diagnosis such as depression, it does not indicate that the person actually has this disorder. They may be physically unwell, or have a related disorder or no disorder at all. At best the checklist result might indicate the need for a clinical assessment and raise the possibility of the presence of a disorder.

4.   A checklist completed at a certain time is a snapshot of the current or recent

      situation. A person's mental health can change even in the absence of known

      interventions or changes in circumstance. It has been established that the DBC-

      A is a reliable measure to track change (Clarke, Tonge, Einfeld, & Mackinnon,

      2003). In addition the suggested rating period on the DBC-A of six months may

      not give a clear picture of the current presentation of a person with an

      intellectual disability. Further investigation is required to explore how the DBC-

      A performs as a screening instrument when an adult with an intellectual

      disability has a diagnosis of a disorder which is often episodic, such as mania.

      This issue was raised by Moss et al. (1998) in relation to the performance of the

      PAS-ADD in identifying psychiatric cases for adults with intellectual disability

      diagnosed with a Bipolar Disorder. It was also identified in a previous study of

      the DBC-A as a possible explanation for some instances of disagreement

      between the DBC-A TBPS and the clinician's ratings of psychiatric caseness

      (Mohr, et al., 2005). A related issue may be the question of the performance of

      the DBC-A in instances of a deterioration in a person's functioning such as that

      seen in cases of dementia. The repeated use of the DBC-A may prove useful in

      tracking behavioural and emotional changes related to cognitive deterioration.

5.   The DBC-A was developed in Australia. When it is used in different countries,

      or even within the Australian Indigenous population, cultural differences may

      need to be considered. It is possible to translate the DBC-A into other language

      versions using the back translation method (Streiner & Norman, 1995), as has

      been done with the DBC-P (Einfeld & Tonge, 2002). Further validation and

      normative studies would be required for any other language version of the DBC-

      A.

2.9 PREVALENCE OF MENTAL ILLNESS IN ADULTS WITH INTELLECTUAL DISABILITY

There are numerous problems in attempting to establish the prevalence of mental health issues in people with intellectual disability. Although many claims have been made over the past 30 years that adults with intellectual disability experience higher rates of mental illness than members of the general population, the evidence to support this contention remains controversial (Deb, Thomas, et al., 2001a).

Many of the studies to date have had some methodological limitations and have led to a wide range of reported psychopathology prevalence rates, from 7% to 97% (Borthwick-Duffy, 1994; King, DeAntonio, McCracken, Forness, & Ackerland, 1994; Wright, 1982)

Although there are differing opinions regarding the prevalence rates of mental health issues in people with intellectual disability (Cooper, Smiley, Morrison, Williamson, & Allan, 2007; Reiss, 1990), recent studies suggest that the prevalence of mental illness in adults with intellectual disability is higher than within the general population (Borthwick-Duffy, 1994; Campbell & Malone, 1991; Chaplin, 2004; Dosen & Day, 2001; Hatton, 2002; Jopp & Keys, 2001; Maughan, Collishaw, & Pickles, 1999; Moss, 2001; Rymill, 2001; Simpson, Creed, & Moss, 1998). If this is correct, it suggests that people with intellectual disability are predisposed to developing a mental illness.

There is evidence of a higher rate of mental illness in adults with severe intellectual disability compared with people with mild intellectual disability, or those without intellectual disability (Birch, Richardson, Baird, Horobin, & Illsley, 1970; Gillberg, Presson, Grufman, & Themner, 1986; Gostason, 1985; Strømme & Diseth, 2000).

Problems in accurately reporting on prevalence rates stem from two main factors:
Identification and definitional issues, and the methods used in collection of the data
(Jacobson, 1990; Priest & Gibbs, 2004).

Results between studies cannot be directly compared for the following reasons:

- There are different ways to report prevalence, for example, point prevalence or
  lifetime prevalence. Researchers often fail to report which timeframe they
  used and therefore results cannot be compared (Hudson & Chan, 2002)

- The assessment of behaviour and mental disorders have been confused in many
  studies, only occasionally being assessed and/or reported separately
  (Borthwick-Duffy, 1994; Deb, Matthews, Holt, & Bouras, 2001; Deb, Thomas,
  & Bright, 2001b)

- Researchers have studied both children and adults in various residential
  settings with all degrees of intellectual disability, often without reporting rates
  for the respective groups separately. For example, there are difficulties in
  reporting on the rates for adults in an institution in the 1990s, compared to
  rates for children, or any other groups within the community, or even to adults
  living in institutions in the 1960s because of changes in service philosophy and
  delivery (Hudson & Chan, 2002)

- Sample studies within the community have often been administratively derived
  and not representative of the population of people with intellectual disability as
  a whole. For example, the results from studies of people referred to specialist
  services are unable to be generalised to the broader population of people with
  intellectual disability. Many studies struggle to include many people with mild
  intellectual disability, many of whom are 'submerged' in the general
  community (Einfeld & Tonge, 1996a)

- The definitions of a mental disorder, a psychiatric problem or an intellectual disability have changed over the time in which the research was done and from study to study, providing limited meaning to the comparisons (Priest & Gibbs, 2004)

- Different methods of assessment have been used in various studies, for example, a psychiatric interview by a specialist psychiatrist, a checklist or rating scale completed by a carer, or a review of clinic files (Deb, Matthews, et al., 2001).

The studies conducted in the UK prior to 1980 were reviewed by Wright (Wright, 1982), starting with the landmark clinical and genetic study of 1280 people with intellectual disability by Penrose (Penrose, 1938). Although Wright recognised the differences between, and flaws in most studies, she concluded that her review confirmed the studies of Heaton-Ward (Heaton-Ward, 1977). Heaton-Ward's research found the rates of mental disorder in the population of people with intellectual disability were probably similar to rates in the general population (Office of Population Censuses and Surveys, 1974).

Singh, Sood, Sonenklar, and Ellis (1991) conducted a review of studies conducted in the 1970s and 1980s which estimated the prevalence of mental illness in individuals with an intellectual disability (Heaton-Ward, 1977; Jacobson, 1982; Matson & Frame, 1986; Reiss, 1982; Rutter, Tixard, & Whitmore, 1970) and concluded that:

1. 8-10% of individuals with an intellectual disability living in institutions have a severe mental disorder requiring treatment

2. Approximately 50% of people with intellectual disability living in an institution are likely to have at least one identifiable psychiatric disorder

3. 20-30% of children with intellectual disability residing in institutions had a mental disorder

4. 20-35% of children with intellectual disability living in the community have a diagnosable mental disorder, compared to only 14-18% of children in the general population

5. Reliable data on the prevalence of mental illness in adults with intellectual disability living in the community was not currently available (Singh, et al., 1991, p. 422).

A study by Reiss (1990) of 205 people with intellectual disability in institutional care found that 31% of the total sample of 205 met the criteria for clinical diagnosis of a mental illness. In another small prevalence study of a community group (n=180), using the RSMB as a screening tool, Sturmey and Colleagues (1996) report an even higher finding of 49%.

This review of the literature suggests that the highest rates are found when screening questionnaires are used and rates are lower when relying on clinical records and interviews.

Ballinger's study of 100 adults in a Scottish institution (Ballinger, Ballinger, Reid, & McQueen, 1991) was rigorous in the use of psychiatric interviews and ICD-9 diagnostic criteria and they found a prevalence 58%.

Collacott and colleagues (1992), conducted a study of people with Down Syndrome (DS) with a matched control group of adults with intellectual disability (due to other pathologies than Down Syndrome) and matched on the basis of age, sex, and type of residence, examined clinical records to find that 51% of the group with Down Syndrome, and 68.5% of the matched controls had undergone a psychiatric

assessment, with 26% of the Down Syndrome group, and 38% of controls receiving a diagnosis.

Rojahn and colleagues (1993), reported an analysis of a very large database from California (*N*=89,000, 91% adult) and New York (*N*= 45,000, 51% adult) intellectual and developmental disability service registers. Within the adult component of the cohort, in New York the majority (59%) of diagnoses were made up of Attention Deficit Hyperactivity Disorder (ADHD), conduct disorder and Pervasive Developmental Disorder (PDD), whilst in the Californian adult cohort these disorders comprise less than a quarter of the group, with schizophrenia making up nearly half of the total. Unfortunately, due to the magnitude of these differences in proportion to diagnosis it was not meaningful to determine an overall period prevalence.

Meins (1993), reports a prevalence study of depressive disorders in an unrepresentative sample of adults with intellectual disability living in and around Hamburg (n=798). The sample included a mix of subjects living in group homes, institutions and a psychiatric hospital. Meins elected to use the Children's Depressive Inventory (CDI) (Kovacs, 1985) as an initial screening instrument, followed by a psychiatric examination (which was not elaborated on) that he conducted of both low and high CDI scoring subjects, who were diagnosed according to modified DSM-III-R criteria. Unfortunately, these findings are compromised because they relied on the diagnostic opinion of only one clinician who additionally, was not blind to the CDI score of each subject examined.

Crews, Bonaventura et al. (1994), studied the case records of an institutionalised group comprising over 80% of people with severe or profound intellectual disability but containing very few people with a mild intellectual disability (3%). Considering that institutional groups are likely to contain disproportionately large numbers of people

with mental health problems, the finding by Crews that the point prevalence rate of a psychiatric disorder was close to that found in the general population might be accounted for by the difficulty that clinicians have in diagnosing psychiatric disorders in people with severe and profound intellectual disabilities or by diagnostic overshadowing where the clinician regards behavioural problems as simply being due to the intellectual disability.

Haveman and colleagues (1994), investigated the mental health status of a stratified sample of adults with intellectual disability living in group homes and institutions in the Netherlands. Psychiatric disorders were reported by the general practitioners, who were specialists in working with people with intellectual disability. Psychiatric assessments performed by these GPs were conducted in a non-standardised way. This component of study design is problematic, and makes the study conclusions difficult to interpret. This study found a prevalence of 23-29%.

Cooper conducted a study (1997) which has many advantages over other studies. Older people (>65 years) registered for Learning Disability services, and a random sample of younger people with intellectual disability from the same area, were individually assessed using well-described instruments, and where standard diagnostic criteria were modified, the modifications were outlined. Although the overall results of prevalence of psychiatric disorder in both groups were high (older group, 68%; younger group 48%), when dementia, possible dementia, Rett Syndrome, alcoholism, autism, and behaviour disorder are removed from the overall totals, the point prevalence rates are almost the same for both groups at approximately 20%.

Simpson (1998) reports the results of a small but methodologically strong study conducted in North-West England. The research sample of adults with intellectual disability was randomly selected from the register of adults with intellectual disability

who were using health and social services. Ninety three adults and their carers were interviewed by a psychiatrist specialising in intellectual disability psychiatry, using a structured interview schedule (the Psychiatric Assessment Schedule for Adults with Developmental Disability (PAS-ADD) (Moss, Prosser, Ibbotson, & Goldberg, 1996)). The interview record was examined to ascribe DSM-IV diagnoses, and 24 individuals received a diagnosis (two delirium, three psychoses, three depression, one mixed affective disorder, 11 anxiety disorder, and four hypersomnia). The one-month period prevalence of an Axis 1 disorder was therefore 25.8% (Simpson, 1998), considerably higher than the prevalence rate for the general population of 16% (Jenkins, et al., 1997). The authors conclude "the sample size is too small to make statistical comparisons" (Simpson, 1998, p. 41).

Maughan, Collishaw and Pickles (1999) report data from a population study of people with a mild intellectual disability from the National Child Development Study, which was a prospective study of all children in Britain born in one week in 1958. This study is valuable because few studies of adults with intellectual disability include people with mild intellectual disability because they often blend into the general population after leaving school. Unfortunately the measure used to assess mental health status, The Malaise Inventory, (Rutter, et al., 1970) is not a widely used instrument and reported only on affective symptoms. Nonetheless, the results of a four to five times higher rate of affective disorder in the intellectual disability group are striking. These authors also compare the results with the bulk of the cohort, and attempt to determine what factors may have influenced the findings. They contrasted a range of measures relating to adult status and functioning and found that the individuals with an intellectual disability faced considerably higher rates of experiencing poor living circumstances and social conditions and multiple periods of unemployment and had a

higher proportion of candidates completely out of the labour market compared to the cohort without intellectual disability (Maughan, et al., 1999). Maughan concluded that men and women with intellectual disability showed a higher risk of psychiatric morbidity in adulthood than the comparison cohort of participants.

A study by Morgan, Ahmed and Kerr (2000) produced an overall prevalence of 16.5%, a much higher finding for an ex-institutional group (42.1%), and a lower rate for a presently institutionalised group (11.3%) and those in the community (15.6%).

Richards, Maughan, Hardy, Hall, Strydom and Wadworth (2001) report findings from another British cohort, the Medical Research Council's National Survey of Health and Development 1946 birth cohort. Again these findings inform the limited information available on the lives and circumstances of people with mild intellectual disability, although the numbers are even smaller than the Maughan (Maughan, et al., 1999) survey. The measures used across this cohort were not validated for use with people with intellectual disability. However for people with mild intellectual disability this may be less of a concern, and they were interview, not self-report measures. Their findings that 19.5% of all participants with intellectual disability scored above the cut-off of the Psychiatric Symptom Frequency Scale (Rodgers, 1994) seem to confirm the earlier reports of Maughan (1999) on prevalence of psychopathology within this population, but they did not agree that early disadvantage was a predictor of poorer mental health.

In a recent methodologically sound study, Deb, Thomas and Bright (2001a) interviewed 101 people with intellectual disability and their carers (from a random sample of 120), known to services in a region of Wales, using instruments with known psychometric properties developed for use with people with intellectual disability. The screening tool Mini PAS-ADD, (Prosser, et al., 1998) identified 22% of

participants as having a psychiatric disorder. The follow-up interview by a psychiatrist (who was blind to the screening result), confirmed a diagnosis in 14.4%. This is a lower rate than the 16% point prevalence rate quoted for the general population, although the rates of schizophrenia and phobic disorder were much higher. Two attempts at estimating prevalence in adults with intellectual disability in Australia have been conducted in Victoria and South Australia. Although it is not explicitly stated in either study, it is likely that most of the clients identified by these surveys lived in the community, because the majority of people with intellectual disability in Australia now live in community based accommodation (Australian Institute of Health and Welfare, 2007).

Firstly, in Victoria a survey of intellectual disability services case managers was undertaken by the Disability Services Branch of the Department of Human Services. The survey asked case workers to identify from 1776 current clients, those current case managed clients with intellectual disability who were either formally diagnosed with a psychiatric disorder those or who 'informally' appeared, in the opinion of the case worker, to have a psychiatric disorder. Ninety-five percent of clients were aged over 15 years. The questionnaires were returned by 64% of the workers, who identified 10.8% of clients with a formal diagnosis, and 7% as possibly having one. Nearly half of the clients with an informal diagnosis had had a formal diagnosis in the past (Disability Services Branch, 1996).

Secondly, a small Dual Disability Service (Rymill, 2001) in South Australia surveyed staff in government and non-government services for adults and children with intellectual disability. The survey questionnaire contained seven 'indicators' that a person might have a mental illness, ranging from 1: Departure from the person's usual pattern and/or level of functioning, to 4: Clusters of symptoms which fit standard diagnostic criteria, to 7: Past or current treatment from a mental health service or

private psychiatrist. Any three out of the seven criteria were taken to indicate that the person had a psychiatric disorder. The overall prevalence rate of psychiatric disorder for adults with intellectual disability was 16.2% (A. Rymill, personal communication, June 2002).

One further publication sheds some light on adult prevalence in the Australian context. In 1991 Einfeld and Tonge (1991) surveyed the mental health of an epidemiologically derived representative sample of 480 children and adolescents with intellectual disability aged 4 -18 years. Psychopathology was assessed using the Developmental Behaviour Checklist – Primary Carer version (DBC-P) (Einfeld & Tonge, 1992), with the cohort being followed up at three-four yearly intervals. The subjects (80% of the original group) were reassessed at Time Two in 1995/96 when nearly half were aged 17-24 years. The 1991 study identified that 43.3% of the cohort rated over the well-defined DBC-P cut-off score for psychiatric caseness. The 1995 study showed that whilst the overall rate of psychiatric caseness had significantly reduced, it still was relatively high at 38.6%. The results showed that the overall level of psychiatric disturbance improved for 15% of the participants and deteriorated for 13% of participants between Time One and Time Two (Tonge & Einfeld, 2000). This ongoing study has concluded that the prevalence of mental illness in young adults with intellectual disability is at least twice that of the general population (Tonge & Einfeld, 2000).

Summarised on Table 4 are the findings of the studies on the prevalence of psychopathology in adults with intellectual disability reported from 1990 to 2007. Even though there is such a wide variation of prevalence rates reported in the literature, due to different survey methodologies, it seems that prevalence of mental illness in adults with intellectual disability is around 20%-30% which is higher than in the general community.

Table 4

Prevalence studies of mental illness in populations with intellectual disability from 1990 – 2009

Author/Year	Sample	Research measures	Findings	Comparison
Cooper, Smiley, Morrison, Williamson & Allan (2007)	Population-based study. (case ascertainment of 3.33% per 1000 adult general population) Assessments completed on 70.6% of eligible population (n=1023). Levels of ID: Mild (38.9%) Moderate (24.2%) Severe (18.9%) Profound (18.0%)	Comprehensive individual assessments using regression analysis by specialist nursing staff using case review, face-to-face assessment with client and family/carer, then referred to Psychiatrist for assessment and diagnostic clarification according to DC-LD, ICD-10-DCR & DSM-IV-TR criteria. Used Psychiatric Assessment Schedule for Adults with Developmental Disabilities (PAS-ADD), C21st Health Check (Glasgow University Affiliated Program, 1001), Present Psychiatric State for Adults with Learning Disabilities (PPS-LD), test for Severe Impairment (1992) and Vineland Scale (Survey form) to determine IQ scores.	Point prevalence of mental ill-health was 40.9% (clinical diagnosis) 35.2% (DC-LD) 16.6% (ICD-10-DCR) 15.7% (DSM-IV-TR) Most prevalent type was problem behaviours. Mental ill-health associated with more life events, female gender, type of support, lower ability, & smoking.	
Hamilton, Sutherland & Iacono (2005)	Adults with ID (n=624) living in either staffed community accommodation or in family or foster homes	Assessed using Developmental Behaviour Checklist for Adults (DBC-A) and 37 item checklist.	Demonstrated association between behavioural and emotional problems and higher rate of life events experienced by people living in supported accommodation and life event scores predicted DBC-A scores.	

Taylor, Hatton, Dixon & Douglas (2004)	1155 adults with ID living in community, residential and hospital settings in North England	Informants who had known participant for median of 24 months completed PAS-ADD checklist	Prevalence of mental health problems was 20.1% Affective/neurotic disorders (14%) Organic disorders (3.9%) Psychotic disorders (10.2%) Significant differences in rates of particular disorders found across gender, age and residence type.	
Cooper, Bailey (2001)	Population based study in UK (n= 207)	Psychiatric assessments conducted using Present Psychiatric Scale- Learning Disabilities (PPS-LD) and Disability Assessment Schedule. Developmental Assessment used Vineland Scale (Survey form)	Rate of psychiatric disorders reported was 49.2% Adults with more severe levels of ID had a higher rate of additional psychiatric disorders	
Deb, Thomas & Bright (2001)	120 Adults randomly selected from 246 people with ID in a region, 101 available for an interview. All subjects living in community. Ages 16-64. No clear definition of ID given.	101 adults and their carers interviewed by trained psychiatrist. 90/101 completed mini PAS-ADD 20 selected for caseness 19/20 interviewed with carers by second psychiatrist, blind to initial diagnosis, with full PAS-ADD interview. Remaining 11 assessed on the DASH-1	Mini PAS-ADD= 20 (22.2%) of cohort diagnosed PAS-ADD/ICD10 = 13 (14.4%) of cohort diagnosed.	General population = 16%
Richards, Maughan, Hardy, Hall, Strydom & Wadsworth (2001)	Total 1946 British birth cohort, 41 with mild ID, 2119 controls	Present State Examination at 36 years Psychiatric Symptom Frequency Scale at 43 years. School teachers behavioural ratings at age 15.	More likely to have a behaviour disorder at school. Four fold increase in risk of affective disorder in mid-life, not accounted for by social and material disadvantage or by medical disorder.	Birth cohort/Control Group

Morgan, Ahmed & Kerr (2000)	Study of the mainly adult population of South Glamorgan Health Authority. ID identified by inclusion on social services register. Divided into institutional, ex-institutional and community groups.	Patient record linkage techniques. Success of study depends on the likelihood of relevant parties coming into contact with services, and the accuracy and thoroughness of coding.	Psychiatric contact Ex-institutional = 42.1% Institutional = 11.3% Community = 15.6% Overall = 16.5% coded for contact with psychiatric services. Contact figures described as 'proxy' prevalence data.	Non-learning disabled comparison group for medical admissions but not for admission rates for psychiatric disorder.
Rymill (2000)	Adults and children in South Australia with an ID receiving services from government or non-government service providers.	Survey of workers, seven criteria for the presence of a psychiatric disorder, with any 3 out of 7 indicating presence of disorder.	16.2% of adults identified as having a psychiatric disorder.	
Maughan, Collishaw & Pickles (1999)	National Child Development Study. 100 mild ID, 7205 non ID comparison group	Malaise Inventory, 24-item self-completion scale, read to subjects if necessary.	29.7% men high Malaise score, 51.1 % of women high Malaise score	9.0% men with high Malaise score, 15.9% women with high Malaise score.
Simpson (1998)	25% random sample of register of adults with an ID using health and social services, n = 93	P AS-ADD Interview, main carer as informant, diagnosis using ICD-1 0 Diagnostic Criteria for Research and DSM-IV diagnoses.	One-month prevalence of DSM-IV Axis 1 disorders was 25.8%. 2 delirium, 3 functional psychoses, 3 depression, 1 mixed affective disorder, 11 anxiety disorders, 4 hypersomnia.	General population, one month prevalence, 16%.
Cooper (1997)	134 people with ID, 65-94 years, compared to a representative sample of younger people with ID (20-64. years) n=73.	Medical assessment, Disability Assessment Schedule, Present Psychiatric State - Learning Disabilities (PPS-LD) a semi-structured subject & informant interview, modified ICD-IO diagnostic criteria.	68% of older group found to have a psychiatric disorder, and 48% of younger group. Schizophrenia 3% in both groups. Depression 6% in older, 4.1 % in younger. Anxiety disorder 9% in older, 5.5% in younger.	

Victoria, Australia, Prevalence survey, (1996)	Clients receiving case management from Intellectual Disability Services in Victoria	Case managers surveyed to report on the number of clients who were formally diagnosed with a psychiatric disorder, and in the opinion of the case manager did have a psychiatric disorder.	10.8% of clients with formal diagnosis. Additional 7% in the opinion of case manager.	
Haveman, Maaskant, Van Schrojenstein Lantman, Urlings & Kessels (1994)	1580 people with ID, stratified sample from 83 group homes and 24 institutions, mostly adults.	Medical 60 item checklist completed by the persons GP, Gerontological Questionnaire (GQ), ratings of challenging behaviour completed by nursing staff, psychiatric disorder reported by GP.	23-29% across age groups of adult population had a diagnosed mental disorder reported by GP. Affective disorder 6.3%, Psychosis 2.6%, Neurotic disorder 4.1 %, Personality disorder 5.8%.	Mild ID Down Syndrome (DS) group only reported to have low rate of psychosis and no other psychiatric disorder. Severe ID DS group had low rate of disorder compared to non DS group.
Crews, Bonaventura & Rowe (1994)	1,273 individuals with ID in State Training Centre, aged 10-80 years, mostly severe and profound ID.	Case records containing DSM diagnosis made by psychiatrist, psychologist or physician.	Point prevalence of psychiatric disorder = 15.55%, higher rates for those with mild ID and males; 8.88% affective disorder.	Compared to general population point prevalence of 12.6% for psychiatric diagnosis and 5.1 % for affective disorder.
Meins (1993)	798 people with ID (older than 19years) in and around Hamburg.	Children's Depression Inventory (CDI) plus psychiatric examination of high and low scorers within 13 days.	Prevalence range for depression from 3% to 9% across residential settings, about 4% for group homes 9% for a psychiatric clinic, 4.8% overall.	Compared to rates in general population.

Rojahn, Borthwick-Duffy & Jacobson (1993)	All individuals with ID registered in New York (91 % adult) and California (5 I % adult).	California (as for study above) New York - Developmental Disabilities Information Survey (DDIS) recording behaviour problems and psychiatric diagnoses .	Psychiatric diagnosis 3.9% (California) and 5.4% (NY).
Collacott, Cooper & McGrother (1992)	371 (98%) people with Down Syndrome (DS) of population in the Leicestershire Health Authority with DS, plus 371 matched controls without DS, 12% hospital group, others in community.	Examination of clinical records. 51% of DS had a psychiatric examination, 68.5% of controls.	25.9% of DS had psychiatric diagnosis, 37.8% of controls. Depression = 11.3% DS, 4.3% controls; Schiz/ Paranoid state =1.6% DS, 5.4% controls.
Ballinger, Ballinger, Reid & McQueen (1991)	100 adults (16+) randomly selected from 168 (from Dundee) in a mental handicap hospital	Psychiatrist interviews using modified Standardised Clinical Interview Schedule (SCIS) ICD-9 diagnosis.	59 patients rated as pathological on SCIS. 80 patients had at least one psychiatric diagnosis.
Jacobson (1990)	42479 children and adults on New York Regional State Register of people receiving services For developmental disabilities. Compared0.22% of total population (18 976 000)	Medical or psychological data in Individual Program Plan	Overall rate of 20.0% had a Psychiatric disability.
Reiss (1990)	205 adults participating in community day programmes randomly selected from enrolment records.	Reiss Screen for Maladaptive Behavior completed by teacher who knew person well.	80 (39%) tested positive for dual diagnosis, 86.7% confirmed on clinical assessment 6-12 months later.
Borthwick-Duffy & Eyman (1990)	78,603 clients receiving services from California Dept of Developmental Disability Services in 1986, 0-86 years.	Client Development Evaluation Report, with sections on behaviour difficulties, and psychiatric disorder if diagnosed by a qualified professional.	Dual diagnosis = 10% of total. Mild ID 54.3%, Moderate ID25.7%, Severe ID 11.5%, Profound ID 8.5%.

CHAPTER 3

UNDERSTANDING INDIGENOUS PEOPLE

3.1 INTRODUCTION

Very little is known about traditional Indigenous health beliefs, particularly prior to

European colonisation, however these traditional beliefs continue to be strongly held

and give meaning to events today in the lives of Indigenous people and are often

underestimated by service providers.

In order to examine the nature and prevalence of intellectual disability and

psychopathology among Indigenous people, these issues must be viewed through the

historical context into which these issues have emerged and play a role in current

Indigenous belief systems. An understanding of the historical cultural factors that

continue to influence Indigenous peoples worldview today is important in order to

respectfully and appropriately interface with the Indigenous population and culture.

The socio-economic disadvantage experienced by Indigenous people today contributes

to the poor health outcomes and higher prevalence of disability and mental health

problems. Indigenous people have had to find ways to incorporate new western

medical model systems into their traditional beliefs on disability and mental health

problems.

A summary of these historical and traditional belief systems is necessary to put this

study of the psychopathology of Indigenous adults with intellectual disability into

context. When using western paradigms or constructs that did not originate in an

Indigenous worldview, background knowledge of traditional beliefs must inform and

permeate both research and service delivery in this area.

Whilst there is a great degree of cultural diversity, particularly related to health beliefs, between the many Indigenous groups and communities (Elkin, 1994; Maher, 1999b; Peile, 1997), there are many factors which contribute to the differences between western health systems and traditional Indigenous values and perceptions of disability and health issues.

3.2 TRADITIONAL INDIGENOUS AUSTRALIANS

There are over 350 million Indigenous people, consisting of over 5000 cultures in 70 countries on every continent in the world (International Work Group for Indigneous Affairs, 2001).

Australian Indigenous people belong to arguably the oldest living culture in the world today. They were dispossessed of their land by European settlers under the guise of the common law principle *Terra Nullius*, a Latin expression meaning land belonging to no one, or empty land (Moore, 1997). Other Indigenous populations in Commonwealth countries have also suffered similar fates due to Colonial invasions of their lands (Jackson & Ward, 1999). However, unlike the experience of the Indigenous people of Aotearoa (New Zealand) or those in North America and Canada, there has never been a formal treaty signed between the Australian Indigenous people and the Australian Government (Jackson & Ward, 1999). Ring and Firman (1998), argue that the absence of such a treaty is associated with the ongoing poor health outcomes and social disadvantage of Australian Indigenous people.

Our current understanding of traditional Australian Indigenous society and culture comes from Indigenous oral traditions, the recordings of early European settlers, and studies by largely European researchers over the last 100 years (Broome, 1994). However most of the research has been undertaken by non-Indigenous people and therefore may be considered at least partly speculative, since many observations were made in times of significant change and upheaval and often without the insights, unique perspectives and understanding of Indigenous people themselves regarding their complex and ancient culture (Broome, 1994).

There is no doubt that Indigenous Australians were the first inhabitants of this continent (Merlan, 2005). There is radio-carbon dated evidence, from Keilor, near

Melbourne, of human remains that are 45 000 years old (Broome, 1994). Even if these are the oldest remains found, it is estimated that Australian Indigenous people have inhabited the Australian mainland for at least 50 000 years, as they are considered to have travelled south from South East Asia when the sea levels were about 130 meters lower than they are today (Broome, 1994; Butlin, 1993).

Although population estimates vary from between 200 000 to 1 million, it is most probable that there were around 300 000 Indigenous people living in tribal groups in Australia at the time of European colonisation in 1788 (Bourke, 1998). These groups, or nations, were divided into over 500 tribes, each with their own distinct territory, history, dialect and culture (Broome, 1994). Within each group, men and women carried out gender-specific roles relating to the obtaining and preparation of food, conducting ceremonies, child rearing, medicine and the making of ceremonial objects, tools, weapons and implements (Broome, 1994).

3.2.1 LANGUAGE

Traditional Indigenous society was arranged into hundreds of language groups of different sizes and geographical areas (Broome, 1994). Most language groups were semi-nomadic and lived throughout defined areas within their territory that ranged in size from 500 square kilometres to 100 000 square kilometres (Broome, 1994). Each language group possessed an intimate knowledge of its territory, the local flora and fauna and the cycles of the seasons (Berndt & Berndt, 1992). These language groups often interacted with one another for trade and ceremonial purposes, typically with groups that were nearest to them (Broome, 1994).

Estimates of the number of languages spoken within Australia at the time of colonisation vary, from 200 to 300. However most researchers estimate that there were around 250 languages (Schmidt, 1990). The main reason given for the varying

estimates is the challenge in determining the difference between a language and a dialect (McConvell & Thieberger, 2001).

Horton (2000) depicts the general location of larger groups that existed prior to colonisation of Australia in the *Aboriginal Australia* map (reprinted with permission at Appendix Q).

Since colonisation, there has been a severe decline in the numbers of Indigenous languages spoken (McConvell & Thieberger, 2001). Although it is reported that there are currently around 90 languages still surviving (Schmidt, 1990), up to 70 of these are considered to be threatened or severely endangered (McConvell & Thieberger, 2001).

3.2.2 INDIGENOUS SPIRITUALITY

Traditional Indigenous society was centred on a system of law which utilises the accumulated wisdom of thousands of previous generations and is often termed as *The Dreaming*. This system incorporates many facets of societal life and provides the framework for living and relating, particularly in relation to social order, economic activity, connections and obligations to country, and spirituality. These beliefs continue to have an influence on Indigenous perceptions and understanding of intellectual disability and mental health.

3.2.2.1 THE DREAMING

The central feature of Indigenous society is the belief in the unity of the spiritual, human and natural world, which is also known as The Dreaming; a term originally coined by the anthropologist William Stanner (1979), and also referred to as the Dreamtime, the Law, the Eternal Dreaming. The Dreaming is the essential link between human beings, the land, and everything that lives in the land (Hume, 2004). It exists outside of western concepts of time and refers to a creation era long ago, and

to a present supernatural world which interacts with the current natural world (Gray, 2000).

In the Dreamtime, supernatural ancestral beings or spirits created the world and everything within it (Hume, 2004). These spirits emerged from the pre-existing formless earth, from spirit homes in the sky, from other faraway places and from beneath the earth (Hume, 2004). As they travelled over the land, they created the physical features of the landscape, sea and sky, sometimes metamorphosing a part of themselves into the features of the environment, or imprinting themselves onto cave walls or into ritual objects (Hume, 2004).

Their *dreaming tracks* are criss-crossed throughout the land over which they moved and emerged from the physical features such as watercourses and riverbeds (Edwards, 1998). The ancestral beings gave custodianship of particular areas of land to certain language groups, which was conditional upon these groups following the law, and observing ceremonies and rituals (Gray, 2000). Through the observation of certain ceremonies and rituals it is thought that humans are able to enter into a direct relationship with The Dreaming (Edwards, 1998).

Although these spirit beings returned to the land after their creative work was done, their power and relevance today is not diminished, their influence is still felt and they continue to be an integral part of ensuring the continuity of human existence and in maintaining the fertility of the land and natural species (Hume, 2004).

Although centred on the creation events, The Dreaming is nevertheless considered to be timeless and has been referred to as "everywhen" to signify this (Stanner, 1979, p. 24). Stanner (1979) also described The Dreaming as "a poetic key to reality" (p.24).

The Dreaming stories show similarities across the regions of Australia, however regional variations reflect local features of the landscape, flora and fauna while some

travelling Dreamings flow through the territory of many language groups, for example the Rainbow Serpent Dreaming story (Gray, 2000).

3.2.2.2 CONNECTION WITH LAND

It is The Dreaming, knowledge of which is bound up in stories, songs and ceremonies, which provides a deep connection for people with the land (Gray, 2000). The sacred bequest of land vested in each member of the language group by The Dreaming provides the foundation for the groups existence and is integral to their land tenure system (Gray, 2000).

In contrast to the commodity, or western, view of rights to land, an Indigenous person's rights to land are incapable of being bought or sold, because people are land and land is people, and therefore cannot be traded (Gray, 2000).

This sacred and multi-dimensional relationship of Indigenous people with the land can be reflected in the concept that the land possesses people just as much as people are seen to possess the land (Maddock, 1972). Since The Dreaming stories only relate to one's own territory, there is no reason to want to own land that belongs to another group (Broome, 1994), and in fact, other land may be considered unsafe and full of dangerous spirits (Jacob, 1991).

No English words are adequate to convey the full sense of the relationship between an Indigenous group and their land, as this "different tradition leaves us tongueless and earless towards this other world of meaning and significance"(Stanner, 1979 p.230).

3.2.2.3 TOTEMS

Another important aspect of Indigenous spirituality is the belief that everyone has a totem (Fryer-Smith, 2002). *Totemism* describes the relationship between an individual

and a particular flora and/or fauna species, or a situation, condition or event (Stanner, 1979).

Each person's totem originates from where their mother was impregnated with a *spirit child* (Broome, 1994). These spirit children are released at certain sacred places by the ancestral beings, for example if a woman was to first become aware of her pregnancy when near the site of a kangaroo dreaming, her unborn child is automatically linked with the red kangaroo totem (Broome, 1994).

In addition to personal totems, groups may also have their own sacred totems which can be traceable through a genealogy of the language group (Fryer-Smith, 2002). Where the totem has a physical form - harming it, killing it and sometimes even touching it – is prohibited (Fryer-Smith, 2002). In order to maintain the spirituality of the totem, special rituals, often done in secret are essential (Edwards, 1998).

3.2.2.4 INDIGENOUS LAW

Indigenous traditional law was believed to have been created by the ancestral spirits of The Dreaming and governs all aspects of a traditional Indigenous person's life, including the observation of ceremonies and rituals, the maintenance of social order, rules for dispute resolution, and economic activity (Australian Law Reform Commission, 1987).

The law has been described as highly practical and representing the accumulated wisdom of hundreds of generations (Berndt & Berndt, 1992). As traditional Indigenous beliefs do not distinguish between the spiritual and physical universes, there is no distinction between secular and spiritual rules or laws (Fryer-Smith, 2002). Breaches of these laws can carry very serious punishment, including death (Australian Law Reform Commission, 1987). Offences warranting death can include the viewing of sacred objects, places or ceremonies by those not allowed to view them, even if this

was unintentional (Australian Law Reform Commission, 1987). In a similar way, the inappropriate disclosure of sacred stories or secrets to a person who is not entitled to know these secrets may also result in the death penalty (Australian Law Reform Commission, 1987).

Punishment under traditional law is usually called *payback* and is based on the principle that "retaliation is the essence of the law" (Berndt & Berndt, 1988 p.360). Appropriate punishments can be decided upon, and administered by the Elders of the group or their delegate(s) (Australian Law Reform Commission, 1987). Customary punishments include:

- Death (either directly, or by means of sorcery or incantation)

- Spearing (of greater or lesser severity)

- Other forms of corporal punishment (such as burning the hairs from the offender's body)

- Individual duelling with spears, boomerangs or fighting sticks

- Collective duelling involving those injured by the offence, or affected by it, and those associated with the offender

- Shaming or ridicule

- Rigorous forms of initiation or teaching

- Compensation (e.g. through adoption or marriage)

- Banishment from the community (Australian Law Reform Commission, 1987).

In cases of serious offences, or continued offending, banishment or exclusion from the community may occur if death is not considered an appropriate penalty (Jacob, 1991). This is considered to be a very serious punishment which causes considerable grief to the offender, who may waste away and die from the sorrow of removal from the individual's community and social culture (Fryer-Smith, 2002).

Although there is no universal application of Indigenous traditional law across the various language groups, there are commonalities of law throughout traditional Indigenous Australia (Fryer-Smith, 2002).

3.2.3 SOCIAL ORGANISATION

3.2.3.1 LANGUAGE GROUPS

The largest social unit in traditional Indigenous society is the language group and this forms the primary basis of individual and group identity (Fryer-Smith, 2002). Membership of a language group is determined by either patrilineal or a matrilineal descent, with marriage typically occurring outside of the group (exogamous) (Jacob, 1991). When married, the woman would usually reside with the husband's family (Fryer-Smith, 2002). Children would retain membership of the language group of their birth throughout their life (Jacob, 1991).

Economic wealth or inherited status holds little value within a language group, rather it is through spiritual activity that elevated social status and recognition may be achieved (Berndt & Berndt, 1992).

3.2.3.2 DIALECT/ FAMILY GROUPS

Smaller sub-groups of a language group may reside in particular tracts of land within the larger language group's territorial boundaries, meeting at regular intervals for ceremonial, social or trading purposes (Jacob, 1991).

The smallest social group in traditional Indigenous Australia would be the family or *hearth* group (i.e. sleeps around a common fire) and might include secondary wives, children, grandparents and other close relatives who move around their traditional territory together (Jacob, 1991).

3.2.3.3 SKIN GROUPS

Traditional Indigenous Law dictates that at birth each child is classified into a social group known as a *skin group* which establishes that child's position within their language group (Fryer-Smith, 2002).

The simplest classification system is that in which members are divided into alternate generation levels, with marriages occurring only within the person's same generation level (i.e. enogamous) (Berndt & Berndt, 1978). In this system, a person is in the same generation level as his or her grandparents, siblings and grandchildren, with his or her parents and children being on an alternate generation level (Berndt & Berndt, 1978).

An additional system of classification which overlays the skin system is the moiety system (meaning divided into half) (Fryer-Smith, 2002). This system divides all human and life forms, including inanimate objects and natural phenomena into two groups with everything in one moiety having its counterpart in the opposite moiety (Bourke & Edwards, 1998).

Moieties are exogamous (i.e. each person marries someone from the opposite moiety) (Bourke & Edwards, 1998), and are significant in the ceremonies, rituals and social interactions within the language group, as well as in the making of 'right' marriages (Bourke & Edwards, 1998).

3.2.3.4 CLASSIFICATORY KINSHIP SYSTEM

In traditional Indigenous society, all relationships were preordained in The Dreaming and determined by law and the kinship system (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005; Elkin, 1969).

Kinship systems comprise a complex web of mutual rights, obligations and responsibilities and constitute a central organisation plank of traditional Indigenous

society. These systems of extended family support are recognised as still strong in many areas, including urban environments (Commonwealth Rehabilitation Service, 1994). In an ideal situation Indigenous people are cared for by their kinship system regardless of why they require that care (Myers, 1979).

Care within the framework of the kinship system does not rely on the individual's physical appearance or achievements (Berndt & Berndt, 1992). For example, responsibility for caring for an individual with an intellectual disability is considered to be the responsibility of the individual's immediate and extended family (Ariotti, 1999), and 'outsiders' will typically not interfere with the 'personal business' of that family (Elliott, 1984).

3.3. CULTURAL ASPECTS

A traditional Indigenous society had strongly defined roles and social mores in order to maintain political, social, cultural and economic stability (Fryer-Smith, 2002). Each community would typically have an elder, or a group of elders who took responsibility for maintaining social cohesion, education and initiation of younger community members, and custodianship of the Law (Fryer-Smith, 2002). The correct observations of mutual rights, obligations and responsibilities are considered important to social cohesion and breaches are met with a range of consequences (Australian Law Reform Commission, 1987).

3.3.1 THE ROLE OF ELDERS

Elders in Australian Indigenous culture are initiated men who are senior male members of their language group, selected to provide leadership and to be ritual leaders on the basis of knowledge of the law and their personal characteristics (such as bravery or compassion) (Fryer-Smith, 2002). Their position as an elder can involve dispute resolution, education of younger people, advice on marriage partners, responsibility for rituals, sacred objects and places, with their main responsibility being custodianship of the law and responsibility for passing it down to the next generation (Jacob, 1991). Traditionally although people with intellectual disability were treated no differently than other members of their family (Ariotti, 1999), it is unclear whether they would take on certain senior roles within their community.

3.3.2 AUTHORITY AND DECISION MAKING

Due to the great diversity across various groups in traditional Indigenous society, there are a wide variety of authority models and decision making processes. However,

Indigenous society typically used the social process of consensus to arrive at important decisions, while elders of the group may have responsibility for final decision making (Elkin, 1976).

An integral aspect of the decision making process is ensuring there is adequate time for deliberation to occur. This point is emphasised by Stanner (1976), who stated that Indigenous people:

> "…Need credible motives for having to choose…They need information…They need time, all the time needed to work out the implications, how this will affect that and how that will affect something else. Time to consider the alternatives, time to take into account new thoughts that did not occur to them earlier. Time to strike balances between winners and gainers, time to make sure of consensus…"(Stanner, 1976 p.201-212)

3.3.3 RECIPROCITY, OBLIGATION, AND AVOIDANCE

In traditional Indigenous society, strict observation of mutual rights, responsibilities and obligations are observed (Fryer-Smith, 2002). Obligations such as giving gifts (e.g. upon betrothal and initiation) and sharing items such as food, make up primary reciprocal principles that the group members live in accordance with (Broome, 1994). Reciprocity also covers the principle of avenging wrongdoing (i.e. the notion of payback). Reciprocity operates as a system of checks and balances in order to maintain social equilibrium and reinforce personal and group relationships (Bourke & Edwards, 1998).

To control personal relationships, kinship rules ordain that certain relatives must avoid one another (Fryer-Smith, 2002), which may include, depending on the particular kinship rule, physical distance, not talking to one another, avoidance of using the other

person's name, or generally acting in a reserved manner around each other (Australian Law Reform Commission, 1987).

The strongest avoidance relationship in the kinship rules relates to the relationship between a man and his mother-in-law, who in the strictest form should not see or speak to one another, or mention the other person's name (Elkin, 1976). Breach of these kinship rules can lead to varying sanctions according to the nature of the rule and the relevant kinship relationship (Australian Law Reform Commission, 1987).

3.3.4 SHAME

The concept of *shame* refers to situations where an Indigenous person has been singled out or identified as different for any reason, be it positive or negative, and typically involves a feeling of embarrassment (Morgan, Slade, & Morgan, 1997), whereas in a western culture, shame is the emotion which arises from the consciousness of something primarily dishonouring in one's own conduct (Moore, 1997). An example of being shamed for a positive reason may be if a person is singled out for public recognition or praise for an achievement. This may be considered uncomfortable and a "shame job" and is similar to the self-conscious shame felt when being singled out to speak in front of a group.

Shame has been identified as a significant factor in Indigenous responses to disability or handicap (Ariotti, 1997; Curry, 1993) and is often associated with being identified as having a disability (Gething, 1997). This can have a negative impact on rehabilitation if the individual's disability is perceived as likely to cause a shame job (Barker, 1997). For example, Indigenous people are shy, or shamed, and therefore reluctant to talk about disability or disabilities within their family (Wolstenholme, 1996). This is considered to be one of the main impediments to accessing disability support services by Indigenous people with a disability (O'Neill, et al., 2004).

The concept of shame is similar in other Indigenous cultures throughout the world, for example, the Navajo nation in North America consider that having a child with a disability may be viewed as a punishment by the spirits and responses of shame may lead to the child being hidden away from the community in order to escape the shame and labelling that families and children might experience should they remain obviously present in the community (Fudge Schormans & Mandamin, 2007). The family may even leave the community altogether in an attempt to find greater tolerance for their child who has a disability. This sense of shame is considered to be so profound in some communities that it may appear as if there are no community members with a disability at all because they have been hidden away or removed from the community (Stuart, 1992). There have been parallel feelings and circumstances in western culture as people with intellectual disability have been hidden in attics and institutions because family are ashamed of having someone with an intellectual disability in their family. Some people today would still try to hide the fact that a person in their family had a certain problem such as intellectual disability or mental illness in order to avoid the perceived stigma associated with these disorders (Gething, 1997).

3.3.5 HEALERS AND SORCERERS

Medicine men and sorcerers have highly valued roles in traditional Indigenous language groups and perform a number of important functions including the curing of illnesses, holding of séances (communicating with spiritual beings), and conducting 'inquests' into unexplained deaths (Berndt & Berndt, 1988).

> "Many magic men have the power do to magic feats by singing magic songs.
> They can sing and cause someone to become mad. They can also sing a
> person's head and thus make them strong. They can sing over a spear wound,

singing as they put their mouth right on the wound, thus causing it to heal up

quickly. They can sing a song and thus give themselves the power to travel at

great speed (for instance when a car has broken down and they need to fetch

help)." (Glass, 1990 p.44)

Sorcery is usually carried out on people from other groups who are thought to have

done something wrong e.g. unfaithful wives and alleged murderers (Berndt & Berndt,

1988). The pointing of the bone is the most widely recognised and frequently used tool

of sorcery (Berndt & Berndt, 1988). Sorcery can be used for punishment when the

appropriate physical punishment may not be considered practicable, for example,

because of the geographical distance to the offender (Fryer-Smith, 2002). The

offender is identified during a ritual ceremony in which a sorcery rite is performed, or

in some cases only threatened (Australian Law Reform Commission, 1987). If the

identified person then becomes sick, mentally ill or dies, then the sorcery is considered

to have been successful.

Typically, once punishment has been carried out the business relating to the offence is

considered to be finished. However if the punishment is interpreted to be an

excessively inappropriate retaliation then it may invite a reaction of reprisal (Berndt &

Berndt, 1988). In these cases, events may escalate to the point where a 'blood feud'

can erupt and may continue for many years after the original offence (Berndt &

Berndt, 1988).

Sorcery is thought to have virulent powers that may affect not only the offender, but

also their family, their descendants and their community, and are feared most strongly

(Reid & Williams, 1984).

The sorcerers treatments can include psychic displays, walking on fire, mysteriously appearing and disappearing, sucking blood, vigorous massage and the use of objects, such as special bones or stones (called "mabarn") (Maher, 1999b).

3.4 AUSTRALIAN INDIGENOUS POPULATION TODAY

3.4.1 DEMOGRAPHIC CHARACTERISTICS

The 2006 Census of Housing and Population reported an estimated 517,174 Indigenous people living in Australia (Australian Bureau of Statistics, 2006a). This amounts to 2.5% of the total Australian population, at 30 June 2006. Approximately 53 300 were identified as Torres Strait Islanders (this comprises 10% of Australia's Indigenous total population) and includes 20 200 people of both Torres Strait Islander and Aboriginal origin (Australian Bureau of Statistics, 2006a). The Indigenous population is growing at a faster rate than the non-Indigenous population (2.2% each year, compared to 1.2-1.7%) (Australian Bureau of Statistics, 2009). The Indigenous population is projected to increase to 721 000 by 2021, an expected increase of 204 000 people from the 2006 population figures (Australian Bureau of Statistics, 2009). In 2006, 32% of Indigenous people lived in urban areas, 43% in regional areas and 26% in remote areas. In comparison, 69% of non-Indigenous people lived in urban areas while only 2% lived in remote areas (Australian Bureau of Statistics, 2006a). Compared with the non-Indigenous population in Australia, the Indigenous population is younger (39% less than 15 years old compared to 20% for non-Indigenous population). The median age for Indigenous people is 21 years, compared with a median age of 37 years for non-Indigenous Australians. The estimated Indigenous resident population size of South Australia is estimated to be 26044, with 16635 of these being Indigenous people over the age of 15 years (Australian Bureau of Statistics, 2009).

Life expectancy for Australian Indigenous people is lower than for non-Indigenous Australians (Bittles, et al., 2002). Higher mortality rates are also reported in the

Indigenous populations of USA, Canada and New Zealand (Allard, Wilkins, & Berthelot, 2004; Grim, 2003; McPherson, Harwood, & McNaughton, 2003), however the improvements in life expectancy and health status of Indigenous people in New Zealand, USA and Canada (Brady, 2003; Ring & Brown, 2003; Ring & Firman, 1998) are yet to be seen in the Australian Indigenous population (Glasson, et al., 2005). The gap in life expectancy between the Indigenous and non-Indigenous populations in Australia is estimated to be about 17 years below that for all Australians (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005). Three quarters (75%) of Indigenous male deaths and nearly two thirds (65%) of Indigenous female deaths occurred before the age of 65 years. This compares with 26% and 16% respectively of deaths for all Australian males and females (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005).

Australian Indigenous people are more likely to experience disability and much lower quality of life due to poorer health with data from a number of reports highlighting higher rates of mortality, diminished life expectancy, lower birth weights, hospital separation rates, higher hospitalisation rates for diabetes, assault and infectious pneumonia, and fetal, neonatal and perinatal death rates (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005; Australian Institute of Health and Welfare, 2006a; Pink & Allbon, 2008; Steering Committee for the Review of Commonwealth/State Service Provision, 2005).

Many factors described in the Steering Committee for the Review of Commonwealth State Service Provision (2005) report interrelate to contribute to the poor health status of Indigenous people compared to non-Indigenous Australians. These include:

- Higher rates of health risk factors such as smoking, obesity, harmful alcohol use, substance abuse and violence

- Geographic isolation and limited access to health services, particularly in remote and very remote areas

- Overcrowded and inadequate housing also contribute to lower health status of Indigenous people. For example, in 2002, 26% of Indigenous people aged 15 years or over lived in overcrowded households

- Language and cultural barriers, lower levels of education, employment and income levels, are also considered to have an impact on the lower health status of Indigenous people.

The most recent available estimates of health services expenditure for Indigenous people are for 2001-02 (Australian Institute of Health & Welfare, 2005). Total recurrent government and non-government expenditure on health services for Indigenous people was estimated at $1788.6 million in 2001-02 (Australian Institute of Health & Welfare, 2005). This was equivalent to $3901 per Indigenous person compared with $3308 per non-Indigenous person.

Factors which contribute to the higher levels of health expenditure on Indigenous people include their average higher levels of morbidity and a much larger proportion of Indigenous people who live in remote Australia where the cost of service provision is higher (Steering Committee for the Review of Commonwealth/State Service Provision, 2005).

Due to the disadvantaged social circumstances of many Indigenous communities, Indigenous people have a significantly lower socio-economic profile than non-Indigenous Australians (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005). Poor socio-economic status has been linked in many studies to an increased risk of mild to moderate intellectual disability (Croen, Grether, & Selvin, 2001; Durkin, 2002; Najman, Bor, Morrison, Anderson, & Williams, 1992).

3.4.2 SOCIAL CONSTRUCTION OF DISABILITY

Research suggests that prior to colonisation Indigenous people with a disability who survived to adulthood were treated and cared for no differently than other members of their family group and there was no collective cultural recognition of the western concept of disability (Ariotti, 1999).

However after colonisation, new words and concepts for disability were introduced to Indigenous people and this impacted on the way they thought about people who had a disability, and changed the way others behaved towards those with disabilities (Ariotti, 1999). In order to make sense of these new words and concepts, Indigenous people tried to incorporate them into their own language by adapting existing words and giving them new meanings (Ariotti, 1999). Although Indigenous people have passively resisted many western beliefs and practices, particularly related to health care (Nathan, 1983), having been taught new words and concepts by the medical and welfare professionals, with the attached stigmatisation, Indigenous people tended to behave in accordance with these new ideas. Fanon (1990), suggests that colonised people internalise negative characteristics that are imposed by the coloniser. Some Indigenous people with an impairment internalise this negative thinking by adopting the stigmatised role of the disabled person (Ariotti, 1997).

Susman (1994) concludes that it is not the functional limitations of an impairment which constitute the greatest problem faced by people with a disability, but rather the stigma of societal and social responses to the impairment.

Historically, in a western society, people with intellectual disability have been singled out for special attention and treatments, and custodial care has resulted in them being removed from their family and community (Finkelstein 1980). These new concepts of disability have been defined by medical and welfare professionals and Fulcher, talking

about the social construction of disability states that "how people with power respond to what they perceive as disability, constructs the nature of disability" (Fulcher, 1989 p.43).

Similar experiences of removal occurred within the Australian Indigenous population for many children (Ariotti, 1999). Unfortunately, the practice of removing children with severe impairments from their families was one of the earliest influences on the construction of the Indigenous understanding of disability (Ariotti, 1999). If the powerful 'helping' professionals diagnosed a child with a disability, the child was typically taken away from the family and community and put into care in an urban setting, usually remote from the family.

A research report on the Anangu Pitjantjatjara Yankunytjatjara (APY) lands in Northern South Australia has concluded that the basis of Indigenous culture was under threat in part due to people being declared 'disabled', and then taken away and losing contact with their roots, which had a negative effect on group cohesion and the overall health of Indigenous culture (Woenne-Green, 1995). The report found that the resulting loss of control had a profoundly negative spiritual and psychological impact, and forms a part of the current perception of disability within Indigenous culture today (Council of Reconciliation, 1994; Ngaanyatjarra Pitjantjatjara Yankunytjatjara Women's Council, 1997).

3.4.3 INDIGENOUS CONCEPTS OF HEALTH AND DISABILITY

The term *health* as is it known in western society, has no direct equivalent words within the traditional Indigenous communities. In a traditional Indigenous society health encompasses all aspects of life. The National Aboriginal Health Strategy (NAHS) presented a definition of health as perceived by Indigenous people:

"Health does not just mean the physical well-being of the individual but refers to the social, emotional, spiritual and cultural well-being of the whole community. This is a whole of life view and includes the cyclical concept of life-death-life." (National Health and Medical Research Council, 1996, p. 4).

The Indigenous people of the Victoria River Valley in the Northern Territory, in the Ngaringman language, describe health as "punyu", which translates to mean a complete state of being, encompassing both person and country. Rose states that: "Punyu is variously translated as good, strong, healthy, happy, knowledgeable ('smart'), socially responsible (to 'take care'), beautiful, clean, and 'safe' both in the sense of being within the Law and in the sense of being cared for" (Rose, 2000, p. 64). Punyu is fostered through a relationship of mutual care between body, land and spirit (Mobbs, 1991) and when people and their country are both punyu, the flow of energy keeps both strong, healthy and fruitful (Rose, 1987).

The 1999 Declaration on the Health and Survival of Indigenous Peoples by the World Health Organisation defines Indigenous concepts of health which incorporate four distinct shared dimensions of life: The spiritual, the intellectual, physical, and emotional (Committee on Indigenous Health, 1999). These dimensions encompass a holistic view of health, and they indicate how Indigenous views of health are expressed on multiple levels where the past, present and future "co-exist simultaneously" (Durie, 2003, p. 510). Considering the holistic but different perspective that Indigenous people have of health issues (Berndt & Berndt, 1992; Mobbs, 1991; Reid, 1983), it is not surprising that many Indigenous people do not distinguish separately concepts of disability and mental illness (O'Neill, et al., 2004). There are well established, direct links between the poor health status of Australian Indigenous people and the various practices that followed invasion and colonisation of

Australia by the British in the 18th century and the removal of people from land and culture (Cunningham & Stanley, 2003).

Since colonisation, the Australian Indigenous population have suffered from the introduction of many infectious diseases such as measles, smallpox, typhoid fever, tuberculosis and influenza into their communities for the first time (Durie, 1998). Further, by the mid 20th century, following a high degree of urbanisation of the Indigenous population, new health risks also emerged (Durie, 2003). These included vulnerability to injury, alcohol, drug and substance misuse, cancer, heart disease, obesity, suicide and diabetes (Durie, 2003). Explanations for the current poor health status of Indigenous Australians can be grouped into four main areas: Genetic vulnerability, socio-economic disadvantage, resource alienation, and political oppression (Durie, 2003).

Ariotti (1999) contends that the westernised or medicalised view, which sees disability as a limitation or incompetence on the part of the individual fails to acknowledge that disability as a concept does not exist in some cultures. Recent studies in the Indigenous population have found that only highly visible disabling conditions such as spinal cord injury, strokes, severe mobility impairments and amputation were recognised as a disability (Gething, 1994; Mokak, 1997; Smeaton, 1996). However, one study of remote Indigenous communities in the Top End (northern part of the Northern Territory) using a health survey supplemented by interviews, found that there does appear to be a distinction between Indigenous perceptions and understanding of physical and intellectual disabilities, with intellectual problems being attributed to both medical and/or supernatural causes (Senior, 2000).

Furthermore, concepts related to intellectual disability may vary, even within an Indigenous community (Sloane, 2003). In an Indigenous community, intellectual

disability is not confined to the limitations and sense of loss experienced by the individual (Ariotti, 1999).

Gething (1995) consulted with Indigenous people with a disability, their families, community elders and carers in New South Wales and found that Indigenous people with a disability would not see themselves as having a disability despite the service providers labelling them as such. Attempts to label people as having a disability are considered to erode community cohesion and cultural identity (Bostock, 1991). McDougall states that "Kooris have always looked after their own special needs people and we don't brand our own people" (McDougall, 1993 p.54). Furthermore, Indigenous people with a disability cannot be seen as a homogeneous group. When taken in the context of other factors impacting on the lives of many Indigenous people, identifying and ameliorating a disability may not be considered a high priority for individuals and their families (Gething, 1994; Hewitt, 1998; Smeaton, 1998).

An Indigenous person is more likely to define themselves by their relationships with their clan and country, rather than their disability (Elliott, 1984). Elliot (1984), in a study of people living in the Top End of the Northern Territory, found that disability was only an issue when it was seen to cause a restriction in the persons participation in activities. Another study found that fulfilment of family roles and engagement with family influenced how 'able' an Indigenous person perceived themselves to be (Senior, 2000).

Caring for the person with a disability is seen as the responsibility of their extended family (Ariotti, 1999; Woenne-Green, 1995). Systems of kinship are still seen to be very strong within Indigenous communities, even in urban areas (Commonwealth Rehabilitation Service, 1994). However, for a variety of reasons, not all families are able to care for their family member with a disability (O'Neill, 1994; Woenne-Green,

1995). The most common reasons for this are highlighted in a study in Western

Australia (Stokes, 1988). These include:

- Not being able to provide for the extra expenses involved in caring for a family

  member with a disability

- The burden of grief and stress carried in a whole community can lead to a

  breakdown in care for individuals

- People with a disability can be vulnerable to exploitation in situations where

  alcohol misuse and family breakdown have occurred

- Many families are unaware of the services that are available to assist them, and

  are not provided with the training necessary to give adequate support to a

  family member with a disability.

This is in addition to the limited capacity of families to care for a family member with

a disability due to the fact that there is a higher proportion of Indigenous people who

are totally dependent due to a profound or severe physical disability compared to non-

Indigenous people (Senior, 1998). Other factors such as poor housing and health need

to be taken into consideration when looking at a family's capacity to provide care and

support for a family member with a disability (London, 1999).

3.4.4 INDIGENOUS RESPONSE TO RESEARCH

There has been historical tension around the definition, collection, analysis and

publication of research related to Indigenous mental health, and also around the

conduct of research generally in this area, with many Indigenous people feeling that

they have been "over-researched" (Hunter, 1991). Houston and Legge (1992) argued

that:

"The main barriers to improving the health of Indigenous people are not

deficiencies in the understanding of biomedical mechanisms and therapeutics.

The main barriers are in the application of existing biomedical and public

health knowledge in contexts which also recognise Indigenous aspirations and

the wealth of existing Indigenous community knowledge." (Houston & Legge,

1992, p. 115).

The Maori writer Linda Tuhiwai Smith (1999), when commenting on Indigenous

people being over-researched, noted: "The word itself, 'research', is probably one of

the dirtiest words in the Indigenous world's vocabulary" (Tuhiwai Smith, 1999, p. 1).

Indigenous people are wary of research and have become distrustful of researchers and

research processes, partly due to the perceived or actual failure of researchers to meet

their ethical obligations to Indigenous communities when conducting research

(Stewart, et al., 2006).

Hunter (1991) believes part of the reason that research has had such a bad reputation

in Indigenous communities relates to research work that has been done in the past

which has not respected the rights of Indigenous individuals and communities.

Anderson (1996) suggested that the history associated with research has "had a

powerful negative impact on the collective memories of Indigenous communities" but

that "within the Indigenous community there is a growing, though tentative,

recognition that research can be a valuable tool if deployed appropriately" (Anderson,

1996, p. 154).

3.4.5 DISABILITY RESEARCH IN AUSTRALIAN INDIGENOUS POPULATION

3.4.5.1 DISABILITY PREVALENCE RATES

Indigenous people in Australia experience a higher burden of disease and lower life expectancy than the non-Indigenous population (Glasson, et al., 2005). Prevalence rates for disability in the Australian Indigenous population come from the 2002 National Aboriginal and Torres Strait Islander Social Survey (NATSISS) (Australian Bureau of Statistics, 2004). The NATSISS collected data relating to the disability status of the Indigenous population that was comparable to that obtained from the 2002 General Social Survey (GSS) of the Australian population (Australian Institute of Health and Welfare, 2006b).

The 2002 NATSISS survey included questions to identify people who had a disability or long-term health condition. Disability was defined as:

> "A limitation, restriction, impairment, disease or disorder, which had lasted, or was likely to last for six months or more, and which restricted a person's ability to perform everyday activities"(Australian Bureau of Statistics, 2004, p. 74).

People who were identified as having a disability or a long-term health condition in the 2002 NATSISS and the 2002 GSS were asked about their need for assistance with core activities: Self-care, mobility, communication. Four levels of core activity limitation were determined, based on whether a person needed personal assistance with, has difficulty with, or uses aids or equipment for any of the core activities. A person's overall level of core activity limitation was determined by the highest level of limitation the person experienced in any of the core activity areas. According to the 2002 NATSISS (Australian Bureau of Statistics, 2004, p. 74) definition, the four levels of core activity limitation are:

- Mild—has no difficulty performing a core activity but uses aids or equipment because of disability

- Moderate—does not need assistance, but has difficulty performing a core activity

- Severe—sometimes needs assistance to perform a core activity

- Profound—always needing assistance to perform a core activity.

Core activities comprise the following tasks contributing to the definition of severe or profound core activity limitation:

- Self-care—bathing or showering, dressing, eating, using the toilet, and bladder or bowel control

- Mobility—getting into or out of a bed or chair, moving around at home and going to or getting around a place away from home

- Communication—understanding and being understood by others: Strangers, family and friends (Australian Bureau of Statistics, 2004).

A recent comparison of the disability status of Indigenous and non-Indigenous people in Australia based on prevalence data from the above two national surveys found that severe and profound disability rates are more than twice as high among Indigenous people than in the non-Indigenous population (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005).

In the 2002 NATSISS there were a number of differences in the screening questions used to confirm disability status and disability type for persons living in remote and non-remote areas. For example, in remote areas respondents were asked fewer screening questions to establish disability status (Australian Bureau of Statistics, 2004). The shortened question module for remote areas was designed to maximise comparability with other surveys. Respondents in remote areas were not asked about

disfigurement/deformity, mental illness requiring help or supervision, conditions that restrict physical activity or physical work (e.g. back problems, migraines), or restriction due to a nervous or emotional condition. The omission of questions on disfigurement/deformity and conditions that restrict physical activity or physical work may have resulted in an underestimate of Indigenous people with a physical disability in remote areas. In addition, the 2002 NATSISS did not explicitly identify people in remote areas with a mental health disability, because there were fewer questions asked in remote areas that related specifically to mental health (i.e. those who had either a mental illness requiring help or supervision, or a restriction due to a nervous or emotional condition). Some people in remote areas with a mental illness will have been correctly identified as having a disability (and therefore included in the total number of people with a disability) if they reported that they were receiving medical treatment or taking medication for a restricting health condition, but the type of disability cannot be determined from this information alone (Australian Bureau of Statistics, 2004).

In reporting the results of the NATSISS survey, it refers to the expanded set of screening questions asked in non-remote areas as the *broader criteria,* with the smaller set of questions asked in remote areas are referred to as the *common criteria* (Australian Bureau of Statistics, 2004).

These criteria are comparable with the criteria used to identify people with core activity limitations in other ABS surveys, such as the 2003 Survey of Disability, Ageing and Carers and the 2002 General Social Survey. However, unlike the 2003 Survey of Disability, Ageing and Carers, the criteria used in the NATSISS do not separately identify people with a long-term health condition only (without disability).

While the NATSISS used the common criteria to establish disability in remote areas and the broader criteria in non-remote areas, the 2002 General Social Survey used only the broader criteria (Australian Institute of Health and Welfare, 2006b).

Whilst the 2002 NATSISS survey of *profound/severe core activity limitation* corresponds with the 2006 Census criteria of *needing assistance with core activities* and are based on similar concepts, the results are not suitable for direct comparison of the prevalence of disability over time (Pink & Allbon, 2008).

The 2002-2007 Commonwealth State/Territory Disability Agreement (CSTDA) recognises the higher disability prevalence rates of two to two and half times those of non-Indigenous people and highlights the heightened vulnerability of Indigenous people with a disability (Australian Institute of Health and Welfare, 2004a). More recently, the National Disability Administrators have accepted recommendations from the Australian Institute of Health and Welfare (Australian Institute of Health and Welfare, 2006b) to update the current ratio of 2.0 applied to the number of Indigenous people in *potential population* calculations (which is the number of people who may at some time require access to specialist disability services), to a ratio weight of 2.4, which has been based on new prevalence estimates (Australian Institute of Health and Welfare, 2006b). The rate ratios are calculated by dividing the proportion of Indigenous people with intellectual disability by the proportion of non-Indigenous people with intellectual disability.

The potential population estimates are based on the number of people with profound/severe core activity limitations identified in the 2002 NATSISS and 2002 GSS (Australian Institute of Health and Welfare, 2006b).

The Australian Institute of Health and Welfare (2006b) reported that 36% of all Indigenous people aged 15 years and over had a disability or long-term health

condition, and were more likely than those without a disability to experience a higher amount of social and economic disadvantage (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005).

In the 2002 NATSISS survey, the level of profound/severe core activity limitations among Indigenous people aged 15 years and over was 8%.

When the proportions of Indigenous and non-Indigenous Australians with a profound/ severe core activity limitation living in non-remote areas are compared (using data from the 2002 NATSISS and 2002 GSS), Indigenous people are between one and a half and three and a half times as likely as non-Indigenous people to have a profound/severe core activity limitation (Pink & Allbon, 2008). When age differences between the two populations are taken into account, Indigenous people were twice as likely as non-Indigenous people to have a profound/severe core activity limitation (Pink & Allbon, 2008).

Thomson and Snow (1994), in a study in the Taree area of NSW, reported on the much higher prevalence rates of disabilities overall and associated handicaps and highlighted the need for greater attention being directed towards health, disability and rehabilitation support for Indigenous people. They found the prevalence of disability in the Indigenous population increased with age (as it does with the non-Indigenous Australian population), however the prevalence for Indigenous people exceeded that of the total population at all ages throughout the lifespan. One quarter of all people surveyed (n=907) identified as having one or more disabilities (n=227), 124 (13.7%) were identified as being handicapped by their disability and 46 (5.1%) were identified as being severely handicapped by their disability (Thomson & Snow, 1994). Intellectual disability was reported in four cases (0.4%).

Developmental delay, including "slow at learning", was reported in 37 instances (4.1%) of all people surveyed. This was the leading condition responsible for a handicap in education. The researchers broadly based this category on the World Health Organisation recommendations (World Health Organisation, 1980) used by the Australian Bureau of Statistics (Australian Bureau of Statistics, 1990) which covered unspecified mental conditions and other specified conditions such as intellectual disability, mental degeneration (due to brain damage), slow at learning, and specific developmental delays (Thomson & Snow, 1994).

Thomson and Snow (1994) defined disability in their research by adapting the Australian Bureau of Statistics definitions of disability (Australian Bureau of Statistics, 1990), which itself was broadly based on the World Health Organisation recommendations, as being someone who had one or more disabilities or impairments which had lasted or were likely to last six months or more (World Health Organisation, 1980). Using this definition, they found that Indigenous people were 2.5 times more likely to have a disability than were the non-Indigenous population. Considering this greater burden of disability within the Indigenous community, the Aboriginal and Torres Strait Islander Health and Welfare Information Unit (1997) weights calculations by a factor of two when planning for future disability support services to account for the increased rates.

3.4.5.2 INTELLECTUAL DISABILITY IN AUSTRALIAN INDIGENOUS POPULATION

The research literature on intellectual disability among Indigenous people can be confusing and difficult to interpret due to the varying criteria used to determine disability and intellectual disability. This confusion permeates the data to date and makes it difficult to be confident about what is actually being referred to and how to

interpret findings. For example it is unlikely that quoted prevalence rates of intellectual disability in Indigenous adults are accurate. Difficulties in accurately reporting intellectual disability prevalence rates include differences in perceptions and understanding of intellectual disability between Indigenous and non-Indigenous people. Other challenges emerge from issues with treatment and support of Indigenous people with intellectual disability and the availability and limited access to disability support services.

The most recent estimate of the prevalence of intellectual disability in the Australian Indigenous community comes from a report by the Australian Institute of Health and Welfare (2007). Intellectual disability was defined as having a condition or problem making it difficult to learn or understand things.

These estimates come from an analysis of data from multiple extensive surveys and administrative data collected on the health and welfare of Australian Indigenous people (Australian Bureau of Statistics, 2002a, 2002b; Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005). This analysis showed about 7% of Indigenous Australians aged 15 years or over had an intellectual disability. There were higher rates of intellectual disability amongst males compared to females (8.2% compared to 5.8%). It is considered that the higher rates amongst males was due to their being more males than females aged 14-44 years in the survey and this compares to the non-Indigenous Australian population (Australian Institute of Health and Welfare, 2003). The survey notes that the prevalence of intellectual disability in remote areas may be underestimated due to some of the survey questions not being asked in remote areas and recommends that better data are needed in order to accurately quantify the prevalence of intellectual disability in remote Indigenous communities (Australian Institute of Health & Welfare, 2007).

There is limited accurate data on the prevalence of intellectual disability within Indigenous communities internationally, however, within the data that does exist, higher rates than the general non-Indigenous population are generally found. For example, the rate of developmental disability in Canada's Indigenous population is believed to be between two to three times greater than rates for non-Indigenous Canadians (Fudge Schormans & Mandamin, 2007). Intellectual disability prevalence rates for Maori people, the Indigenous people of New Zealand are also higher across all age groups, compared to non-Indigenous New Zealanders (Statistics New Zealand, 2001).

It is considered that the higher rates of intellectual disability in Australia may be partly attributed to by the higher rates of poor antenatal care and maternal and child accidents, substance abuse and disease within the Indigenous community (Connors & Donnellan, 1993; Factor & Fulton, 1999)

People with intellectual disability are more likely than those without intellectual disability to experience a wide range of disadvantages including socio-economic disadvantages, social exclusion, institutionalisation, rejection, abuse and neglect (Emerson, 2007). Further, while Indigenous people suffer much higher levels of disadvantage compared to non-Indigenous people, those with a disability are likely to experience even further degrees of social and economic disadvantage (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). When compared with Indigenous people without a disability, those with a disability were half as likely to have completed Year 12 (12% compared to 24%), more likely to be living on lower incomes, and one quarter as likely to be employed (12% compared to 59%) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). Compared to non-Indigenous children, Indigenous children living in

Indigenous households are less likely to be living with a parent, experience a lower weekly household income, are more reliant on income support, and are more likely to have parents who left school early and who are unemployed (Daly & Smith, 2005). The disadvantages increased in more remote areas compared to less remote areas and the damage to a person's quality of life was compounded with each additional risk factor (Daly & Smith, 2005).

Glasson and colleagues (2005) extracted data from the Disability Services Commission (DSC) of Western Australian to assess the prevalence, survival patterns and causes of death for Indigenous people with intellectual disability. This data was linked to two other state-based databases, the Hospital Morbidity Data System and the Deaths Registry, with additional linkages to the National Death Index.

The DSC is the central support body for people with intellectual disability in Western Australia and has maintained records of referrals to DSC since 1952, which include data on the level of intellectual disability according to the American Association on Mental Retardation (AAMR) guidelines(American Association on Mental Retardation, 1992) , general demographic information, co-morbid conditions, and up to three clinical diagnoses based on Heber (1959) classifications. Heber classifications unfortunately incorporate the 'borderline' IQ category into the mild intellectual disability grouping, thereby inflating the overall intellectual disability group size by an unknown, but likely to be a considerable factor.

After linkage of the data with the Department of Health records, Glasson et al (2005) were able to survey a total of 734 Indigenous people with intellectual disability (as defined by Heber), comprising 423 (57.6%) males and 311 (42.4%) females (Glasson, et al., 2005).

They found that although Indigenous people comprised only 3.5% of the population in Western Australia, 7.4% of all people registered for intellectual disability services in the state were Indigenous Australians.

Glasson et al. (2005) found that Indigenous Australians with intellectual disability suffer from a considerably higher burden of disease and lower life expectancy than the non-Indigenous population with intellectual disability. Median survival was 55.1 years for men and 64.0 years for women, with a mean age of death (n= 102) of 19.6 years. The leading causes of death in this population group were respiratory diseases, diseases of the circulatory system and accidents.

They found the level of intellectual disability was assessed as borderline or mild (IQ 55-85) in 40.7% of cases, moderate (IQ 40-54) in 19.9%, severe and profound (IQ < 40) in 12.1%, and the level had not been specified in 27.2% of cases.

Unfortunately, as earlier described, due to the DSC data being based on the Heber (1959) classifications (which coded a person with an IQ of 70-85 as having a 'borderline' intellectual disability), the prevalence rates in this study are not reflective of current definition practices which are based on the widely accepted definition and classification of intellectual disability (DSM-IV-TR) developed by the American Psychiatric Association (American Psychiatric Association, 2000). Therefore, by using the Heber classifications, the results would be expected to yield a higher prevalence rate of intellectual disability within the population group. In fact, the majority (40.7%) of cases within this study were within the borderline or mild classification). It is unfortunate that the categories of borderline and mild were not separated in this study, as this would have allowed more accurate comparisons with prevalence data from other studies.

Glasson et.al. (2005) concluded that in order for more effective targeting of appropriate prevention and intervention services and policies to meet the needs of Indigenous people, there was an urgent need for further research into the prevalence and patterns of intellectual disability within the Indigenous community.

Yami Lester, an elder of the Yankunytjatjara people in northern South Australia (who is profoundly visually impaired), and is a well known spokesperson on disability issues has been advocating for a National Indigenous disability register since 1981 in order to facilitate further research, determine prevalence rates and improve national policy and service development (Lester, 1993).

3.4.5.3 INDIGENOUS PERCEPTIONS OF INTELLECTUAL DISABILITY

The National Aboriginal and Torres Strait Islander Social Survey identified the question of Indigenous conceptualisation of disability as a topic requiring further research and discussion (Australian Bureau of Statistics, 2002b). Although Indigenous beliefs about the causation and treatment of illness generally have been examined (Reid, 1983; Taylor, 1977b; Wimiydji & Peile, 1978), very little is known about the perception of intellectual disability within the Indigenous population prior to colonisation and in the modern context (O'Neill, et al., 2004).

There are only passing references to Indigenous people with disabilities in the journals and writings of the early colonial explorers, missionaries and anthropologists (Ariotti, 1997). Ariotti (1999) concludes from his study of historical documents that Indigenous people with intellectual disability were "treated and cared for no differently from other members of the group or clan" (Ariotti, 1999, p. 218). However, he suggests that on occasions, people with severe impairments were left behind to die as the group travelled through their country, and there was a limited practice of infanticide in all Australian Indigenous tribal groups (Ariotti, 1999). Many

Indigenous people with disabilities were generally accepted as part of the whole community and were considered "normal in the sense that they are part of the *accepted diversity of humanity*, involving the acknowledgement and acceptance of difference" (Branson & Miller, 1992, p. 18, emphasis in original). A disability was regarded as simply part of the person in the context of the social world in which they lived (Brisenden, 1986).

Indigenous perceptions of intellectual disability are dynamic and evolving and are intimately linked with Indigenous history, culture and language (Ariotti, 1999). Tipper and Dovey (1991) state that modern day differences in cultural values and perceptions of disability are the most significant obstacle to providing effective services for Indigenous people with a disability. However there is a dearth of detailed information about these cultural differences and good data about Indigenous people with a disability (Beneforti & Paradies, 1998; Bostock, 1991; Littlewood, 2006; McLennan & Madden, 1997; Smeaton, 1998).

In the limited research available on intellectual disability within the Indigenous population, the following issues can be identified.

1) Indigenous people do not wish to identify themselves as having a disability (Gething, Poynter, Redmayne, & Reynolds, 1994). Barker (1997) found that a person may experience considerable concern if the individual's disability is perceived as a likely cause for a 'shame job'. This concept of shame is a specific cultural factor that has been identified as significant in Indigenous people's responses to disability (Ariotti, 1997). A report from the Northern Territory Department of Health Housing and Community Services found that there was significant social stigma associated with being labelled as 'handicapped' and that the word was disliked, as it is in non-Indigenous groups (Curry, 1993).

2) Intellectual disability is a relatively new concept for many Indigenous people, who are more likely to describe the way intellectual disability affects a person (Ariotti, 1999).

3) The traditional beliefs of Indigenous people in Australia have changed over time with the changing circumstances in which they live (Maher, 1999b). However, while many Indigenous viewpoints have been modified since European colonisation, there has been less of a shift in beliefs regarding the causes of illness and disability (Reid, 1983). It is possible that this is due to the traditional health beliefs continuing to play a role in giving meaning to events and thereby helping people to deal with serious illness and death (Maher, 1999b).

4) There are barriers to access of adequate information on disabilities, such as causative factors, genetic influences, knowledge of rights and entitlements (National Disability Administrators, 2004).

5) There are considerable language and communication barriers, especially in more remote areas. A large number of Indigenous people still communicate primarily in their native language, with English as a second, third or lesser used language (National Disability Administrators, 2004). Disability service providers have been slow to recognise and accommodate to the use of a variety of primary languages. One in five Indigenous people aged 15 or over living in a remote area have difficulty understanding and/or being understood by service providers and 43% were living without a working telephone in their household (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005).

3.4.5.4 TREATMENT/ SUPPORT ISSUES

In order to provide effective health services and support to an Indigenous person with an intellectual disability, the person must be viewed by service providers through their

individual perceptions of disability and in the context of their culture and lifestyle (Elliott, 1984; Maher, 1999a). Differences between western and traditional Indigenous cultural values and perceptions of disability are the most significant obstacle to providing effective services for Indigenous people with a disability (Tipper & Dovey, 1991).

The National Disability Advisory Council (1999) were advised by Indigenous representatives that incorrect assumptions and inappropriate procedures used by health service providers and other professionals were major barriers for Indigenous people in accessing effective services and support. For example, the Sharing Stories report (National Disability Administrators, 2004) described the failure of service providers to appreciate the great diversity of cultural understandings, beliefs and values, community politics and concepts. This had led to inaccurate assumptions, insensitivities and inappropriate interventions being delivered by 'outside' service providers despite the presence of positive personal qualities of the staff in the service (Ingstad & Whyte, 1995).

O'Neill (1994) has also described the tendency for service providers to underestimate the influence of the diverse cultural beliefs on Indigenous perceptions of disability throughout Australia, and how difficult it is to get an understanding of each regional cultural belief system.

As a result, estimates of the use of disability services by Indigenous people with a disability suggest that as many as one third may not be utilising the services that could be made available to them (O'Neill, et al., 2004).

3.4.5.5 AVAILABILITY AND ACCESS TO SERVICES

Even when services for people with a disability are available, there are many reasons why they may not be utilised by people in Indigenous communities, which include:

- A poor awareness of entitlements, service options, rights and advocacy options and confusion about which agency provides what services (National Disability Administrators, 2004).

- A reluctance to use these services because of suspicious attitudes towards past government policies of separation and removal of people with a disability from their families and community (National Disability Administrators, 2004).

- A reduction in service utilisation reduces as the distance from urban areas increases. Around one quarter of Indigenous people in Australia live in remote or very remote areas, compared with only 2% of non-Indigenous people (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2005). The range of services available, such as mental health care, behavioural support, physiotherapy, personal care, respite and education are adversely affected by the vast geographical distances and the sparse and relatively small population of people with a disability in remote areas (National Disability Administrators, 2004).

- The increased costs associated with providing and accessing these services. For example, the Commonwealth Grants Commission (2002), recognised a number of factors that led to higher costs of providing services in remote areas which included: Fuel, plane charters, and travel allowances (National Disability Administrators, 2004).

- Language barriers. English is a second, third or lesser used language with a significant number of Indigenous people, with more than one in ten Indigenous people reporting that they speak an Australian Indigenous language at home (Australian Bureau of Statistics, 2006a).

- Physical environment barriers. These might include problems in getting home modifications, lack of sealed roads and pavements (posing mobility issues), and the number of people living in overcrowded houses (Kendall & Marshall, 2004).

- Bureaucracy issues. Agencies may have inappropriate eligibility criteria and restrictive procedures. Referring agencies, such as doctors and health clinics may have limited information on service options available, and there is often a lack of coordination between agencies and different levels of government (National Disability Administrators, 2004).

- Workforce issues. Recruitment and retention of staff, lack of support and professional development of trained staff, inadequate numbers of Indigenous workers (National Disability Administrators, 2004), and racist attitudes have all been identified as factors both in the community and among service providers which negatively impact on the delivery of good services to Indigenous people (London, 1999).

3.5 ASSESSMENT OF INTELLECTUAL DISABILITY IN THE INDIGENOUS POPULATION

There are many concerns about the value and appropriateness of using conventional, standard IQ assessment tools with individuals from different cultural backgrounds, as no test can be completely unbiased or culture free (Plank, 2001; Tseng, 2001). Formal IQ assessment tools available such as the Wechsler Preschool & Primary Scale of Intelligence – Third Edition (WPPSI-III) (Wechsler, 2002), Wechsler Intelligence Scale for Children – Third Edition (WISC-III) (Wechsler, 1991), Wechsler Adult Intelligence Scale – Third Edition (WAIS-III) (Wechsler, 1997a), Wechsler Memory Scale – Third Edition (WMS-III) (Wechsler, 1997b) and the Stanford Binet Intelligence Scales (Thorndike, Hagen, & Sattler, 1986). Each has limited utility in providing an accurate cognitive assessment of Indigenous people with intellectual disability. These tests do not have specific norms for this population and most of the content favours people who have a knowledge of and familiarity with western society and culture (Butcher, Nezami, & Exner, 1998).

The Indigenous population lives in a broad range of urban and rural environments with a great diversity of life experiences. For example, an Indigenous person living in a remote desert location would have significantly different experiences from an Indigenous person living in a large city on the coast.

Since intelligence is imbedded in and defined by the culture within which it is measured (Sattler, 2001), Indigenous people from less westernised environments are unfairly penalised as they are unlikely to have experienced the same culture as the dominant society and therefore are unlikely to perform as well and as a consequence they are likely to receive reduced intelligence scores on standard IQ tests which can lead to inaccurate diagnostic decisions (Flanagan, McGrew, & Ortiz, 2000).

It is also evident that the language used in some tests may be unfamiliar and therefore the examinee is placed at a disadvantage when attempting the test (Wettinger, 1997). In addition, Davidson (1988) identified that there is a large degree of suspicion of intelligence tests by many Indigenous Australians which is also likely to adversely affect their participation and the outcome of any individual testing activity.

It is also important to consider the different communication styles and learning strategies between Indigenous and non-Indigenous Australians (Wettinger, 1997). For example, in Indigenous culture it can be considered impolite to ask a question of someone who doesn't know the answer (Kearins, 2000).

To date, only a few attempts have been made to develop or modify psychometric tests which would be suitable for this population (McCarthy, Dyer, & Hunter, 2002).

Two psychometric tests that have been developed in an attempt to overcome some of the problems of cultural specificity are the Queensland Test (McElwain & Kearney, 1970) and the Nonverbal Abilities Test (Rowe, 1986).

Whilst the Queensland Test is probably one of the best examples of a culturally fair intelligence test, there are a number of areas where biases might affect an individual's performance, such as the degree of western cultural contact (McIntyre, 1976) and there is debate about whether or not the test items follow Indigenous patterns of skills (Kearins, 1976). Due to similar limitations, the Nonverbal Abilities Test met with limited acceptance amongst clinicians and is no longer available (McCarthy, et al., 2002).

The presence of limitations in adaptive behaviour is also a criterion for the diagnosis of intellectual disability and needs to be assessed relative to the person's social and cultural group and not from a western middle class perspective.

3.6 THE MENTAL HEALTH OF THE AUSTRALIAN INDIGENOUS POPULATION

3.6.1 INDIGENOUS PERCEPTIONS OF MENTAL HEALTH

Understanding the complexity of another culture's mental health concerns is fraught with difficulty and challenges (Eley, et al., 2006). Mental health for Indigenous people should be viewed within an holistic and community lifestyle framework, which is related to both past and present issues, and is not necessarily individualised or compartmentalised (Brown, 2001).

Traditional views of illness, including mental illness, emphasise social and spiritual dysfunction as a key cause of illness (Maher, 1999a). Maher (1999), utilising the framework outlined by Mobbs (1991) for integrating information from multiple researchers on traditional health beliefs, compiled the table below which outlines the 'traditional Indigenous health beliefs'.

Table 5 *Framework outlining 'traditional Indigenous health beliefs (from*

Maher, 1999 p. 231)

Categories of illness causation	Causes of illness	Examples of resultant conditions
Natural (part of everyday life, generally result of temporary states of weakness)	Emotions (resentment, sulking, shame, worry, homesickness, grief, jealousy, anger, anxiety) Dietary factors Physical assault and injury	Loss of appetite, weight loss, listlessness, pain, suicide or attempted suicide Diarrhoea, coughs and lung complaints, headaches Physical injuries
Environmental	Winds The moon Climate: Excessive heat or cold	Pain, stomach ache, diarrhoea, chills Epilepsy or fitting in children Colds, aches, headache, respiratory complaints, diarrhoea
Direct Supernatural (transgression of the Law)	Breach of taboos: taboos of place-sacred sites; taboos of ritual/ceremony; taboos of relationship; (parenthood, childhood, avoidance, incest, mortuary); taboos of menstruation; Spirits of the dead	Multiple possible effects including: Swellings, vomiting, diarrhoea, drowsiness, madness, death, nausea, lethargy, difficult pregnancy, injured foetus, deformed child, skin sores, epilepsy, neck pain with headache, leprosy, pneumonia, broken bones Weakness, vomit a lot and lose interest in living, influenza, sickness or death, madness
Indirect Supernatural Intervention (all illness attributed to sorcery is understood ultimately to be the result of social or religious offences, intergroup or intragroup conflict)	Boning, singing, painting	Multiple possible effects including: Death, serious injury and illness, sterility, congenital defects, physical malformation
Emergent/ Western (conditions only known by Indigenous society since colonisation)	Social and epidemiological changes which have occurred post colonisation of Australia	Alcohol-related illness, substance abuse, spina bifida, cerebral palsy, diabetes, heart disease, cancer, sexually transmitted disease, smallpox, measles, bronchitis, influenza, diarrhoea

Sources: (Ariotti, 1997; Elkin, 1994; Elliott, 1984; Honeyman & Jacobs, 1996; Mobbs, 1991; Nathan, 1983; Peile, 1997; Reid, 1983; Scarlett, White, & Reid, 1982; Scrimgeour, Rowse, & Lucas, 1997; Taylor, 1977a, 1977b; Tonkinson, 1982; Toussaint, 1989).

Although there is limited research into the specific health beliefs of Indigenous people today, or of the variety of mental health beliefs, many of the Indigenous medical belief systems outlined in the literature (Cawte, 1974; Peile, 1997; Reid, 1983; Shannon, 1994; Waldock, 1984) are similar despite coming from different parts of the country (Maher, 1999). The general approach is that individual wellbeing is strongly related to effectively discharging one's responsibilities and obligations to the social group and also to the land itself (Morgan, et al., 1997).

The Radford report, *Taking Control* (Radford, et al., 1990), recognises that Indigenous mental health is difficult to define due to there being limited research into prevalence, classifications and diagnoses in any remote culture and needs to be considered in a historical, cultural and situational context (Brown, 2001).

Instead of using the terms *mental illness* or *mental health*, the term *emotional and social wellbeing* is preferred by Indigenous people as it reflects a more holistic concept of mental health which incorporates the social, emotional and cultural wellbeing of the whole community and reflects a more positive approach to health (Australian Health Ministers, 2003; National Aboriginal Community Controlled Health Organisation (NACCHO), 1993).

Since the arrival of Europeans, there has been very little recognition by western mental health professionals of the profound spiritual links of the Australian Indigenous people to their land (Jackson & Ward, 1999). The subject of land is considered paramount to Indigenous people's sense of belonging and health (Hunter, 2004).

The Royal Australian College of Physicians declared that the continued dispossession from land is a fundamental cause of the poor mental health status of Indigenous people in Australia (Royal Australian College of Physicians, 1997).

"Next to shooting Aboriginal people the surest way to kill us is to separate us from our part of the earth" (Reid & Trompf, 1992, p. xi).

Psychological problems such as poor self-esteem, unresolved anger and grief are closely related to social justice issues affecting the Indigenous population (Aboriginal and Torres Strait Islander Social Justice Commission, 2004; Turale & Miller, 2006) .

3.6.2 PREVALENCE OF MENTAL ILLNESS AMONG INDIGENOUS PEOPLE

Research over the last 30 years (Cawte, 1988; Eastwell, 1982; Gracey, 1987; Hunter, 1993; Moodie, 1973) has greatly assisted our understanding of Indigenous mental health (Brown, 2001; Cawte, 1988).

From his research throughout Arnhem Land in the Top End of Australia, Eastwell (1977) highlighted several culturally bound mental illnesses relating to anxiety and depression which was being felt by the community largely as a result of the speed of cultural change that was occurring within their communities. He argued the need for mental health professionals to gain an understanding of Indigenous culture prior to engaging Indigenous clients.

Gracey (1987) discussed connections between higher mental illness levels and health risk factors such as malnutrition and infections within the community.

Cawte (1988) documented 13 unique types of clinical presentations of depression from his research within Indigenous communities in north Queensland. He found higher rates of mild and moderate depression within these communities compared to non-Indigenous rates.

There are also several major national reports (Australian Aboriginal and Torres Strait Islander Report, 1994; The Burdekin Report on Human Rights (Burdekin, 1993); and

the *Ways Forward* document (Swan & Raphael, 1995) that highlight unmet needs of

Indigenous people with mental illness. Each of these reports identifies significant

deficits in existing services which include: difficulties in accessing services, language

and cultural barriers, poor coordination between service agencies and between levels

of government, recruitment and retention of adequately trained staff, insufficient

Indigenous staff, inadequate cross-cultural training and racism (National Disability

Administrators, 2004). Although the actual prevalence of mental illness within the

Indigenous population is unknown and is confounded by culturally inappropriate

methods of diagnosis (Smallwood, 1996), there are a number of data available that

suggest that the mental health of Australian Indigenous people is poor and the

prevalence of common mental illnesses such as anxiety and depression is high

(Australian Bureau of Statistics, 2004; Australian Bureau of Statistics & Australian

Institute of Health and Welfare, 2008; Human Rights and Equal Opportunities

Commission, 1997). It has been estimated that there is a five-fold risk of involuntary

psychiatric admission for Indigenous people (Human Rights and Equal Opportunities

Commission, 1993).

In his report to the National Inquiry into the Human Rights of People with Mental

Illness, Burdekin (1993) states that:

> "Despite the absence of epidemiological data, evidence presented to the
>
> Inquiry by Indigenous people indicates that mental illness amongst Indigenous
>
> people is a common and crippling problem. However, often, mental illness
>
> goes undiagnosed, unnoticed and untreated. There is also evidence of further
>
> impact on mental health because the health system does not recognise or adapt
>
> programs to Indigenous beliefs and law, which causes a gap between service
>
> providers and the users of the service." (Swan, cited in Burdekin, 1993 p.692)

The Radford report *Taking Control* (Radford, et al., 1990), recognises that the incidence, classification and diagnosis of mental ill health is difficult to describe in any remote culture. This view is best reflected by National Aboriginal Community Controlled Health Organisation (NACCHO, 1993) which stated that:

> "Mental health must be considered in the wider Indigenous concept of health and well-being. This requires that their health issues be approached in the social emotional context, and that both social and emotional health and psychiatric disorders encompass oppression, racialism, environmental circumstances, economical factors, stress, trauma, grief, cultural genocide, psychological processes and ill-health." (cited in Swan & Raphael, 1995, p. 1).

Airhihenbuwa (1995), cited in Brown (2001), states that cultural explanations for causation of mental illnesses must also be assessed before diagnosis and treatment may be successful.

No mention is made in these reports of the special needs in relation to mental health care of Indigenous people with intellectual disability.

Further research and better national data is needed before more accurate prevalence estimates on the mental health of Australian Indigenous people can be made (National Health and Medical Research Council, 2002; Social Health Reference Group, 2004; Swan & Raphael, 1995).

3.6.3 APPROACHES TO TREATMENT AND HEALING

Despite mental illness being considered as a major challenge for the Indigenous population (Swan & Raphael, 1995), there are "glaring deficiencies" in our knowledge of mental illness in the Australian Indigenous population (Hunter, 2003, p. 150). Current diagnostic tools used to assess mental illness in this population do not adequately take into account the unique and diverse social, cultural, educational and

family issues (Brown, 2001). New tools should be developed and further research dedicated to this area in order to improve the correct diagnosis and assessment of mental illness (Vicary & Westerman, 2004).

Spirituality plays an important role in Indigenous culture and has a large influence over Indigenous perceptions of mental health and wellbeing (McLennan & Khavarpour, 2004; O'Brien, 2005; Vicary & Westerman, 2004; Ypinazar, Margolis, Haswell-Elkins, & Tsey, 2007), with cultural and/or spiritual causes often suspected when a person becomes unwell.

O'Brien (2005) describes cultural and/or spiritual causes for many illnesses, including mental illness were often considered when a person became unwell. The illness could be understood as payback for previous transgressions, being 'sung to', married the 'wrong way' and other cultural and spiritual explanations (O'Brien, 2005).

Any weakness in a person's wellness was considered to predispose the person to illness and increase their vulnerability of being influenced by malevolent spirits (Vicary & Westerman, 2004). Indigenous people would usually only access western models of health treatments after due consideration was given to traditional methods of healing, including methods to build resilience against spirits to increase wellness (Vicary & Bishop, 2005; Vicary & Westerman, 2004).

Family and community relationships are considered to be important to emotional, physical and cultural health and to social cohesion and healing within a community (McLennan & Khavarpour, 2004).

Issues within Indigenous communities today such as family violence, alcohol and other substance misuse indicate a loss of traditional family and community values and cultural identity (O'Brien, 2005; Vicary & Bishop, 2005). Indigenous people have experienced loss of culture, spirituality, roles, and sovereignty of their land with a loss

of respect for the ways things were once done. The resulting loss of control, power and hope in their life impacts on levels of mental health and one's ability to cope with stressful situations (Emden, Kowanko, de Crespigny, & Murray, 2005; O'Brien, 2005). Traditional healers are considered to have exceptional knowledge and powers to help cure illnesses and are often the first point of reference for community members when sickness occurs (Gray, 1979; Scarlett, et al., 1982; Soong, 1983). Use of traditional healers as part of health treatment options is supported by various health services in Australia (Territory Health Services, 1997).

Bush medicine is still in wide use throughout remote Indigenous communities and there is widespread knowledge of the uses of bush medicine (Scarlett, et al., 1982). There are many bush medicine remedies, often individual remedies for specific symptoms (Nathan, 1983; Peile, 1997; Saggers & Gray, 1991). Bush medicine remedies may include herbal preparations, massage, restricted diet and the use of ochre, smoke, steam and heat (Peile, 1997; Reid, 1983).

Throughout many Indigenous cultures, people continue to have cultural interpretations about illnesses, including mental health, which are often attributed to external forces or reasons (Moldaysky, 2004; Reid & Trompf, 1992; Westerman, 2000) which could result in the individual experiencing symptoms that are consistent with mental ill health (Sheldon, 2001; Vicary & Andrews, 2001) (Sheldon, 2001; Vicary & Andrews, 2001; Westerman, 2000).

Often, mental health problems will manifest themselves spiritually and culturally and therefore can often only be resolved by not just understanding the potential origins of the problem, but also adequately exploring the extent to which the particular mental health issue is symptomatic of the individual's underlying cultural and/or spiritual issues (Vicary & Westerman, 2004).

Differences in understandings of the cause of mental illness or disability will impact management, compliance and how the person responds to their illness or disability. An appreciation of Indigenous views of illness causation, including the important role of supernatural intervention, the knowledge of the variety of Indigenous medical treatment methods and the role played by traditional healers will assist mental health professionals in their interactions with Indigenous people with mental health issues or intellectual disability (Maher, 1999b). Although there is a great diversity of beliefs, many of the Indigenous health belief systems from throughout Australia share many similarities (Peile, 1997; Reid & Trompf, 1992). It is important to note that the belief in supernatural causes of illness may not be restricted only to Indigenous communities in rural and remote regions, but may also occur amongst Indigenous people living in cities and regional areas (Brady, 1995).

Culture is a moving, dynamic entity and is always changing (Kirmayer, 2006), with the traditional beliefs of Indigenous people being adapted to the changing circumstances in which they live (Ypinazar, et al., 2007).

Therefore it is necessary for mental health professionals to continue to explore and listen to the voices of Indigenous people to further understand both their cultural beliefs and their lived experience concerning mental health and mental health problems. Further, in order to work effectively with Indigenous people with mental health issues, the mental health professional needs to recognise the intertwining of spirituality and particularly relationships with family, land and culture (Slattery, 1994). These beliefs should be respected and acknowledged as part of the healing process. In fact, the differences in Indigenous and western health beliefs can provide an indication of the broader differences in world view between these cultures.

Many Indigenous people express fear of and will avoid western mental health treatment options and professionals (Vicary & Westerman, 2004). Reasons for this include the impact of being labelled as having a mental illness, and the shame and the stigma attached to such labels (Vicary & Bishop, 2005). This fear of what may happen, such as being hospitalised away from their country, or the impact of medication on the person's ability to fulfil their social and community roles, often means that families will try to cope by themselves with a mentally ill person, engaging with western mental health services only when they have reached a crisis point (Vicary & Westerman, 2004).

When providing advice for any health related conditions, the health care professional should provide a clear biomedical explanation of the illness or death and of the cause and respect the family's wish if they choose to include traditional Indigenous medicines or treatment as part of the patient's ongoing care (Reid & Mununggurr, 1977).

A recent national Indigenous mental health policy report (Swan & Raphael, 1995) found that the present mental health service system in Australia does not adequately recognise Indigenous beliefs, law and cultural understandings, which causes a gap between service provider and user and, as a result, mental distress in the Indigenous community often goes unnoticed and untreated.

There is an urgent need for more culturally appropriate education to provide skills and knowledge to seek assistance and overcome stigma (Vicary & Bishop, 2005). For example, depression may be considered to be part of an individual's character or "that's just the way he is", and may be ignored until the individual's behaviour becomes severe (Vicary & Bishop, 2005). It is thought that the lack of recognition and subsequent treatment may be a contributing factor to the higher frequency of

suicide and emergency hospitalisations that occur within the Indigenous population

(Nagel & Thompson, 2006; Vicary & Bishop, 2005).

3.7 MENTAL ILLNESS AMONG INDIGENOUS PEOPLE WITH INTELLECTUAL DISABILITY

Although mental health issues are recognised as being important nationally, little is known about the mental health of Indigenous people with intellectual disability. No mention is made in the national reports described earlier into Indigenous mental health of the special mental health care needs of Indigenous people with intellectual disability.

International and Australian research indicates that mental illness is 2-3 times more common in non-Indigenous people with intellectual disability, with illness rates reported to be 30-40% in this population (Cooper, et al., 2007; Einfeld, et al., 2006). This means that it is numerically a bigger public health issue than schizophrenia in the total Australian population. Less than 10% of people with intellectual disability and a mental illness receive the services they require to help them with their mental illness (Einfeld, et al., 2006).

The nature of the distribution of mental illness in adults with intellectual disability in Australia and the mental health needs of specific groups such as Indigenous adults is poorly understood. Factors which might predict or protect against mental health problems in Indigenous individuals with intellectual disability such as cause and level of disability, gender and living circumstances have not been determined. There is not only a need to describe the prevalence and nature of mental illness and contributing factors in adults with intellectual disability in Australia consistent with the third National Mental Health Plan 2003-2008 and the 2003 National Research Priorities of Healthy Ageing, but also in Indigenous Australians with intellectual disability.

There are significant challenges in people with intellectual disability in obtaining appropriate diagnoses for a range of reasons such as diagnostic overshadowing, higher

rates of physical health problems, and difficulties in assessment and the application of diagnostic criteria applicable to people without intellectual disability. These issues are even more complex in Indigenous people with intellectual disability. There is no gold standard assessment instrument that adequately considers the issues related to people with intellectual disability, particularly if they are from another culture.

Carer completed questionnaires that describe these disturbances make an essential, effective and inexpensive contribution to the assessment and treatment of individuals. This research project aims to build on work into this important and emerging area of mental health in the field of intellectual disability within Australia by investigating the mental health of Indigenous Australian adults with intellectual disability.

3.8 SUMMARY

In summary, traditional Indigenous beliefs about health and illness are much more holistic than western belief systems and there is a diversity of views and concepts about mental illness and intellectual disability currently held in the Indigenous community. Despite both mental illness and intellectual disability being considered major challenges within Indigenous communities, little is known about the nature and prevalence of both these problems within the Australian Indigenous population. There are many difficulties in accurately assessing and diagnosing mental health problems and intellectual disability in this population and current assessment tools may have limited use due to them not adequately taking into account the unique cultural and social issues within this population. These complexities have led to a consensus that further research is required in this area. There are tensions within the Indigenous community towards research and it is essential that research is conducted appropriately. Therefore, given that so little is known about this subject, the Lifespan study aimed to investigate this topic and do so in a culturally sensitive and appropriate manner.

CHAPTER 4

AIMS AND METHODOLOGY

4.1 RESEARCH AIMS

The primary aims of this project were to:

1. Describe the population of Indigenous adults with intellectual disability in South Australia and how they differ from the non-Indigenous population with intellectual disability

2. Determine the prevalence and nature of psychopathology in Indigenous adults with intellectual disability in South Australia and the lower half of the Northern Territory, in urban, regional and remote communities in comparison to a large community cohort of non-Indigenous Australian adults with an intellectual disability.

A further aim was to explore the social, environmental and cultural context of intellectual disability and mental illness in the Indigenous community. A subsidiary aim of the research project was to describe the potential usefulness and limitations of a carer completed checklist (the DBC-A) in the assessment of psychopathology in Indigenous adults with intellectual disability.

In addition qualitative information was collected to further explore various aspects of intellectual disability and psychopathology in the Australian Indigenous population in order to increase our understanding of how intellectual disability and psychopathology is perceived by the Indigenous community now, and how that might differ from traditional society.

4.2 FUNDING AND SUPPORT

This research project was undertaken in conjunction with the Lifespan research project, an Australian Research Council Linkage Grant funded epidemiological research project conducted in South Australia from 2005 to 2008, exploring the mental health of all people 16 years and older registered in South Australia with intellectual disability.

The Lifespan research project received additional support and funding from three South Australian (SA) Industry Partners: The Intellectual Disability Services Council (IDSC) (now Disability SA, in the South Australian Department of Family and Community Service), Minda Inc (an Adelaide based non-government disability support organisation) and The South Australian Department of Education and Children Services (DECS). These industry partners provided the study with assistance in identifying, locating and contacting individuals with an intellectual disability on their registers. Additional funding for the research was also provided by the APEX Foundation for Research into Intellectual Disability and the Helen Macpherson Trust.

4.3 ETHICS

Ethics approval for the Lifespan research project was gained from the Monash University Standing Committee on Ethics in Research Involving Humans, the South Australian Department of Health Human Research Ethics Committee, and the South Australian Department of Education and Children's Services (see Appendices B, C & D).

In addition, as this project was conducted with Indigenous people, this research project applied for and received further ethics approval from the Aboriginal Health Research Ethics Committee of the Aboriginal Health Council of South Australia (see Appendix E). Two additional applications were subsequently made to this committee:

1. In response to feedback from Indigenous disability groups and the experience during the trial data collection phase, a request for an amendment to the ethics approval was sought and approved by this committee (see Appendix F). The amendment sought approval to offer a $30 voucher Woolworths (supermarket chain) voucher to the carer/parent/guardian who gave consent and completed the questionnaire. $30 cash was provided when the research was conducted in remote areas where there were no Woolworths stores.

2. The second amendment sought approval for the inclusion of additional questions to be asked of no more than 10 participating family carers in an interview format (see Appendix G). Approval for this was granted. As with the previous amendment, it was proposed to provide an additional $30 Woolworths voucher to the carer/parent/guardian and each individual with an intellectual disability who agreed to participate in the interview (or cash equivalent where there are no Woolworths in the town/community) in recognition of the expenses incurred.

4.4 QUESTIONNAIRE BOOKLET

Data was collected from participants using the Lifespan Questionnaire Booklet which contained the DBC-A, ABAS-II and demographic information (see Appendix A).

4.4.1 DEMOGRAPHIC SURVEY

Demographic information requested about the Indigenous person with intellectual disability in the carer-completed questionnaire included: the individual's name, gender, date of birth, ethnicity (whether they identified as an Aboriginal and/or Torres Strait Islander), whether they were from a non-English speaking background (NESB), the name of their service provider, the relationship of the person completing the questionnaire to the individual with an intellectual disability, the level and cause of their intellectual disability, any previous diagnosis of mental illness, the medication the individual currently takes, any physical/sensory/communication impairments, chronic health problems, living arrangements and daytime activities, socialisation skills and relationships with others, personal strengths, skills and favourite activities, Life Events and stress factors, and finally, the age and living status of parents. The questionnaire also requested culturally relevant information, specifically whether the individual had moved from or lost contact with their cultural group, and what level of stress this may have caused.

4.4.2 DEVELOPMENTAL BEHAVIOUR CHECKLIST FOR ADULTS (DBC-A)

The Developmental Behaviour Checklist for Adults (DBC-A) (Mohr, et al., 2005) (see Appendix A) was used as the measure for psychopathology in this research project for the following reasons:

1) It was the chosen measure of emotional and behavioural disturbance in adults with intellectual disability for the Lifespan research project and would hence provide a large representative cohort of non-Indigenous participants to compare results with

2) There are no specific psychopathology measures that have been designed for use in the Indigenous population with intellectual disability

3) The DBC-A is an Australian developed comprehensive carer-completed checklist of behavioural and emotional problems experienced by adults with intellectual disability with satisfactory psychometric properties. It has been translated into 21 languages.

The Developmental Behaviour Checklist (DBC-P, Primary carer version) (Einfeld & Tonge, 1992), a carer completed checklist of behavioural and emotional disturbance in children and adolescents with intellectual disability was the structural parent of the DBC-A. The DBC-P was modified to include items relevant to adults with intellectual disability. In a series of studies (Mohr, et al., 2005) it has been shown to have acceptable psychometric properties, including concurrent validity with two similar, but not as comprehensive, carer-completed scales in this area (the Aberrant Behavior Checklist, and the PAS-ADD Checklist), and with the reliable ratings of psychopathology made by experienced clinicians.

Also the DBC-A has been shown to identify those at risk of having a psychiatric disorder and has factorial validity. The six-factor solution derived from an exploratory factor analysis of over 500 DBC-As yielded 6 subscales with factorial validity which describe behavioural syndromes (Disruptive, Self absorbed, Psychological disturbance, Anxiety/Anti-social, Social relating, Depressive). Groups of items on the

DBC-A also indicate the possible presence of a range of psychiatric disorders, such as psychotic illness, mood disorder, anxiety disorders and autism (Mohr, et al., 2005). Scoring every item on the DBC-A yields a Total Behaviour Problem Score (TBPS) and there are 6 subscale scores. A score of 51 and above indicates probable clinical caseness and the definite need for psychiatric review (see Section 2.7 for further details).

4.4.3 THE ADAPTIVE BEHAVIOUR ASSESSMENT SYSTEM II FOR ADULTS

The Adaptive Behaviour Assessment System II for Adults (ABAS-II Adult (Ages 16-89)) (Harrison & Oakland, 2003) (see Appendix A) was used in this study. It provides a comprehensive, norm-referenced assessment of adaptive skills for individuals with intellectual disability aged from birth to 89 years and was undertaken in America (Harrison & Oakland, 2003). The Adult form includes 239 items, with 20 to 27 items per skill area assessed. The ABAS-II Adult measure was also to be used in the Lifespan research project to help identify the presence of an intellectual disability in the individual who was the focus of the questionnaire and was therefore considered to be appropriate to be included in this research in order to provide comparable data. Indigenous adults were included in this study if they were eligible to receive a service from Disability SA. All potential clients in SA are required to have an IQ assessment and a diagnosis of intellectual disability. In cases where the level of intellectual disability was not recorded in the client database, the results of the ABAS-II were used to help determine the person's level of intellectual disability.

4.5 IDENTIFICATION AND SELECTION OF PARTICIPANTS

Potential participants for this study were identified from the Department Family and Community Disability Services register. All clients aged 16 years or older who were identified as Aboriginal and/or Torres Strait Islander on the register were eligible to participate in the research project. The register contained all Indigenous people (Aboriginal or Torres Strait Islander) with intellectual disability who had previously been registered for disability support from the Department and were assessed as being eligible to receive intellectual disability services (i.e. having an intellectual disability). Therefore this research sample was derived from an administrative group.

Eligibility for intellectual disability services from Disability SA requires that clients satisfy all three criteria of the international definition of intellectual disability:

- Significant limitations in intelligence—that is an intelligence quotient (IQ) of about 70 or less as measured on a standardised intellectual assessment test
- Significant limitations in the skills needed to live and work in the community, including difficulties with communication, self-care, social skills, safety and self-direction
- Limitations in intelligence and living skills that is evident before the person is 18 years of age.

A formal assessment by a psychologist or other appropriately qualified professional is required to diagnose intellectual disability prior to acceptance of eligibility by the service. The assessment for registration usually occurs in childhood. An assessment of the person's living skills may also be required. This is usually done by interviewing a parent, teacher or someone else who knows the person well.

In order to ensure that disability services are delivered in a culturally respectful manner Disability SA also offers further supports for Indigenous clients with intellectual disability, their families and carers. This includes a specialist team of Indigenous staff to help clients or their families use disability services, advocate on behalf of the client and/or their family, and provide Indigenous case managers and workers if required.

Further assistance and information for Indigenous clients and their families is offered through the Aboriginal Unit within the Office for Disability and Client Services.

4.5.1 CONSULTATION

Prior to approaching service providers and families, key Indigenous representative groups were consulted in order to ensure the research was conducted in a culturally appropriate manner. This included meeting with the Aboriginal Health Council of South Australia, the Aboriginal Disability Network of South Australia and the Manager of the Department of Family and Communities Aboriginal Disability Unit. The project benefited from the ongoing collaboration and support of these agencies and during the course of the research regular reports were provided to them. This provided an opportunity to meet with the local elders and informally discuss issues related to conducting the research. Advice from these groups was incorporated into the data collection methods in order to ensure cultural appropriateness. This included a trial of the questionnaire by a parent, and main care provider, of an Indigenous male with an intellectual disability. The parent provided feedback on the user-friendliness of it, including suggestions on how to frame certain questions within the booklet to help with ease of understanding. An additional recommendation from the Aboriginal Disability Network of South Australia was to include the offer of reimbursement to

unpaid carers for the time and any inconvenience of participating in the research project. It was thought that this best reflected contemporary research practice within the Indigenous community and met the expectations of participants for reciprocity and a valuing of their contribution. It was also agreed to undertake the data collection with a personalised approach by the most appropriate person, such as a known Case Manager or the individual's Aboriginal Service Coordinator, rather than a mail-out. As part of raising awareness of the Lifespan research project with the partner agency staff and potential participants, a range of activities were undertaken to share information about the project. These included:

1. A launch of the research project by the South Australian Minister for Family and Community Services

2. Delivery of various information sessions at related disability conferences

3. A quarterly newsletter was published and distributed as widely as possible in order to keep people informed of the activities of the research project (see Appendix H for an example of the quarterly newsletter)

4. A Lifespan website was developed on the Monash University Centre for Developmental Psychiatry and Psychology home page and provided links to relevant information and regular updates of progress of the research project. The address for the website is:

   http://www.med.monash.edu.au/spppm/research/devpsych/lifespan.html

5. Information sheets on the Research Team, Research Process, Project Benefits, Selected Bibliography and Indigenous Research were developed and included in information packages given out at conferences and the Disability SA Expo (see Appendix I)

6. Lifespan news items appeared on local TV news and radio in the Riverland region of SA

7. The researchers visited all regional Disability SA (DSA) offices and also attended Disability SA team meetings in Berri, Mount Barker, Murray Bridge, Port Augusta, Whyalla, Salisbury, West Lakes, Daw Park, Highgate, Regency Park, Gilles Plains, and Christies Beach

8. Meetings were conducted with Regional Managers, Aboriginal Liaison Officers from the Aboriginal Disability Unit and Disability SA Team Managers and Service Coordinators to explain the research methodology and the way Service Coordinators could assist in data collection and appointments with families

9. In conjunction with the respective Regional Managers, a Service Coordinator was identified for each potential participant and they were consulted to determine the preferred method of approach to participants and their families. This was either by telephone or direct contact from the Aboriginal Service Coordinator, the Case Worker, or the researcher, depending on the individual's circumstances.

Due to the widespread scatter and mobility of the Indigenous population in the far north of South Australia, particularly throughout the Anangu Pitjantjatjara Yankunytjatjara (APY) Lands, and the tri-state arrangements for disability support in these areas, the research boundaries were expanded to include the Central Australia region of the Northern Territory. This extension was also required because a number of Indigenous clients on the Department's SA database were found to be living in the Alice Springs region.

In the APY Lands, meetings were held with the Manager of Aboriginal Services in the SA Department of Family and Community Services in order to identify and agree on the preferred methods to contact families of eligible DSA clients living in the APY Lands. The APY Lands are part of the Western Desert in Central Australia and cover 102,360 square kilometres in the far north-west of South Australia in and around the Musgrave ranges. There are approximately 2700 Indigenous residents in the APY Lands, living in small communities and homelands. The lands are owned by Anangu people (a preferred term used by Indigenous people living in this area), and as a region are referred to as the APY Lands, which are managed by a body corporate (see attached map of APY Lands at Appendix J).

In the Northern Territory, the Northern Territory Department of Health and Community Services agreed to support the research project and meetings were held with the relevant Regional Director of Aged and Disability Services in order to decide on the preferred methods of data collection in this region. Further meetings with the Ngaanyatjarra Pitjantjatjara Yankunytjatjara (NPY) Women's Council, Northern Territory Public Guardian's Office, Disability Service Providers throughout the region, the Manager and Behaviour Specialists within the Positive Behaviour Support Unit (a specialist behaviour support unit for people with a disability within the NT Department of Health and Community Services), and the Local Area Coordinators (Case Managers within the NT Department of Health of Community Services) were conducted in order to explain the research methodology and discuss any relevant issues. These meetings and information sessions were conducted in each region prior to any contact with potential participants in the Northern Territory.

4.5.2 LAYING THE FOUNDATION WITH THE INDIGENOUS COMMUNITY

The project was fortunate to receive ongoing support from the Aboriginal Disability Network of South Australia (ADNSA). This is a State reference group made up of Indigenous representatives from all regions in South Australia who meet to discuss issues related to disability in the Indigenous community. Attendance at the regular ADNSA meetings provided an opportunity to:

- Discuss the aims of the Lifespan project and provide regular updates of progress. This included discussing examples of the questions included in the data collection, a review of the DBC-A and ABAS-II and other relevant discussions on the proposed methodology of data collection and seeking input and ongoing feedback into the need to make any changes to ensure cultural sensitivity and maximise participation

- Participate in general discussions on intellectual disability and mental illness issues as they relate to Indigenous participants community

- Discuss the need for further research to help understand the prevalence and nature of these issues.

The ADNSA assisted with direction and advice on who were the appropriate community bodies and senior people in the Indigenous community to consult and the level of consultation each group/person might prefer.

Recommendations from these meetings included a desire for shared learning, advice on data collection methodology, and the inclusion of reimbursement of participant expenses. It was recommended that instead of completing a mail out to potential participants, a preferred approach would be to individually contact potential participants through arranged initial introductions from appropriate Indigenous

contacts in the community, members of the Disability SA Aboriginal Disability Team, ADNSA committee members and appropriate community bodies and senior people within the Indigenous community prior to the collection of data.

General discussions were held with network members on the anxiety of community and family members about research, the possible benefits and negative impacts of research and the publishing of results in an appropriate manner. Suggestions on how best to communicate the results of the research to participants and their communities were discussed and agreed upon, together with the need to be sensitive to historically problematic relationships between communities and academic researchers in Indigenous communities. The researcher was invited by the ADNSA to attend a weekend retreat at Camp Coorong, south of Adelaide, with the committee members and volunteered at a cultural awareness day run by ADNSA.

Prior to finalising the research methodology, the relevant Service and Policy Managers and personnel throughout the various State and Territory Disability and Health departments, service providers, Public Guardians and Public Advocates and the Aboriginal Health Council Ethics committee were consulted. Prior to data collection, numerous trips were made to regional centres to visit service providers, elders from Kuarna, Narangga, Pitjantjatjara, Arrernte and Ngarrindjeri communities, families and departmental offices in the Riverland, South East, North, Far North and the North-West regions of the state to provide information about the research and seek their involvement in it.

4.5.2.1 COMMUNITY

In addition to extensive consultation with directly interested parties, time was spent building relationships and trust within the broader Indigenous community in South Australia and the Northern Territory. This included attendance and involvement in

existing community forums such as cultural awareness days, volunteering with the Journey of Healing committee and other groups in numerous community events and meetings to recognise and raise community awareness of Indigenous issues, such as Sorry Day, Healing Hands, Reconciliation SA events, the Australian Prime Minister's Apology Speech at Elder Park, other barbeques, dinners, Aboriginal College open days, and various cultural celebrations.

Staff from other research institutions throughout Australia, particularly within South Australian and Northern Territory were consulted. This included:

- Meeting with the Director of the Monash University Centre for Australian Indigenous Studies

- Meetings were held with the Disabilities Research Unit (DRU), University of Adelaide, to discuss related areas of research interest and the Lifespan research methodology

- Presentation at University of Adelaide School of Paediatrics and Women's Health. An invitation was extended from the Children, Youth and Women's Health Service Research unit to provide an overview of the Lifespan research project and research methodology

- Presentations at Flinders University Department of Disability Studies of several tutorials to undergraduate students on mental illness in Indigenous adults with intellectual disability.

- Meetings with Flinders University Aboriginal Health Research Unit (FAHRU) research managers to discuss Lifespan research project aims and methodology. Presentation of seminars on Lifespan research project and regular participation in monthly seminars, picnics, workshops.

- Consultations were held with academics at David Unaipon College of Indigenous Education and Research (part of the University of South Australia) and a tutorial conducted with undergraduate psychology students enrolled in the *Indigenous Australians: Culture and Colonisation* unit. This unit is the first compulsory unit on Indigenous issues in an undergraduate psychology degree in Australia. The researcher was invited to attend the undergraduate psychology Indigenous cultural subject for the semester.

There was also ongoing engagement with other related groups such as the South Australian Aboriginal Health Network (AHN) with regular attendance at their monthly education sessions and presentation of the research project and methodology. Feedback was sought and gained on the research methodology from various AHN professionals working in related fields such as South Australian Indigenous community managed health services.

Meetings were held with other Indigenous researchers undertaking related research projects, such as increasing employment opportunities for Indigenous people within the public service and also a project exploring the health issues of young Indigenous people living in Adelaide.

4.5.2.2 CONFERENCES/WORKSHOPS

There were other opportunities to present information on the Indigenous component of the Lifespan study during the course of the research project such as:

- Volunteering on the planning committee for the University of South Australia's annual Indigenous Psychology Conferences in 2007 and 2008. Further information about the research project at this conference was presented

- Attendance at the RANZCP and Queensland Centre for Rural and Remote Mental Health 2006 and 2008 Creating Futures Conferences

- Speaking at the 2006 Policy Conference *Empowering Individuals and Families in the Human Services* in Melbourne

- Speaking at the 2007 Disability and Rehabilitation Professionals Association (DaRPA) Conference at Flinders University

- Presenting at the 2006, 2007, and 2008 annual disability conferences coordinated by the South Australian Department of Families and Communities

- Presenting at the Australasian Society for the Study of Intellectual Disability (ASSID) Conference in 2008 *Principles, Policies and Practices: The search for evidence* in Melbourne

- Presenting 2 papers at the International Association for the Scientific Study of Intellectual Disabilities (IASSID) 2nd Asia Pacific Regional Congress titled *Creating Possibilities for an Inclusive Society* in Singapore in 2009

- Attending a training workshop on the *Mental Health and Psychological Assessment of at risk Aboriginal Clients* conducted by Dr Tracey Westerman, Managing Director of Indigenous Psychological Services in Western Australia.

4.6 INTERVIEWS WITH CARERS

Meetings were held with many carers of Indigenous participants throughout the research project. These were mainly parents of participants, although there were several foster carers and people who had formally and informally adopted a participant. Particularly in remote Indigenous communities, there were many other family members, such as a sister, aunty, or grandparent who were the main care provider.

After prior contact with the care provider, either via telephone, letter, or an appropriate health worker asking the carer if they would be happy to meet the researcher, face to face introductions to the carers were often facilitated by a third party; usually an Indigenous Liaison, Disability, or Health Worker. The purpose of the research was discussed and consent was sought to participate in the study which included answering some further questions related to four key areas that have a relationship with the emotional and behavioural wellbeing of Indigenous people with intellectual disability:

- Perceptions of intellectual disability & mental health

- Disability support issues

- Service satisfaction

- The individual with a disability's contribution to community and valued roles.

These meetings were often conducted with the help of an interpreter who spoke the appropriate language in a conversational manner and with consent the responses were either written down on paper, or recorded on a voice recorder and later transcribed.

4.7 DATA COLLECTION

This research was conducted in urban, regional and remote communities throughout South Australia and the Northern Territory with Indigenous people in each area. A research approach was developed in consultation with them that was intended to be collaborative, inclusive and sensitive to their needs.

All data collection field trips to remote regions in northern South Australia, the APY Lands and Alice Springs, were undertaken with a Cultural Liaison Officer who could provide language interpretation support if required. Each journey took at least a week to travel throughout the various communities, often travelling several thousand kilometres. In South Australia participants were located on the west coast of South Australia in several communities beyond Ceduna and in Port Lincoln, Port Augusta and Whyalla. There were several trips to Alice Springs which also involved travelling through Coober Pedy, Marla, and throughout the APY Lands to communities on the border of South and Western Australia. One trip included travelling to Tennant Creek and communities nearby. Other trips in South Australia included: the Riverland, Yorke Peninsula, Fleurieu Peninsula, the South East region and throughout the Mount Lofty Ranges. A travel schedule is attached for further information (see Appendix K).

Throughout the various research trips, some informal time was spent in each community to gain an appreciation of the community dynamics and unique issues facing the particular community.

The relevant permits were always gained prior to entry onto Indigenous lands and the relevant councils were advised of the visit. When advising of a forthcoming visit, an offer of a meeting with any council/community member who wanted to discuss the research project was made. On entering a community or homelands, the local council,

clinic or elders house was visited first to discuss the purpose of the visit to the community.

4.7.1 PROCEDURE

Carers in families and accommodation services who knew the adult with an intellectual disability well were contacted by either the Aboriginal Disability Service Coordinator or their Disability SA Service Coordinator, or the researcher. Carers were provided with information about the research project and asked whether they would agree to participate in the research project by completing the questionnaire booklet.

4.7.2 CONSENT

Carers read a comprehensive plain English information form attached to a consent form (see Appendix L) which fully described the project and gave their informed consent. In those situations where the individual with an intellectual disability was able to provide informed consent they also received a Plain Language Statement (see Appendix L), had the survey explained by the Service Coordinator or the researcher, and gave consent for their carer to participate. An interpreter translated the consent information if required.

4.7.3 DATA FOLLOW UP

Database searches on the Disability SA database and follow up phone calls were conducted by the researcher to collect missing information in questionnaires and missing responses.

4.7.4 DATA RECORDING AND STORAGE

The project staff had details of date of birth, gender, level of intellectual disability and type of living arrangement to be able to stratify the cohort. A secure and password protected database system was developed for the purpose of storing project information. Measures to ensure confidentiality of individuals who participated in the study included each returned Lifespan questionnaire being given a confidential unique code number and entered onto the database with this unique code with no other information attached that was able to identify the participant (i.e. names, addresses, contact details). A file was created for each returned questionnaire and was secured in a locked storage cabinet within a locked and alarmed facility at all times.

CHAPTER 5

RESULTS

This chapter reports on the results of the Indigenous participants in the Lifespan research project. Data were gathered over a period of 18 months. The chapter is presented in 3 sections:

- 5.1. Population Characteristics results - collected in the Lifespan questionnaire booklet (see appendix A)

- 5.2. Psychopathology of participants including results from the Developmental Behaviour Checklist – Adults (DBC-A) and factors associated with psychopathology of the participants. Comparisons of results with the non-Indigenous participants of the Lifespan project are reported in most cases.

- 5.3. Qualitative information - the lived experiences of the Indigenous participants and their carers, from the interviews with family members and carers of Indigenous participants with intellectual disability throughout South Australia and the central Australia region of the Northern Territory. This section includes results on Indigenous perceptions of intellectual disability and mental illness and attitudes towards disability services.

5.1 POPULATION CHARACTERISTICS

5.1.1 PARTICIPATION RATES

Out of a total population of 198 Indigenous adults on the combined SA and Alice Springs Disability Services (central Australia region of the Northern Territory) client registers, 161 Indigenous adults with intellectual disability participated in this study. This represents an 81% participation rate (see Table 6 below). The total potential

population included all Indigenous clients on the South Australian Disability Services (including Alice Springs) database who have intellectual disability after removing from the database people who had deceased or moved out of South Australia and the Northern Territory, or who had Aspergers Disorder and not an intellectual disability. Throughout the data collection process, it was found that there was considerable mobility of this population, particularly movement between State and Territory borders and throughout regional areas.

At the time they entered the study 60% of participants were living in South Australia and 40% were living in the Northern Territory.

Table 6

Indigenous participation rates

	N (%)
SA + Alice Springs Register	198 (100)
Participants	161 (81)
non-Participants	37 (19)

This study was part of The Lifespan Project, a study of the mental health of adults with intellectual disability living in South Australia. For the purposes of developing norms for the DBC-A, postcodes were selected that formed a representative sample of the population of adults registered with intellectual disability services in South Australia. The participation rate of selected postcode regions resulted in a 73% questionnaire return rate ($N= 806$) in these areas, which were subsequently called the *Gold Postcodes*. Analysis of the results found no differences between the Gold group and participants from other postcodes on key demographic and response variables, so they were subsequently amalgamated, giving a total of 1450 non-Indigenous participants in the Lifespan study.

The data from this representative population of non-Indigenous adults with intellectual disability in Australia is used as a comparison group for the Indigenous population who participated.

5.1.2 AGE AND GENDER

Sixty percent of the Indigenous population were males and 40% were females, a slightly higher percentage of males than in the non-Indigenous group. The Indigenous sample is much younger than the non-Indigenous sample, for example, there are double the number of Indigenous participants under 35 years (57%), compared to the non-Indigenous group (27.9%). The mean age of the Indigenous sample is 33.7 years (range 16-83 years) and this is over nine years younger than the non-Indigenous sample population of 42.9 years (range 16-85 years) (see Table 7 below).

Table 7

Age range and gender

		Indigenous	Non-Indigenous
		N (%)	N (%)
Gender	Male	96 (60)	816 (56)
	Female	65 (40)	634 (44)
Age Range (years)	16-18	18 (11.2)	76 (5.2)
	19-24	30 (18.6)	127 (8.7)
	25-34	44 (27.3)	203 (14)
	35-44	40 (24.8)	365 (25.1)
	45-54	15 (9.3)	371 (25.5)
	55 up	14 (8.7)	308 (21.2)
Mean age in years		33.7	42.9

5.1.3 LEVEL OF INTELLECTUAL DISABILITY

Just under one third of Indigenous participants had mild intellectual disability (32%),

or moderate intellectual disability (31.5%) and a slightly larger group had severe or

profound intellectual disability (36.5%). These levels of intellectual disability

compared closely with the non-Indigenous population (see Table 8 below).

Table 8

Level of intellectual disability

ID Level	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Mild	53	(33)	512	(35)
Moderate	50	(31)	434	(30)
Severe/Profound	58	(36)	503	(35)
Unknown	0	(0)	1	(0.07)
Total	161	(100)	1450	(100)

5.1.4 GEOGRAPHIC CHARACTERISTICS AND NON-ENGLISH SPEAKING BACKGROUND (NESB) STATUS

The Australian Standard Geographical Classification (ASGC) (Australian Bureau of

Statistics, 2008) is used by the Australian Bureau of Statistics for the collection and

dissemination of geographically classified statistics. The ASGC utilises a Remoteness

Structure which classifies areas of remoteness into six broad geographical regions

called Remoteness Areas (RAs) based on Census Collection Districts (CD) (see Table

9 below). The Accessibility/Remoteness Index of Australia (ARIA) measures the

remoteness of a point based on the physical road distance to the nearest Urban Centre

in each of the five classes.

Table 9

ASGC Remoteness Areas (RA) (Australian Bureau of Statistics, 2008)

ASGC Remoteness Area	Description
Major Cities of Australia	CDs with av. ARIA value of 0 to 0.2
Inner Regional Australia	CDs with av. ARIA value > 0.2 and < or equal to 2.4
Outer Regional Australia	CDs with av. ARIA value > 2.4 and < or equal to 5.92
Remote Australia	CDs with av. ARIA value > 5.92 and < or equal to 10.53
Very Remote Australia	CDs with av. ARIA value > 10.53
Migratory[1]	Composed of off-shore, shipping and migratory CDs

[1] The Migratory Remoteness area was not required as a classification in this research project because it is exclusively composed of off-shore, shipping and migratory CDs that were outside of the geographical boundaries of this research project.

Forty percent of Indigenous participants resided in a major city (see Table 10 below). This is less than half the proportion of non-Indigenous participants living in a major city (84.5%). Over 40% of Indigenous participants resided in remote or very remote areas, with the remaining 18% percent residing in inner and outer regional areas. Forty percent of Indigenous participants identified as being from a non-English speaking background (NESB) compared with only 6% of non-Indigenous. The proportion of Indigenous people from a NESB increases significantly in the remote (89% from a NESB background) and very remote areas (54%) compared to the city (12%) and regional areas (5% average) (see Table 10 below).

It should be noted that the definition of non-English speaking background for this project was broader than just including people (or their parents) who were born overseas in a non-English speaking country. It also included individuals who grew up in a family who spoke a non-English language at home. This includes those people who predominantly spoke any of the numerous Indigenous languages.

Table 10

Geographic characteristics and non-English speaking background status

Remoteness Area	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Major city	65	(40)	1223	(84.5)
Inner Regional	17	(11)	115	(8)
Outer Regional	11	(7)	105	(7.2)
Remote	55	(34)	5	(0.3)
Very Remote	13	(8)	0	(0)
Total	161	(100)	1448	(100)
NESB	65	(40)	92	(6)

Figure 1 *Percentage of Participants in each Remoteness Area*
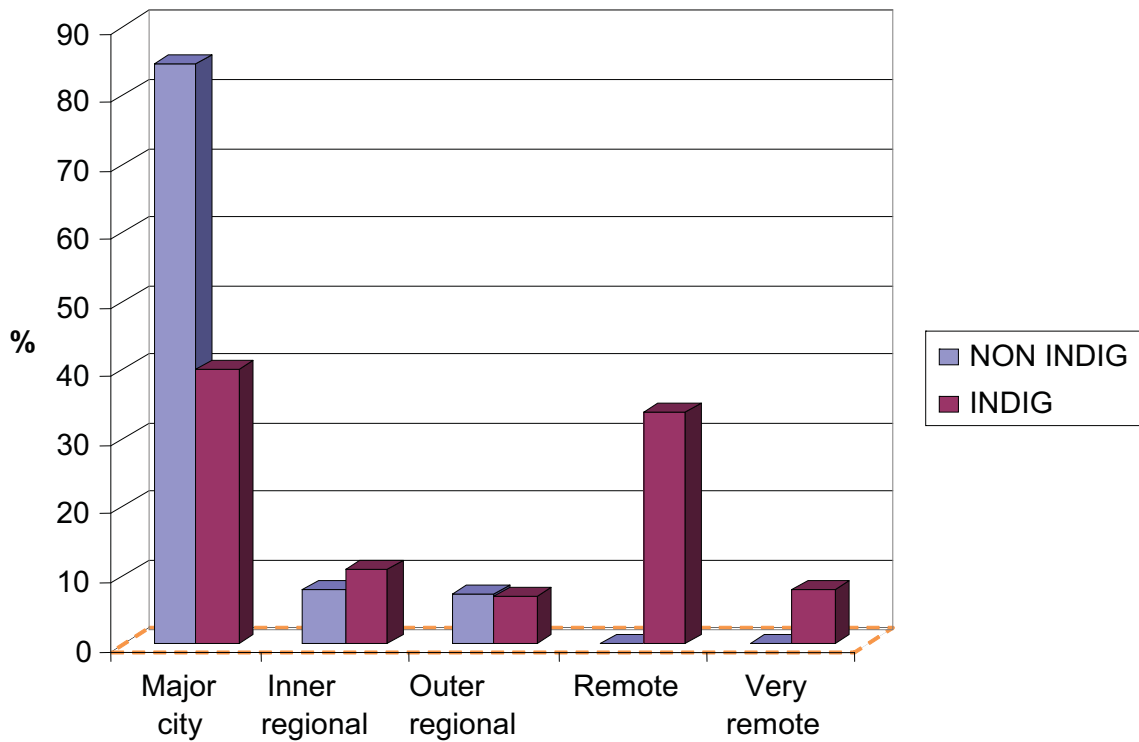
Figure 2 *Percentage NESB in each Remoteness Area*
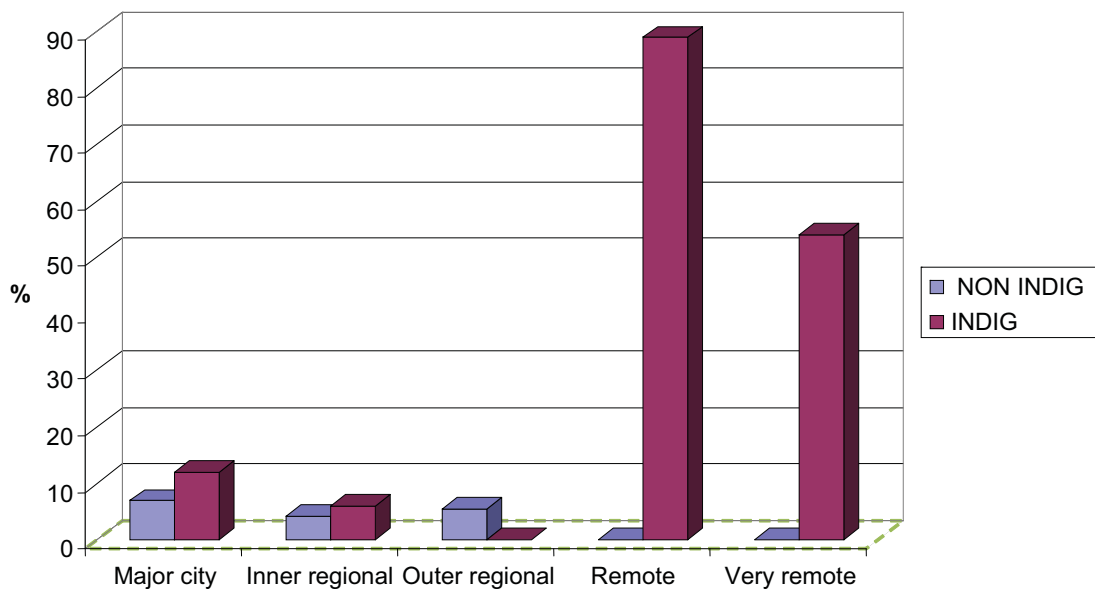
5.1.5 RELATIONSHIP OF PERSON COMPLETING THE QUESTIONNAIRE TO THE PERSON WITH INTELLECTUAL DISABILITY

Approximately 70% of questionnaires for both Indigenous and non-Indigenous participants were completed by the individual's paid carer (see Table 11 and Figure 3 below). A greater proportion of non-Indigenous questionnaires was completed by the individual's mother, father or grandparent (24%), compared to Indigenous questionnaires (15%). Of the Indigenous questionnaires, 7.4% were completed by the foster parent, compared to only 0.14% for non-Indigenous. The 8.7% of *Other* completers for the Indigenous questionnaires include the individual's Public Guardian, other family members and unpaid carers.

Table 11

Relationship of person completing the questionnaire to the individual

Relationship	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Mother	21	(13)	291	(20)
Father	2	(1.2)	61	(4.2)
Grandparent	1	(0.6)	3	(0.2)
Foster parent	12	(7.4)	2	(0.14)
Paid carer	111	(69)	1050	(72.4)
Other	14	(8.7)	43	(3)
Total	161	(100)	1450	(100)

Figure 3

Relationship of Person Completing Questionnaire
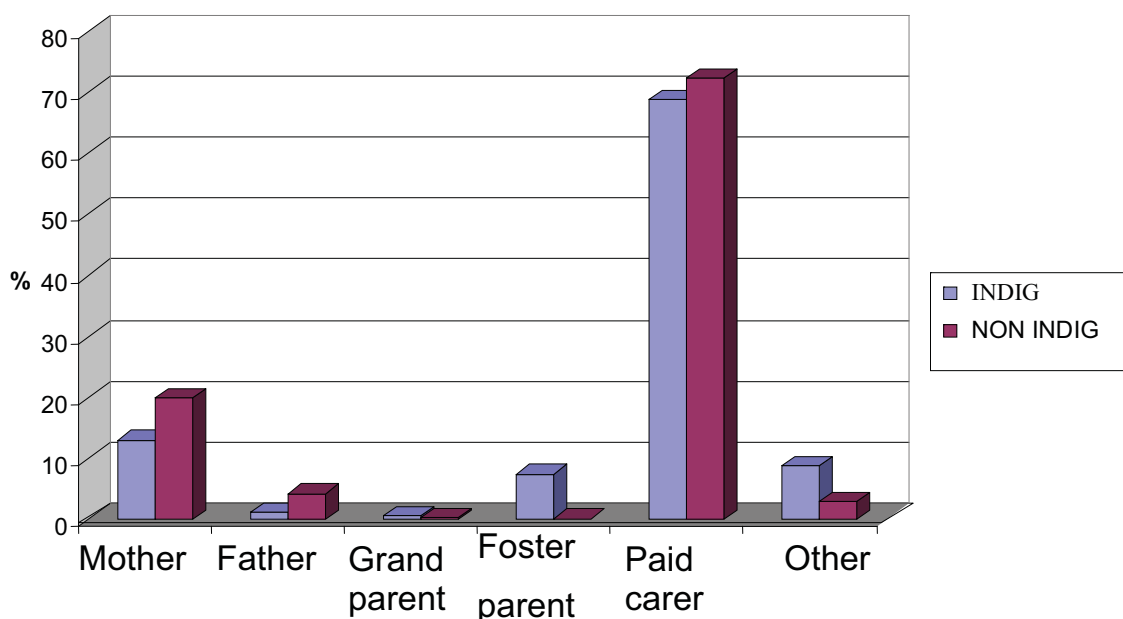
5.1.6 DESCRIPTION AND REPORTED CAUSE OF

INTELLECTUAL DISABILITY

Forty two percent of Indigenous participants and 54% of non-Indigenous participants reported the cause of intellectual disability (see Table 12 below). Of these, the highest reported cause of intellectual disability for Indigenous participants was Acquired Brain Injury (ABI) occurring during the developmental period (20%) and for non-Indigenous participants was Down syndrome (32.1%). 17.1% of Indigenous participants reported associated Cerebral Palsy (10.4 for non-Indigenous participants). 10% of Indigenous participants reported having an Autism Spectrum disorder (15.3% non-Indigenous participants).

45% of Indigenous participants reported an *Other* category (see Table 13 below). The reported causes for Indigenous participants in the *Other* category were Fetal Alcohol

and substance abuse syndrome (10/32), perinatal infection/ trauma/ prematurity 14/32

and genetic metabolic disorders 8/32.

Table 12

Reported cause of intellectual disability

Reported Cause of ID	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Autism Spectrum Disorder	7	(10)	121	(15.3)
Cerebral Palsy	12	(17.1)	82	(10.4)
Down syndrome	4	(5.7)	253	(32.1)
Fragile X syndrome	0	(0)	10	(0.13)
Prada-Willi syndrome	0	(0)	8	(1)
Tuberous Sclerosis	0	(0)	8	(1)
Williams syndrome	1	(1.4)	1	(0.1)
Acquired Brain Injury	14	(20)	9	(1.2)
Other	32	(45.7)	296	(37.6)
Total	70	(43% of total)	788	(54% of total)

Table 13

Reported (other) cause of intellectual disability

Reported Cause of ID	*N*	(%)
Perinatal infection/ trauma/ prematurity	14	(43.75)
Fetal alcohol and substance abuse syndrome	10	(31.25)
Genetic/ metabolic abnormalities	8	(25)
Total other	32	(100)

5.1.7 PHYSICAL DISABILITIES OF PARTICIPANTS

The Lifespan Questionnaire Booklet (see Appendix A) included questions relating to

the individual's ability to see, hear, use their arms and legs for day-to-day activities,

and their ability to speak. It is worth noting that feedback on the question of whether

the individual can see if wearing glasses indicated that there may have been some confusion for the person completing the questionnaire as to what the question meant. It is therefore likely that the responses to this question over-represent the number of people who answered *No* to this question due to the responder thinking that if the individual, who may be able to see perfectly, was required to wear glasses, they would then be unable to see properly. This result was particularly pronounced in the Indigenous population due to difficulties interpreting the wording of the question. The results (see Table 14 below) show that the Indigenous participants had approximately double the rate of hearing problems than the non-Indigenous participants (3.8% could not hear and 15.6% could hear *Somewhat*, compared to 1.75% and 7.3%).

Table 14

Physical characteristics of participants

Are they able to:		Indigenous		Non-Indigenous	
		N	(%)	*N*	(%)
See if wearing glasses?	No	53	(34.6)	146	(10.4)
	Somewhat	13	(8.5)	78	(5.6)
	Yes	87	(56.8)	1172	(83.9)
Hear?	No	6	(3.8)	25	(1.75)
	Somewhat	25	(15.6)	104	(7.3)
	Yes	129	(80.6)	1301	(91)
Use arms?	No	16	(10)	111	(7.8)
	Somewhat	27	(16.8)	136	(9.5)
	Yes	118	(73.3)	1182	(82.7)
Use legs?	No	26	(16.3)	122	(8.5)
	Somewhat	20	(12.5)	130	(9.1)
	Yes	114	(71.3)	1177	(82.4)
Speak?	No	42	(26.3)	336	(23.6)
	Somewhat	29	(18.1)	223	(15.6)
	Yes	89	(55.6)	868	(60.8)

5.1.8 CHRONIC MEDICAL/HEALTH PROBLEMS

Over 60% of both Indigenous participants and non-Indigenous participants were reported to be suffering from a current chronic medical or health problem (see Table 15 below).

Table 15

Chronic medical/health problems

Chronic medical/health problems?	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Yes	104	(65)	878	(61.5)
No	53	(33.1)	504	(35.3)
Don't know	3	(1.9)	45	(3.2)
Total	160	(100)	1427	(100)

The main categories of chronic medical or health problems are listed in Table 16 below. Indigenous participants showed higher rates of neurological/epilepsy health problems than non-Indigenous participants (57.1% compared to 47.5%) and lower rates of cardiovascular disease (10.4% compared to 21.4%) and much lower rates for gastrointestinal health problems (0.6% compared to 11.9%). For descriptions of other health conditions see Appendix M.

Table 16

Description of chronic medical/health problems

Description	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Neurological/epilepsy	60	(57.1)	430	(47.5)
Diabetes/endocrine disease	28	(26.6)	197	(21.7)
Respiratory	21	(20)	154	(17)
Musculoskelatal/arthritis	12	(11.4)	184	(20.3)
Cardiovascular disease	11	(10.4)	194	(21.4)
Gastrointestinal	7	(0.6)	108	(11.9)
Genito-urinary	7	(0.6)	38	(0.4)
Total	105	(100)	905	(100)

5.1.9 LIVING ARRANGEMENTS

Approximately one quarter of all Indigenous and non-Indigenous participants lived with their family or friends (see Table 17 below). Forty three percent of Indigenous participants (compared to 37% of non-Indigenous participants) lived in supported accommodation in the community, while only 8.6% Indigenous participants lived in larger residential facilities, compared to 31% non-Indigenous participants.

One in 10 Indigenous participants lived in foster care arrangements, which is much higher than the 0.2% of non-Indigenous participants living in foster care. This rate includes adults who remained living with their carers after formal foster care arrangements expired once the individual turned 18 years old. 8.6% of Indigenous participants (6.6% non-Indigenous participants) lived independently.

Table 17

Living arrangements

Where does the person live?	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
With family/friends	41	(25.4)	335	(23.1)
In foster care	17	(10.5)	3	(0.2)
In small unit - supported	70	(43.4)	546	(37.7)
In large residential facility	14	(8.6)	458	(31.6)
Independently	14	(8.6)	97	(6.6)
Other	5	(3.1)	9	(0.6)
Total	161	(100)	1448	(100)

5.1.10 IF MOVED IN LAST 12 MONTHS, WHERE FROM?

Over 28% of Indigenous participants (see Table 18 below) had experienced a move in the last 12 months, which is more than double the rate of non-Indigenous participants who had moved in this time (13%). Over 40% of Indigenous participants (and 20% of

non-Indigenous participants) had moved from living with family or friends. Nearly

one quarter of all Indigenous participants had moved out of a small residential unit,

with a much higher rate of non-Indigenous participants (48%) moving from a large

institution, compared to 13% of the Indigenous participants group.

Table 18

Moved in last 12 months

Where did they move from?	Indigenous N (%)	Non-Indigenous N (%)
Family/friends	19 (41.3)	40 (21)
Foster care	1 (2.1)	1 (0.5)
Small unit - supported	11 (23.9)	43 (22.6)
Large residential facility	6 (13)	92 (48.4)
Independent living	2 (4.3)	8 (4.2)
Other	7 (15.2)	6 (3.1)
Total	46 (100)	190 (100)
% of people moved in last 12 months	28.5%	13.1%

5.1.11 MAIN DAYTIME ACTIVITY

Approximately 40% of the Indigenous participant sample had no organised day

activities for the entire week, and this contrasted sharply with the reported rate (15%)

in the non-Indigenous group. The main organised activity for both groups was *day

activity/retirement programs*, however only one third of Indigenous participants were

involved compared to 44.5% of non- Indigenous participants. Indigenous participants

also participated at much lower levels in supported vocational settings (12%)

compared to non-Indigenous participants (32%), however both groups had only 2.4%

representation in open employment (see Table 19 below).

Table 19

Main daytime activity

What is the person's main daytime activity?	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
No organised activity	66	(40.9)	211	(14.8)
School/tertiary education	18	(11.1)	83	(5.8)
Day activity/retirement program	53	(32.9)	635	(44.5)
Supported workshop	20	(12.4)	457	(32.1)
Open employment	4	(2.4)	35	(2.4)
Total	161	(100)	1421	(100)

5.1.12 HOURS/ WEEK SPENT IN ACTIVITIES

Indigenous participants and non-Indigenous participants showed comparable levels of hours spent each week in activities with roughly 20% spending less than 10 hours a week in organised activities, just over 20% spending between 10-20 hours, and nearly 60% spending more than 20 hours in activities (see Table 20 below).

Table 20

Hours/week spent in activities

Number of hours per week spent in activities	Indigenous		Non-Indigenous	
	N	(%)	*N*	(%)
Less than 10 hours	12	(14.3)	164	(14.0)
10-20 hours	29	(34.5)	259	(22.1)
More than 20 hours	43	(51.2)	748	(63.9)
Total	84	(100)	1171	(100)

5.1.13 RELATIONSHIP WITH OTHERS

Most carers of both Indigenous and non-Indigenous participants identified that their closest relationship was with a family member (58.6% Indigenous participants, 60% non-Indigenous participants) (see Figure 4 below). The next highest category of close relationship was with paid workers (46.7% Indigenous participants, 41.8% non-Indigenous participants) and then co-residents (16% Indigenous participants, 17.7% non-Indigenous participants). A significant percentage (34.6%) of Indigenous participants identified *Other* relationships as being close, and this included descriptions of close relationships within their broader family and community.

Of concern is the high number of all participants (27% Indigenous participants, 22% non-Indigenous participants) who were identified as having a close relationship with no one.

Figure 4

Relationship with Others
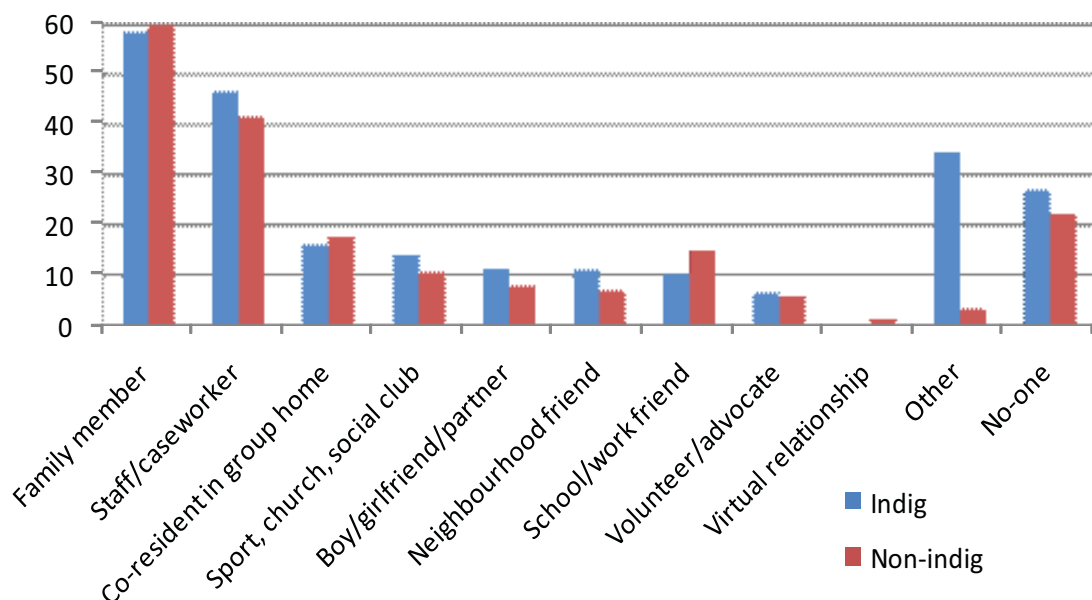
5.1.14 LIFE EVENTS

Indigenous participants with intellectual disability were reported to have had twice as many Life Events (LEs) in the past 12 months, on average, than did non-Indigenous participants (mean LE = 2.68 Indigenous participants to 1.31 non-Indigenous participants). 70% of all Indigenous participants reported at least one LE in the last 12 months, compared to 55% of non-Indigenous participants. The Standard Deviation is 2.92 for Indigenous participants and 1.22 for non-Indigenous participants (see Table 21 below). Regression analysis of the LEs was conducted (see Appendix N) that found that Indigenous participants with intellectual disability had, on average, about one more LE in the past 12 months than non-Indigenous participants after age, gender, and city or non-city residence are taken into account and that age is negatively associated with the number of LEs.

Table 21

Life Events

Group	Obs.	% 1 or more LE		Mean	Standard Error	Standard Deviation	95% Conf. Interval
		N	(%)				
Indigenous	161	113	(70.1)	2.68	.23	2.93	2.23
Non-Indig	1448	801	(55.2)	1.32	.05	1.23	1.23

Indigenous participants were noted to have reported higher rates of all types of LEs (apart from *Having trouble with superiors at school* which was roughly the same as non-Indigenous participants) (see Figure 5 below), with approximately double the rate for the more significant LEs, such as serious illness or hospitalisation, death of a close relative or family member, victim of crime or assault, and problems in the family and

household than non-Indigenous participants. The rate of substance abuse was reported to be 11 times higher for Indigenous participants than non-Indigenous participants.

Figure 5

% reported Life Events in last 12 months
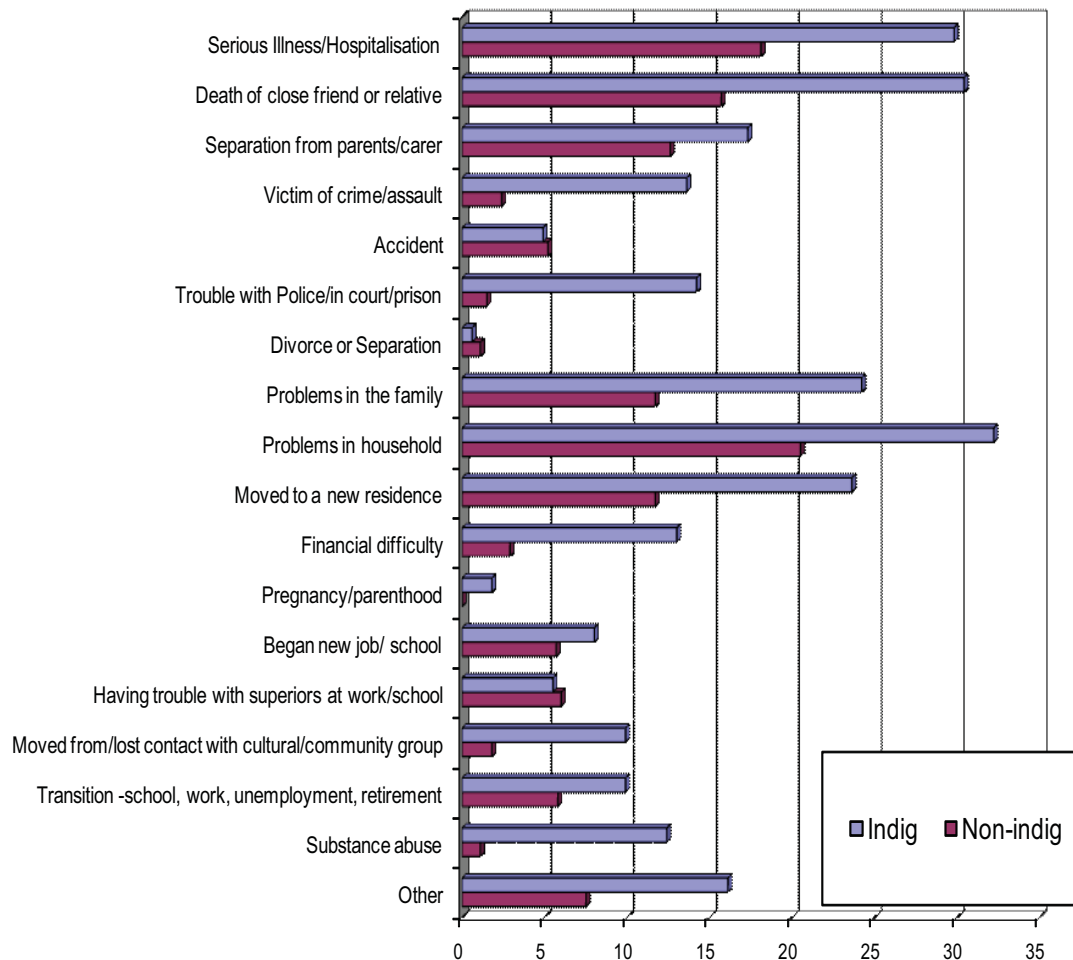
5.1.14.1 LIFE EVENTS STRESS DATA

The t-test of stress levels for LEs shows that for those participants who experienced one or more LE, 70% of Indigenous participants (compared to 60% of non-Indigenous participants), identified the LEs experienced was thought to have been either moderately or severely stressful (see Table 22 below). This is a significant difference in levels of stress.

Table 22

Stress levels for Life Events: t test with equal variances

Group	Obs.	Mean	Standard Error	Standard Deviation	95% Conf. Interval
Indig	112	.7	.04	.37	0.63 - 0.77
Non-Indig	794	.6	.02	.44	0.57 - 0.63
Combined	906	.61	.01	.43	0.58 - 0.64
Difference		-.1	.04		-0.18 - -0.64

5.1.14.2 LIFE EVENTS AND AGE

The data presented in Table 23 (below) indicates that LEs were more commonly reported to have been experienced by Indigenous participants, compared to non-Indigenous participants in all age groups. There was also was a gradual decrease in number of LEs for older participants (see Figure 6 below).

Table 23

Mean number of Life Events for age groups (years)

Age Groups	Indigenous	Non-Indigenous
16-18	3.9	2.2
19-24	3.5	2.3
25-34	2.6	1.7
35-44	2.3	1.2
45-54	2.1	1.1
55+	1.4	0.8

Figure 6.

Count of Life Events vs. age for Indigenous participants
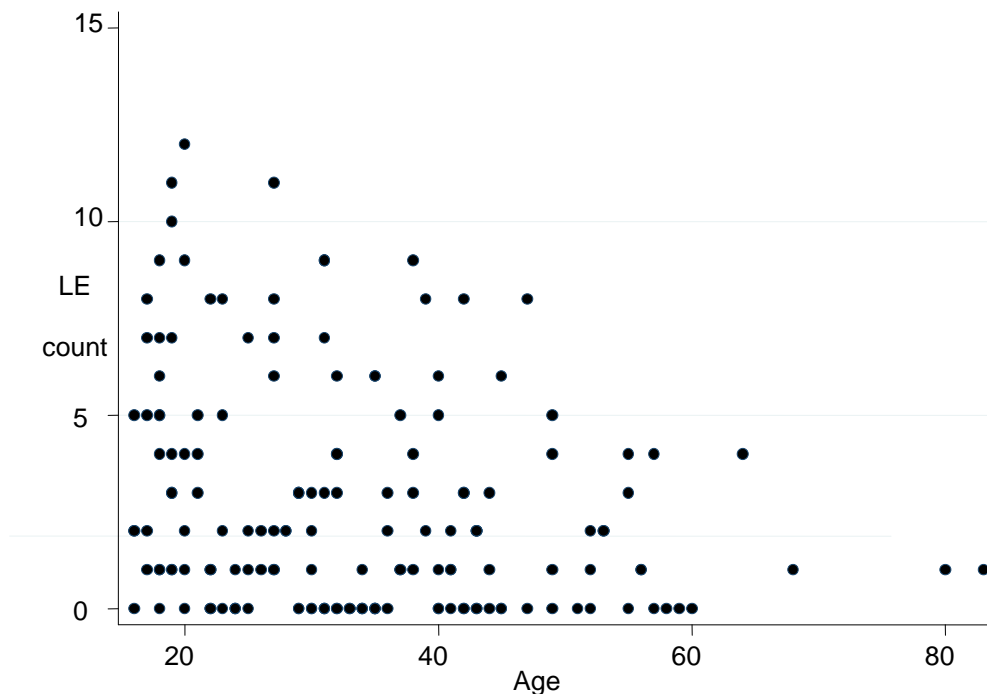
A regression analysis of the number of LEs and age, Indigenous status and level of intellectual disability shows that the number of LEs is negatively associated with age of subject (see Table 24 below). The number of LEs is also negatively associated with level of intellectual disability. Indigenous participants with severe or profound intellectual disability were reported to have had .99 fewer LEs, on average, than those with mild intellectual disability. Indigenous participants with moderate intellectual disability have .31 fewer LEs reported, on average, than those with mild intellectual disability. After the effects of age and intellectual disability are accounted for there is a strong positive association of number of LEs with Indigenous status, with Indigenous participants having an average of 1.1 more LEs than non-Indigenous participants.

Table 24

Logistic regression of number of Life Events on age, Indigenous status and level of intellectual disability

Num LE	Odds Ratio	Std. Err.	t	P>t	95% Conf. Interval
Age	-.03	.00	-9.50	0.00	-.04 - 0.02
ID: Moderate	-.32	.11	-2.88	0.00	-0.53- -0.1
ID: Severe	-.99	.11	-9.37	0.00	-1.2 - -0.78
Indigenous	1.11	.15	7.47	0.00	0.82 - -1.4
Const.	3.01	.15	20.70	0.00	2.73 – 3.3

5.1.15 AGE OF PARENTS

Approximately one quarter of the biological parents of Indigenous participants were deceased (27% fathers, 23% mothers) (non-Indigenous participants' fathers: 33%, mothers 25%).

The mean age of Indigenous participants' mothers (excluding those whose age was unknown and those who were deceased) was 51.8 years, nearly 10 years younger than non-Indigenous participants' mothers (mean age 61.4 years) (see Figure 7 below).

The mean age of Indigenous participants' fathers was 52.7 years, nearly nine years younger than non-Indigenous participants' fathers (61.5 years) (see Figure 8 below).

The age of Indigenous participants' parents was unknown in 40.6% of cases (24% for non-Indigenous participants).

Figure 7.

Age distribution of Indigenous and non-Indigenous Mothers
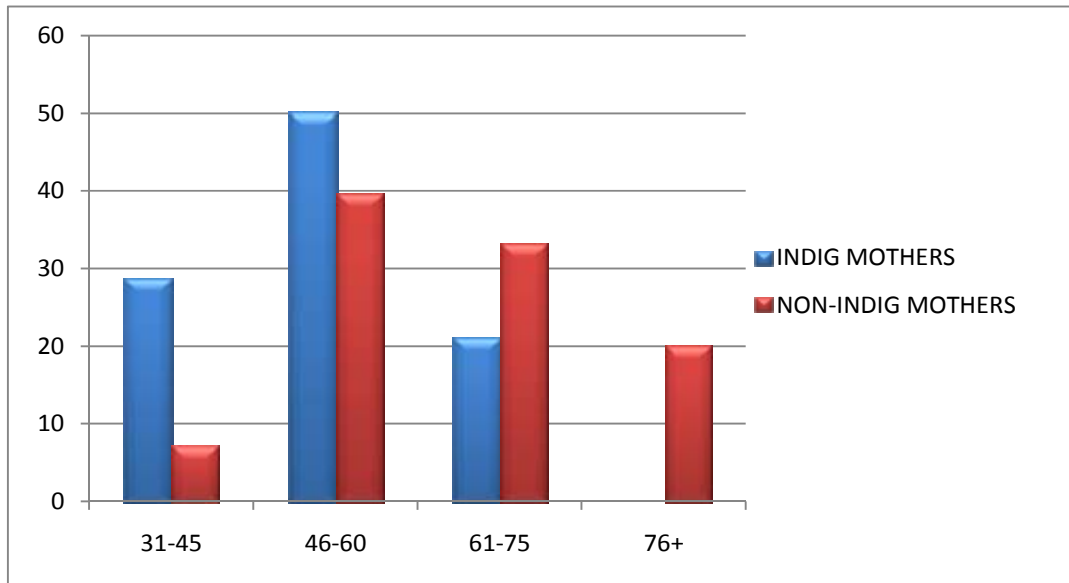
Figure 8.

Age distribution of Indigenous and non-Indigenous Fathers
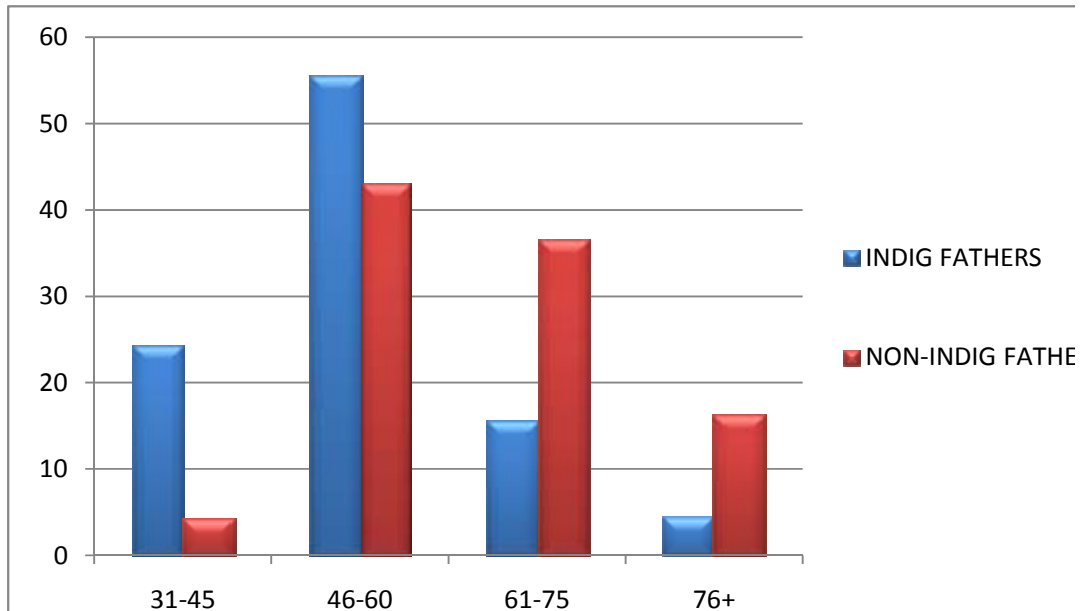
5.2 PSYCHOPATHOLOGY OF INDIGENOUS PARTICIPANTS WITH INTELLECTUAL DISABILITY

5.2.1 PREVALENCE OF PSYCHOPATHOLOGY

Levels of psychopathology as measured by the DBC-A can be expressed using three different statistical calculations:

1. The Mean Item Score (MIS), the total score on the DBC-A divided by the number of items checked

2. The proportion of items positively checked (PIC), the number of DBC-A items rated 1 or 2

3. The Intensity of Items scored (II), which measures the proportion of positively checked DBC-A items that scored two (0, 1, 2 score system)

The results for Indigenous participants are presented in Table 25 below. The MIS is 22% higher for Indigenous participants, and the PIC and II are 18.5% and 15% higher respectively.

In addition, the proportion of participants who were identified as being a DBC-A case was higher amongst the Indigenous participants, compared to the non-Indigenous participants (29.2% compared with 21.1%) (see Table 25 below). A case equals a Total Behaviour Problem Score (TBPS) score of 51 or above on the DBC-A and indicates that the individual has a probable psychiatric disorder or significantly high levels of psychopathology. The DBC-A TBPS cut-off level was determined by using a Receiver Operating Characteristics (ROC) analysis which involves analysis of the percentage of cases above and below the cut-off score on the basis of comparing clinical interview data with DBC-A scores.

Table 25

DBC-A results

	Case	MIS	Std. Dev.	PIC	Std. Dev.	II	Std. Dev.
Indigenous	.292	.38	.27	.28	.17	.32	.23
Non-Indig	.211	.31	.22	.24	.15	.28	.23

Regression analysis of the MIS, PIC and II (see Table 26 below) shows the MIS (on a 0-2 scale) on the DBC-A was 0.31 on average for non-Indigenous participants and .07 higher (.38) for the Indigenous participants.

The proportion of DBC-A items checked (on a 0-1 scale) (PIC) on the DBC-A was 24% on average for non-Indigenous participants and .04 higher (28%) for the Indigenous participants.

The intensity index (proportion of 2s among the positively checked items) (II) on the DBC-A was 28% on average for non-Indigenous participants and 4% higher (32%) for Indigenous participants. The results of the three methods of scoring the DBC-A were all significantly higher for the Indigenous group compared to the non-Indigenous group.

Table 26

Regressions of overall DBC-A scores on Indigenous participant's status

	Mean item score (MIS)	Proportion of items checked (PIC)	Intensity index (II)
Indigenous	**0.07**	**0.04**	*0.04*
Non-Indig.	**0.31**	**0.24**	**0.28**

p-value code: >.05 <.05 **<.01** <.001

5.2.2 PSYCHOPATHOLOGY AND LEVEL OF INTELLECTUAL DISABILITY

Indigenous participants with moderate intellectual disability level scored higher MIS, PIC and II than those with mild (5% higher) or severe/profound intellectual disability level (14% higher) (see Table 27 below). Those with mild intellectual disability level scored higher MIS and PIC than those with severe/profound intellectual disability, although the II of these two levels of intellectual disability were the same.

Table 27

DBC-A results for Indigenous participants intellectual disability levels

Level of ID	MIS	PIC	II
Mild	.39	.28	.32
Moderate	.41	.30	.34
Severe/Profound	.36	.27	.32

When considering the caseness level of participants with different levels of intellectual disability, 34% of Indigenous participants with mild intellectual disability were identified as cases, reducing to 28% for those with moderate intellectual disability ,and 26% for those with severe or profound level of intellectual disability (see Table 28 below). While the mean caseness levels of Indigenous participants in the moderate and severe/profound intellectual disability groups were similar to the non-Indigenous sample, they were more than double the non-Indigenous levels for those with mild intellectual disability (34% compared to 16%).

Table 28

% of DBC-A cases by intellectual disability level

Final ID assignment	Indigenous Case %	Non-Indigenous Case %
Mild	34	16
Moderate	28	25
Severe/profound	26	23
Total	29.2%	21.1%

5.2.3 PSYCHOPATHOLOGY AND DEGREE OF REMOTENESS

The MIS for Indigenous participants increases according to the distance from a major city using the ASGC Remoteness Areas (see Table 29 below). The MIS of Indigenous participants living in a city was .32, and this progressively increased to .55 for those living in very remote areas.

There was a similar increase in PIC, with city dwellers scoring a PIC of .24 and those living in very remote areas scoring a PIC of .37.

The intensity of item scored also increased from .31 in the city, to .46 in very remote areas.

Table 29

DBC-A results for remoteness

REMOTENESS	MIS	PIC	II
City	.32	.24	.31
Inner Regional	.31	.22	.40
Outer Regional	.41	.28	.42
Remote	.44	.33	.27
Very Remote	.55	.37	.46

5.2.4 PSYCHOPATHOLOGY AND AGE

The MIS, PIC and II of Indigenous participants all decreased with age, with the MIS of 16-19 year olds being over double that of those aged 55 and over (see Table 30 below). The II, MIS and PIC for those aged 16-19 are all higher than for those who are older.

Table 30

DBC-A results for Indigenous participants age groups

Age Group	MIS	PIC	II
16-18	.54	.35	.48
19-24	.37	.27	.30
25-34	.36	.27	.32
35-44	.36	.28	.27
45-54	.36	.28	.25
55up	.24	.19	.29

5.2.5 PSYCHOPATHOLOGY AND AGE RANGE

In the study, 21.8% of the total combined Indigenous participants and non-Indigenous participants sample were identified as being a *case*. More Indigenous participants (29.2%) were cases compared to non-Indigenous participants (21.1%) (see Table 31 below).

Age is negatively associated with caseness for both Indigenous participants and non-Indigenous participants, with fewer cases occurring as the participants get older. For example, 50% of Indigenous participants and 43% of non-Indigenous participants aged 16-18 years were cases which decreased to 14% (Indigenous participants) and 15% (non-Indigenous participants) for those older than 54.

Table 31

DBC-A results for caseness by age groups

Age Group	ALL		Indigenous		Non-Indigenous	
	N	(%)	N	(%)	N	(%)
16-18	41	(44.0)	9	(50)	32	(43)
19-24	53	(34.1)	9	(30)	44	(35)
25-34	67	(27.2)	13	(30)	54	(27)
35-44	80	(19.7)	10	(25)	70	(19)
45-54	62	(16.2)	4	(27)	58	(16)
55up	48	(14.9)	2	(14)	46	(15)
Total case	351	(100)	47	(100)	304	(100)
% of total	21.8%		29.2%		21.1%	

5.2.6 FACTORS CONNECTED WITH PSYCHOPATHOLOGY

A Logistic regression was undertaken of DBC-A caseness compared against age, gender, moderate vs. mild intellectual disability, severe/profound vs. mild intellectual disability and Indigenous status (see Table 32 below). The regression showed that DBC-A caseness was not related to Indigenous status after age, gender and intellectual disability levels are controlled.

It also showed that:

- the probability of caseness declines with age

- caseness levels are greater for moderate than mild intellectual disability (Odds Ratio (OR) =1.7)

- caseness levels are greater for severe/profound vs. mild intellectual disability (OR=1.6)

- caseness is not related to gender.

Table 32

Logistic regression of factors connected with DBC-A caseness

Case	Odds Ratio	Std. Err.	z	P>z	95% Conf. Interval
Age	.97	.004	-6.85	0.00	0.96 - 0.98
Female	.93	.12	-.59	0.56	0.7 - 1.19
ID: Moderate	1.69	.26	3.37	0.00	1.2 – 2.3
ID: Severe	1.61	.25	3.08	0.00	1.2 – 2.2
Indigenous	1.16	.22	0.79	0.43	.8 – 1.7

5.2.7 NON-ENGLISH SPEAKING BACKGROUND (NESB)

For the purposes of this research project, the NESB category in question 5 included

participants who grew up in a household where a language other than English was

spoken and those who parents spoke another language (other than English) as their

primary language (this includes the various Australian Indigenous languages).

Indigenous participants who identified as being from a NESB showed higher levels of

psychopathology than those who were not from a NESB (see Table 33 below). The

MIS for participants from a NESB scored 22.5% higher than participants who were

not from a NESB (0.43 compared to 0.35). The PIC for Indigenous participants from

a NESB was 27.5% higher than Indigenous participants who were not from a NESB

(0.32 compared to 0.25).

Table 33

Indigenous psychopathology and NESB

Is the person from a NESB?	MISBDC-A	PICDBC-A
Yes	0.43	0.32
No	0.35	0.26

5.2.8 MIXING WITH OTHERS AND CASENESS

The person completing the Lifespan questionnaire was asked where the participant chooses to mix with other people. Analysis of any relationships between the *if* and *where* the Indigenous participant mixes with others and the participant's DBC-A caseness score found that there is generally no evidence of any relationship between the levels of social mixing and caseness (see Appendix O). However, one item, which asked whether the participant mixes with others on outings in their community (e.g. Going to movies), showed nearly half the rate of caseness for participants who did mix with others on outings, compared to those who did not (18.4% compared to 35.8%) (see Table 34 below).

Table 34

Mixing with others and caseness

Does he/she mix with other people on outings?	Case *N* (%)	No Case *N* (%)	Total *N* (%)
Yes	11 (18.6)	48 (81.4)	59 (100)
No	29 (35.8)	52 (64.2)	81 (100)
Total	40 (100)	100 (100)	140 (100)

5.2.9 PSYCHOPATHOLOGY AND LIFE EVENTS

Indigenous participants who were identified as being cases experienced over double the rate of LEs in the last 12 months (4.21) compared to 'non-cases' (2.05). Further, 83% of Indigenous participants (compared to 69% non-Indigenous participants) who were identified as being cases, had experienced at least one LE in the last 12 months (see Table 35 below)

Table 35

Proportion of cases with at least one LE and mean LEs

Caseness	Indig	Non-Indig	Indig Mean NLEs
No case	65%	51%	2.05
Case	83%	69%	4.21

A logistic regression demonstrated that LEs were positively and independently linked with both Indigenous status and DBC-A caseness levels. The odds of having any LE are 1.83 times higher for Indigenous participants than for non-Indigenous participants. The odds of having any LE are 2.4 times higher for DBC-A cases than for non-cases (see Table 36 below).

Table 36

Logistic regression of any LE on Indigenous status and DBC-A caseness

Any LE	Odds Ratio	Std. Err.	z	P>z	95% Conf. Interval
Indigenous	1.83	0.33	3.31	0.00	1.28 – 2.61
Case	2.41	1.13	1.87	0.06	0.96 – 6.06

The rate of caseness almost doubles for Indigenous participants who experienced a *Bereavement* LE in the last 12 months (41% compared to 22%) (see Table 37 below). This increase is much higher than that reported for the non-Indigenous participants (from 20% to 26%).

Table 37

Caseness and bereavement Life Event

Bereavement	Indigenous %	Non-Indigenous (%)
Yes	41	26
No	22	20

The rate of caseness is 2.7 times greater for Indigenous participants who experienced trouble with police, courts or time in prison (see Table 38 below). The results are similar for non-Indigenous participants (2.6 times). Further, Indigenous participants experienced nine times the rate of trouble with police, courts or time spent in prison compared to non-Indigenous participants (14.2% compared to 1.5%) (see Figure 5).

Table 38

Caseness and trouble with police/courts/time in prison Life Event

Police/prison	Indigenous %	Non-Indigenous (%)
Yes	65	52
No	24	20

A logistic regression shows Indigenous participants have six times the odds of those who answered *No* to *Trouble with Police/courts/prison* LE of being a case after age, gender and level of intellectual disability are accounted for (see Table 39 below).

Table 39

Logistic regression of DBC-A caseness and trouble with police/prison

Case	Odds Ratio	Std. Err.	z	P>z	95% Conf. Interval
Age	0.98	0.02	-1.11	0.27	0.95 – 1.01
Female	0.88	0.37	-0.3	0.76	0.39 – 2.0
ID: Moderate	0.84	0.43	-0.35	0.73	0.31- 2.3
ID: Severe	1.12	0.57	0.22	0.83	0.41 – 3.0
Police/Prison LE	6.1	3.28	3.36	0.00	2.13 – 17.5

5.2.10 FACTOR BASED SUBSCALE SCORES

Significant subscale score differences were found between the Indigenous and non-Indigenous participants on the following subscales.

5.2.10.1 ANTISOCIAL SUBSCALE

Indigenous participants have significantly higher mean MIS on the Antisocial subscale than do non-Indigenous participants (see Table 40 below). This is because on average they have a significantly greater range of the behaviours of the subscale registered for them (PIC) and because on average they are more likely to be scored at the intense level (2) (II).

5.2.10.2 DEPRESSIVE SUBSCALE

Indigenous participants have significantly higher mean MIS on the Depressive subscale than do non-Indigenous participants. This is because on average they have a significantly greater range of the behaviours of the subscale registered for them (PIC).

Table 40

Factor-based subscale scores

		Disrup	Psychdis	Selfabs	Antisoc	Depress	Socrel
MIS	Non-Indig	*0.42*	0.33	0.3	***0.27***	***0.3***	0.51
	Indig	*0.49*	0.37	0.33	***0.38***	***0.44***	0.57
PIC	Non-Indig	0.33	0.25	0.21	**0.21**	***0.24***	*0.37*
	Indig	0.37	0.27	0.23	**0.27**	***0.34***	*0.42*
II	Non-Indig	0.21	0.28	0.34	***0.22***	0.22	0.32
	Indig	0.23	0.29	0.38	***0.35***	0.24	0.3

p-values for differences: >.05 *<.05* **<.01** ***<.001***

Disrup= Disruptive, Psychdis= Psychological Disturbance, Selfabs= Self Absorbed, Antisoc= Antisocial, Depress= Depressive, Socrel= Social Relating

Regressions of MIS for the whole DBC-A and six factor-based subscales on age, gender, level of (assigned) intellectual disability and Indigenous status (see Table 41 below), show that the Depressive and Antisocial subscales are significantly and

positively associated with Indigenous status after age, gender and level of intellectual

disability are controlled (Depressive 0.117- p-value <.001; Antisocial 0.087 – p-value

<.01).

Table 41

MIS Regression for age, gender, intellectual disability level and

Indigenous status for DBCA total score and subscale scores

		DBC-A	Disrup	Psychdis	Selfabs	Antisoc	Depress	Socrel
age		*-0.004*	*-0.004*	*-0.005*	*-0.004*	*-0.003*	*-0.003*	*-0.005*
female		-0.007	0.029	0.016	**-0.041**	0.003	0.018	*-0.142*
ID -	moderate	*0.074*	*0.090*	*0.084*	*0.130*	0.015	-0.006	*0.120*
ID -	sev/prof	*0.072*	0.030	-0.048	*0.326*	*-0.117*	-0.024	*0.181*
Indig		0.031	0.035	-0.008	-0.012	**0.087**	*0.117*	0.011
cons		*0.440*	*0.532*	*0.535*	*0.344*	*0.433*	*0.415*	*0.670*

Typeface code for p-values; >.05, **<.01,** *<.001*   **ID = mild ID = reference**

Disrup= Disruptive, Psychdis= Psychological Disturbance, Selfabs= Self Absorbed,

Antisoc= Antisocial, Depress= Depressive, Socrel= Social Relating

The regression shows that age is significantly negatively associated with scores on all

subscales, that female gender is significantly and negatively related to the Self

Absorption and Social Relating subscales. Further results on the factors are included

in Appendix P. There were also significant associations found with moderate and

severe/profound levels of intellectual disability, compared with mild intellectual

disability.

5.3 QUALITATIVE INFORMATION

During the course of the research project, extensive travel was conducted throughout South Australia and the lower half of the Northern Territory in order to:

1. Introduce the aims of the research

2. Discuss with the Indigenous community workers and carers the most culturally appropriate and sensitive way to conduct the research

3. Collect the information from individuals living in these areas.

Throughout the Indigenous community there continues to be a marked suspicion of researchers who may not be conducting research in culturally respectful ways and excluding Indigenous people from involvement in their research (Holmes, Stewart, Garrow, Anderson, & Thorpe, 2002) . The travel and consultation described in this and previous sections was undertaken to attempt counteract this view.

These trips covered all geographic regions including major cities, inner and outer regional areas and remote and very remote areas. It also included visiting many families in Indigenous controlled communities throughout SA and the NT, particularly on Yorke and Eyre Peninsulas, in the mid north of SA, the Riverland, throughout the APY Lands bordering the SA/NT and WA border, and communities in the central desert region of NT.

In addition to collecting information in the study questionnaire booklet from family members and other carers of people with intellectual disability, additional questions related to three key areas that may have a relationship with the emotional and behavioural wellbeing of Indigenous people with intellectual disability were asked. These key areas of enquiry were:

- The Indigenous person's understanding of the terms *intellectual disability* and *mental health*

- Their access to and satisfaction with disability support services

- How the individual with a disability was accepted by, engaged with and contributed to living in the individual's community and if there were any key issues of concern regarding people with intellectual disability.

5.3.1 LIVED EXPERIENCES

The researcher became familiar with the lived experiences of people with intellectual disability within their community and a wide range of factors that impact negatively on the lives of Indigenous people with intellectual disability.

The key issues of concern related to:

- Suicide

- Substance abuse

- Removal and isolation of the individual with intellectual disability from their community and culture and accommodation restrictions

- Access and attitudes to Disability Support Services.

The qualitative information obtained on these key issues will be incorporated into the discussion of the findings of this study (Chapter 6).

5.3.2 PERCEPTIONS OF INTELLECTUAL DISABILITY AND PSYCHOPATHOLOGY

Research indicates that very little is known about the perception of intellectual disability within the Indigenous population (O'Neill, et al., 2004) and there were thought to be no known words for intellectual disability in Indigenous languages (Ariotti, 1997).

Interviews were conducted with family members and Indigenous carers of individuals with intellectual disability to explore their perceptions of intellectual disability and mental illness and ascertain if they used Indigenous terms to refer to these concepts. Below are accounts of these interviews and a summary of the main terms used by Indigenous people to describe people with intellectual disability.

The names of subjects have been changed and locations have been generalised to protect the privacy of participants and carers in the Lifespan research project.

1. Robert is afraid of being teased (mainly by younger children) and being called "crazy". His mother reported that "Robert stays in inside all the time" watching satellite television. When asked about Robert's disability, his mother said that he was "wrong in the head" and maybe this was from petrol sniffing when he was younger, but she was not sure. She did not know of any Pitjantjatjara words for this (intellectual disability) but thought that his disability was different to mental illness (i.e. she said that he doesn't have a mental illness).

2. Alice is shy and afraid of the continual teasing she gets from the kids her age and the older kids. Alice's auntie, who is also her primary carer, said that others call her "rama rama or crazy one", but she is protected from these taunts mainly by staying close to her family when in the community.

3. Katie says that she gets depressed often and thinks about her time growing up and getting teased. She said she doesn't like talking about the past as "bad things happened". She said that she was called "rama rama" and a word that means she has "no good ears" (she is partially deaf in one ear). She also said that some of the other residents tease her and tell her off about not looking after Jessica.

Of particular interest in one interview was the carer's excellent knowledge of Pitjantjatjara, the local Indigenous language in use throughout the area. He spoke of people with intellectual disability being called "kata rama" –meaning "wrong head" or "head wrong" or "head silly, stupid, mad" (version of rama rama). Kata meaning "head" (as in "Kata Tjuka" or the Olga's (a large rock formation in the Northern Territory), meaning many heads, i.e. they look like, or are considered by locals as being the "many heads" of spiritual elders).

When talking about the brain, David looked up the Pitjantjatjara word for brain – "Ngukunpa". He hasn't heard of this word being regularly used in communities.

He gets teased all the time by other kids, but the older men treat him with respect.

When asked about what he is called, Samantha said that people in the community use the word "ruta ruta" which is an Eastern Arrernte word "same as rama rama" (which she said is from the Luritja language group). She said it means "deaf, something wrong in the head" it is "different to blindness and seizures". When asked about the meaning of intellectual disability and mental illness, she said "rama rama" and confirmed that there is no perceived difference between intellectual disability and mental illness in their language/culture although she added that sometimes a person with intellectual disability is called "Inkakurna" which means they have bad legs or can't walk.

When talking about the past, Samantha said that in the old times, people with a physical or significant intellectual disability would have been left behind, as the community was always moving through their land and valued being "strong". "If someone is too old or weak, they are left under a tree or in a cave with food... this was the same with all the desert mobs (central Australia)". "If you find them bones, you

got to leave them there... some people have found them and taken them away... it's no good".

When asked how this may influence perceptions today, she said "anything to do with intellectual disability was always blamed on sorcery" and "It still goes on now". This was translated to mean that many Indigenous people still hold these views of spiritual influence in disability/mental illness today.

In another interview, the carer, who is Indigenous, stated that "warrangi" would be the Ngarrindjeri term used when referring to a person with intellectual disability, in this case, her brother. She said that, because of her brothers older age, he would also be called a "warrangi jilabi cornie" (crazy old man), and that "warrangi" seems to have the meaning of crazy, mad and it is the same term as "buntha", which is another Indigenous term commonly used in South Australia (see Table 42 below).

Below is a summary of the terms reported to be commonly used within the Indigenous communities throughout South Australia and the Northern Territory to describe the individual with intellectual disability.

Table 42

Common terms used to describe Indigenous people with intellectual disability in SA & NT

Language Group	Term	Meaning
Pitjantjatjara	rama rama	crazy, wrong in the head, no good ears
	kata rama	wrong/silly in the head, mad one
Ngarrindjeri	warrangi	crazy, mad, silly, going off your head
Narangga	buntha	crazy, mad, silly
Kuarna	yammiamma	mad, teacher
Eastern Arrernte	ruta ruta	deaf, something wrong in head (different to blindness and seizures)
	Inkakurna	have bad legs, can't walk

5.3.3 SUMMARY OF PERCEPTIONS OF INTELLECTUAL DISABILITY AND PSYCHOPATHOLOGY

In summary, it was common for Indigenous people to report their own (and their community's) belief in spiritual influences and sorcery as a cause of intellectual disability and mental illness, and "It still goes on everywhere now". Some people interviewed thought that intellectual disability was different to mental illness, while others thought there was no difference.

It was commonly reported (and observed in several cases) that people with intellectual disability were being teased by others and that the individuals were depressed as a result of this teasing.

Whilst the terms commonly used appear to be derogatory and incorrectly assign "craziness" to people with intellectual disability, it was also reported that older Indigenous people preferred not to use terms such as these, instead focussing on family membership and role of the individual and accepting their "limitations".

5.4 SUMMARY

In summary, this chapter has provided results of the Lifespan study which include the demographic and health characteristics of Indigenous adults with intellectual disability living in South Australian and Northern Territory. Results on the prevalence and nature of psychopathology of this group have also been provided, together with information gathered on the lived experiences of Indigenous carers and individuals with intellectual disability and their understanding of intellectual disability.

These results show a higher level of psychopathology within this group compared to the non-Indigenous cohort, with rates of DBC-A caseness increasing according to the distance participants live from a major city. The study showed that the Indigenous cohort were nine years younger than the non-Indigenous participants and found higher levels of psychopathology among younger Indigenous participants, with levels decreasing as participants got older.

Particular findings show higher levels of depressive and antisocial behaviour, suicidal tendencies and substance abuse among the Indigenous participants, with these results being confirmed from information on surrounding concerns gathered in the various communities.

There were also much higher levels of LEs occurring in the Indigenous cohort with resulting increases in psychopathology in those individuals who experienced a higher number of LEs.

The interviews with Indigenous carers confirmed many of the quantitative findings in this study and in the literature, including key issues relating to suicide, substance abuse, support needs, cultural safety and concerns that Indigenous adults with intellectual disability are being isolated from their family and country, while being supported in government funded services a long distance from their family.

CHAPTER 6 DISCUSSION

6.1 RESEARCH AIMS

The primary aims of this project were to:

1. Describe the population of Indigenous adults with intellectual disability in South Australia and how they differ from the non-Indigenous population with intellectual disability

2. Determine the prevalence and nature of psychopathology in Indigenous adults with intellectual disability in South Australia and the lower half of the Northern Territory, in urban, regional and remote communities in comparison to a large community cohort of non-Indigenous Australian adults with intellectual disability.

A further aim was to explore the social, cultural and environmental context of intellectual disability and mental illness in the Indigenous community.

A subsidiary aim was to describe the usefulness and limitations of a carer completed checklist (the DBC-A) in the assessment of psychopathology in Indigenous adults with intellectual disability.

In addition, qualitative information was collected to further explore various aspects of intellectual disability and psychopathology in the Australian Indigenous population. These key areas of enquiry were:

- The Indigenous person's understanding of the terms *intellectual disability* and *mental health*

- Their access to and satisfaction with disability support services

- How the individual with a disability was accepted by, engaged with and contributed to living in their community and if there were any key issues of concern regarding people with intellectual disability.

6.2 INDIGENOUS ADULTS WITH INTELLECTUAL DISABILITY IN SOUTH AUSTRALIA

In Chapter 5.1 the profile of the Indigenous sample of adults with intellectual disability and the differences between the Indigenous sample and the representative Lifespan sample are described. These differences in age, sex ratio, prevalence of intellectual disability, socio-economic profile and language use have implications for further research and services provision.

6.2.1 AGE AND SEX

Sixty percent of the Indigenous participants were males. The Indigenous sample is much younger than the non-Indigenous sample, for example, there are double the number of Indigenous participants under 35 years (57%), compared with non-Indigenous participants (27.9%). The mean age of Indigenous participants is 33.7 years (range 16-83 years) and this is over nine years younger than the non-Indigenous sample population of 42.9 years (range 16-85 years). The non-Indigenous mean age of 43 years compares closely with the mean age of 43.9 years from a recent large study of over 1000 adults with intellectual disability in the UK (Cooper, et al., 2006). The nine year difference in mean age of Indigenous and non-Indigenous participants is consistent with national figures (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008) which shows over a 10 year difference of median ages between Indigenous and non-Indigenous people with a disability. The Commonwealth State/Territory Disability Agreement National Minimum Data Set (CSTDA MDS) shows that Indigenous users of CSTDA services were younger on average than non-Indigenous users (median age 25 years, compared with 32 years) (Australian Institute of Health and Welfare, 2007). However, the median age of these two sample groups of Indigenous people with a disability is still older than the broader Indigenous

population in Australia, where 50% of this population is aged 21 years or less (Australian Bureau of Statistics, 2006a). Fertility rates for Australian Indigenous females are higher than non-Indigenous females and they are more likely to give birth at a younger age (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). The younger mean age of the Indigenous population relates to higher birth rates and is also reflected in the finding of higher levels of psychopathology presenting in younger people.

The Indigenous population is growing at a much faster rate than the non-Indigenous population and is projected to increase from 517 000 to 721 000 by 2021 (Australian Bureau of Statistics, 2009). Urgent action is needed to prepare for the expected increase in this population in terms of planning for improved service delivery and policy development to ensure improvements in access to culturally appropriate disability and mental health services.

The difference in rates of intellectual disability between the sexes is probably partly a reflection of the higher overall prevalence of intellectual disability among males aged 15–44 years (Australian Institute of Health & Welfare, 2007), and this difference is mirrored in other Australian studies (Australian Institute of Health and Welfare, 2003). These age and sex differences were confirmed in this study which also found a higher rate of intellectual disability in younger males compared to females (60%, compared to 40%).

It is well recognised that more males have intellectual disability (approximately 1.4:1) which is probably due to x-linked genetic disorders that predominantly affect males such as Fragile X Syndrome and Autism (Gecz, 2004; Partington, Mowat, Einfeld, Tonge, & Turner, 2000). The Australian Institute of Health and Welfare has estimated that in the Indigenous population 8.2% of males have an intellectual disability

compared to 5.8% of females which is also a ratio of 1.4:1 (Australian Institute of Health & Welfare, 2007).

6.2.2 PREVALENCE AND CAUSES OF INTELLECTUAL DISABILITY

The prevalence of intellectual disability in Indigenous adults is considered to be approximately 2.5 times greater than the wider Australian population (Australian Institute of Health & Welfare, 2007). The prevalence of intellectual disability in Australia is considered to be between 1%-1.5% of the population. The Indigenous population in South Australia in 2006 was estimated to be 26044, with 16635 of these people aged 15 years or older (Australian Bureau of Statistics, 2009). Therefore, by dividing the number of Indigenous people aged 15 years or older living in South Australia by the percent of the population with intellectual disability and multiplying this by 2.5 will provide an estimate of the number of Indigenous people with intellectual disability aged 15 years or older and living in South Australia.

16635 x 1% x 2.5 = 416

16635 x 1.5% x2.5 = 624

There were a total of 198 Indigenous adults with intellectual disability registered in South Australia, which is less than 50% of the estimated total using the 1% of population calculation, and less than a third of the estimated total using the 1.5% calculation. This unmet need is much greater if only using the number of people who were able to be contacted (i.e. those who were active clients and whose whereabouts could be verified) and not including those who were no longer active clients. Using this method, there were 133 people. This represents 21-32% of the South Australian Indigenous adult population with intellectual disability.

There are obviously many more Indigenous adults with intellectual disability who are unknown and not registered with any service providers in South Australia. This shows that Disability Services are registering fewer Indigenous people with intellectual disability than expected and many Indigenous adults with intellectual disability are missing out on much needed services.

There are significant social, economic and health inequalities within the Indigenous community, with factors such as impoverished living environments possibly contributing to the higher levels of intellectual disability associated with an increased risk of perinatal general infections, such as meningitis, poor perinatal care and prenatal maternal alcohol and substance abuse (Glasson, et al., 2005). A study by Glasson (2005), found non genetic prenatal and perinatal risks factors that are known to be associated with intellectual disability in 36% of cases. These factors included physical trauma, substance misuse, infections and low birth weight. Excessive alcohol consumption during pregnancy is also a known risk factor associated with Fetal Alcohol Syndrome (FAS) and intellectual disability (Minns, 1997). The 2001-02 Western Australian Aboriginal Child Health Survey (WAACHS) survey, estimates 23% of the mothers of Indigenous children born in Western Australia reported that they had consumed alcohol during pregnancy (Zubrick, et al., 2004). Smoking during pregnancy is also linked to higher rates of intellectual disability (Drew, Murphy, & Yeargin-Allsopp, 1996). Low birth weight or prematurity is also a causal risk factor for intellectual disability (Middle, Johnson, Alderdice, Petty, & Macfarlane, 1996; Waugh, et al., 1996). The WAACHS survey reported more than double the proportion of low birth-weight babies born to Indigenous mothers, compared to non-Indigenous mothers (Leeds, et al., 2007). These factors above are likely to contribute to the

finding of a 2-2.5 times increase in the prevalence of intellectual disability in the Indigenous population, compared with the general population.

There are fewer genetic causes of intellectual disability in the Indigenous population, compared to the non-Indigenous population, although the numbers are relatively small which may indicate a lack of investigation (genetic screening) in the Indigenous population which may reflect inadequate levels of paediatric medical care.

The highest reported cause of intellectual disability for the Indigenous group was Acquired Brain Injury (20%) and for the non-Indigenous sample was Down syndrome (32.1%). The reported causes of intellectual disability for Indigenous participants in the *Other* category were: Fetal Alcohol and Substance Abuse Syndrome (10/32), perinatal infection/ trauma/ prematurity (14/32) and genetic metabolic disorders 8/32. It is possible that these results underreport the prevalence of FAS, partly due to the lack of paediatric expertise to diagnose the condition (Australian Human Rights Commission, 2008), and the likelihood that those reported as having an Acquired Brain Injury (ABI) may also have FAS. There is limited data on the prevalence of FAS in the Australian Indigenous population, however it has received more attention in North America where rates are much higher within the Indigenous population (Donovan, 1992), with some estimates of FAS in Indigenous children being as high as nearly 20% of all births (Williams, 1999). FAS is regarded as the leading known cause of intellectual disability within this population (Loock, 1998). Since the first medical descriptions of FAS, studies have varied as to occurrence rates. Prevalence rates of FAS in North America have been described as a crisis situation (Donovan, 1992) and are estimated to be as high as 190 per thousand live births (Robinson, Conry, & Conry, 1987).

Research in Australia has found estimated rates of FAS to be around three Indigenous children per thousand live births (Glasson, et al., 2005).

There was no reported cause of intellectual disability for over 50% of the Indigenous sample and 45% of the non-Indigenous participants in the Lifespan Study. This is not unexpected as in other Australian studies the cause for intellectual disability in the non-Indigenous population is reported to be unknown for between 30-60% of cases (Minns, 1997; Partington, et al., 2000).

This study is only able to report on the prevalence of intellectual disability when it is defined administratively (those who receive services from disability service providers). However, the high rate of over 50% with an unknown cause of intellectual disability in the Indigenous group, together with only 41.5% of the Indigenous participants having had a formal IQ assessment to determine their intellectual disability, may mean that the administrative prevalence of intellectual disability in this population is not an accurate reflection of the community prevalence. As outlined previously, given the lower rates of treated mental illness within NESB populations, it is likely that the prevalence of intellectual disability within the Indigenous population is actually higher than the rates determined by registration with disability services (O'Neill, et al., 2004). There may be a range of reasons why Indigenous people are unable to, or are reluctant to access disability services, even when they are available. Cultural and social issues such as different understandings and values have been identified as the most significant barriers to service delivery (Tipper & Dovey, 1991). Language barriers and different understandings of concepts of disability and mental health can negatively affect access to and delivery of services (Henderson, 1993). Other barriers can include inaccurate cognitive evaluations for a range of reasons including a lack of validity in the assessment of intellectual disability. There are many

potential pitfalls and problems surrounding the accurate and culturally appropriate assessment and diagnosis of intellectual disability within the Indigenous population. For example, there is a lack of culturally appropriate intelligence tests and a cultural bias in standard intelligence and cognitive tests (Cairney, Clough, Jaragba, & Maruff, 2007). The difficulty of accurate assessment and diagnosis is further compounded when English is not the first language spoken, especially in remote communities (Ministerial Advisory Committee: Students with Disabilities, 2003).

A recent research study of youth offenders found that despite the majority of young Indigenous adults having difficulty with comprehension, communication, numeracy and literacy skills, for most of the study participants practical reasoning was close to mainstream norms (NSW Department of Juvenile Justice, 2003). The report considered that low numeracy and literacy achievements were a product of poor engagement with education, transience and other compounding factors, such as chronic middle ear infection (Otitis Media), and not necessarily intellectual disability (Australian Human Rights Commission, 2008).

In this study, roughly a quarter of all participants were unable to vocalise and this is consistent with the level of severe/profound intellectual disability of all participants, which was 35%.

If the number of Indigenous adults with intellectual disability registered with a South Australian disability service is accurate, this study has found that there is a much lower level of disability service registration and therefore a higher level of unmet need within this population.

6.2.3 LANGUAGE AND GEOGRAPHICAL SPREAD

This study found that 40% of the Indigenous participants were from a Non-English Speaking Background (NESB) compared with only 6% of non-Indigenous

participants. The definition of Non-English Speaking Background for this project was broader than just including people (or their parents) who were born overseas in a non-English speaking country. It also included individuals who grew up in a family who spoke a non-English language at home. This includes people who predominantly spoke any of the numerous Indigenous languages.

The proportion of Indigenous people with intellectual disability from NESB increased significantly in the remote (89% from NESB background) and very remote areas (54%) compared to the city (12%) and regional areas (5% average). These higher rates of NESB in remote and very remote areas appear similar to Australian Bureau of Statistics (2006a) information on the Australian Indigenous population which indicates that while 12% of Indigenous people reported that they speak an Indigenous language at home, the rates increased from 1% in major cities to 56% in very remote regions. Further, nearly three quarters (74%) of Indigenous people who speak an Indigenous language at home live in very remote areas, and over half of all Indigenous people in Australia who speak an Indigenous language at home live in the Northern Territory (Australian Bureau of Statistics, 2006a). The higher proportion of Indigenous participants who identified as being from a NESB in this research project can probably be partly explained by the broader definition of NESB that was used for the purposes of this research project. The higher proportion might also reflect a relative over representation of Indigenous people with intellectual disability in more remote communities, or perhaps that Indigenous people with intellectual disability who are from a NESB have less opportunity to attend school or otherwise learn and use English.

The Australian Bureau of Statistics (2006a) reports that almost a third of Indigenous people live in major cities but 43% live in regional areas and 26% in remote and very

remote areas. This varies greatly from the non-Indingenous population, with nearly 70% living in major cities and less than 2% living in remote and very remote areas in Australia . This different population distribution was even more apparent in this study with 40% living in the city but 42% in remote/very remote areas. This needs to be taken into account in the allocation of service funding and resources and approaches to service delivery.

6.2.4 HEALTH

The level of chronic medical and health problems was high in Indigenous participants, however, it was similar to the non-Indigenous participant rates (65%, compared to 61.5%). Of the types of conditions, epilepsy was the most common in both groups, followed by diabetes. Considering the wealth of research about the higher levels of chronic health issues in the Indigenous population, it is surprising that this research showed little difference between Indigenous and non-Indigenous rates. This is possibly further evidence that it is the presence of intellectual disability that is the main determining factor for the higher rates of chronic health problems in people with intellectual disability. The high prevalence rate confirms research that has found that people with intellectual disability have higher levels of, and more complex, health needs than the general population (Cooper, Melville, & Morrison, 2004). Furthermore, research has shown that individuals with intellectual disability have a different pattern of health conditions, such as epilepsy, respiratory disease and congenital heart disease, and a higher level of unmet health needs (Cooper, et al., 2004).

Chronic health problems such as diabetes and heart disease, have an earlier onset (on average 10 years earlier) for Indigenous compared to non-Indigenous people in

Australia (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008).

Indigenous people suffer from a burden of disease two to two and a half times greater than non-Indigenous Australians (Australian Bureau of Statistics, 2006b). The leading causes of this burden are cardiovascular disease (18%) and mental disorders (16%) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). The leading causes of the burden of disease differ between Indigenous males and females, with anxiety and depression being the third leading cause for males and the first for females (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). In this study, over 60% of both Indigenous and non-Indigenous participants were reported to suffering from a current chronic medical or health problem. This rate is equal to recent results of the NATSIHS survey (Australian Bureau of Statistics, 2006b), which found 65% of Indigenous people reported at least one long term health condition in 2004-2005 and have an earlier onset on chronic health conditions and shorter life expectancy than non-Indigenous people. Therefore in the wider Australian community having an intellectual disability carries a similar high risk for chronic poor health as exists for Indigenous populations. Both situations are unacceptable in this affluent country and point to the need for improved health services for both Indigenous Australians and Australians with intellectual disability.

6.2.5 ACCOMMODATION

More than one in ten of the Indigenous participants in this study were living in some type of foster care arrangement, which was a significantly higher proportion than for non-Indigenous participants (0.2%). Roughly 40% of both Indigenous and non-Indigenous participants were living in supported accommodation in small units (6 persons or less) and there was a significantly lower proportion of Indigenous

participants living in large institutional accommodation (8.6%, compared to 31.6% non-Indigenous). The higher proportion of Indigenous participants in foster care arrangements may reflect the greater degree of community ownership of the responsibilities of care for Indigenous people with intellectual disability, as many participants were in the care of other Indigenous family or community carers. It may also reflect the dearth of other accommodation service options available.

There is evidence of higher rates of emotional or behavioural problems in young Indigenous people living in foster care arrangements. For example, the Western Australian Aboriginal Child Health Survey (WAACHS) found that young people living in foster care were more than two times more likely to be at high risk of clinically significant emotional or behavioural difficulties than those living elsewhere (Zubrick, et al., 2004). However, these findings may or may not relate to Indigenous adults with intellectual disability who are in foster care. It is even possible that the foster care of Indigenous adults with intellectual disability is a helpful care alternative reflecting Indigenous culture and not generally available as an option in non-Indigenous Australia.

There was greater mobility amongst Indigenous participants in this study, with 28.5% (double the rate for non-Indigenous of 13.1%) having experienced a move of residence within the last 12 months. There was also double the number of Indigenous people with intellectual disability who had moved from living with family or friends (41.3%, compared with 21%). These results are consistent with figures from a national social survey of Indigenous Australians (Australian Bureau of Statistics, 2002b), which found a higher rate of mobility in Indigenous people, compared to non-Indigenous people, with nearly one in three Indigenous individuals aged 15 years and over having moved dwellings within the last 12 months. This level of mobility has implications

for service delivery and is likely to create problems for care management and the types of services which are centre-based.

6.2.6 DAYTIME OCCUPATION AND ACTIVITY

Just over 40% of Indigenous participants identified that they had no organised activities during the daytime (compared to 14.8% non-Indigenous participants). Indigenous participation in supported employment was significantly lower than non-Indigenous (12.4% compared to 32.1%). This reduced participation in mainstream service system models, which have historically excluded people with intellectual disability from mainstream vocational and recreational options such as open employment and community based supported living, is also shown in the findings of relatively few Indigenous people residing in large institutions.

Participation rates in open employment were also very low for both Indigenous and non-Indigenous participants (at 2.4% respectively). This participation rate is consistent with recent research that shows not only a lower proportion of Indigenous adults accessing employment services (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008), but also lower labour force participation levels by people with a disability (Australian Institute of Health and Welfare, 2003). However, it is likely that the low rate of participation in open employment reported by the Australian Institute of Health and Welfare (2003) over-represents the number of unemployed participants because it also includes those people who were older than the usual working age, and therefore would not typically be included in labour workforce statistics.

These findings point to a need to improve participation rates in daytime activity for Indigenous people with intellectual disability who have clearly much less opportunity even than non-Indigenous people with intellectual disability.

6.2.7 PARENTAL AGE

The mean age of living Indigenous mothers, where their age was known was 51.8 years, nearly 10 years younger than the mothers of the non-Indigenous sample (mean age 61.4 years). The mean age of the fathers of Indigenous participants was 52.7 years, nearly nine years younger than the fathers of non-Indigenous participants (61.5 years). This compares closely to ABS & AIHW findings of Indigenous carers being 12 years younger than non-Indigenous carers (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). The age of Indigenous parents was unknown in 40.6% of cases (24% for non-Indigenous parents). The age of mothers when they conceive and give birth can affect the healthy development of the fetus, with one period of increased risk of fetal complications occurring for pregnancies in the teenage years (Laws, Grayson, & Sullivan, 2006). Recent research showed the median age of Indigenous mothers was 25 years, 5 years lower than non-Indigenous mothers (Leeds, et al., 2007), and 23% of Indigenous females who gave birth were aged 20 years or less (compared to 4% for non-Indigenous mothers). The Northern Territory had the highest rate of Indigenous females who gave birth while aged less than 20 years (29%), and in South Australia it was 22% (Leeds, et al., 2007).

In this study, the mean age of Indigenous mothers when they gave birth was 24 years old (mean year 1973). This is over 4 years younger than the mean age of non-Indigenous mothers when they gave birth (28.2 years, mean year 1964). These findings have implications for the need to provide culturally sensitive antenatal and postnatal care for young Indigenous mothers, partly to perhaps prevent some causes of intellectual disability and also to detect developmental problems early and initiate early intervention.

The birth rate for Indigenous Australians is increasing more rapidly and exceeds that of non-Indigenous Australians which highlights the need for increasing access to and availability of culturally appropriate intellectual disability services which also have expertise in providing culturally appropriate mental health support in order to effectively plan and respond to the likely increased demand from an increasing population of Indigenous people with intellectual disability in the future.

6.3 PSYCHOPATHOLOGY IN INDIGENOUS ADULTS IN SOUTH AUSTRALIA

6.3.1 NATURE AND PREVALENCE OF PSYCHOPATHOLOGY

This study has discovered a number of findings in relation to the nature and prevalence of psychopathology in Indigenous adults with intellectual disability in comparison with non-Indigenous adults with intellectual disability. All reports of prevalence are describing a 6 month period prevalence.

The study identified 29% of Indigenous participants as cases on the DBC-A, compared to 21% of non-Indigenous participants and 22% for both groups combined. These results suggest that clinically significant mental health problems are about 40% (relative risk 1.4) more likely in the Indigenous population compared to the non-Indigenous population of adults in South Australia with intellectual disability. This increased burden of mental health problems was mainly accounted for by cases in the younger adult population (50%). The present study's finding of prevalence levels of psychopathology in the non-Indigenous sample is similar to recent research in UK populations (Deb, Thomas, et al., 2001a; Taylor, Hatton, Dixon, & Douglas, 2004) which report an overall prevalence of mental health problems of 20.1% -22.2% amongst adults with intellectual disability. These rates contrast with another UK study of psychopathology in adults with intellectual disability which found the level of psychopathology to be approximately 40% (Cooper & Bailey, 2001; Cooper, et al., 2007). The variation in rates might be accounted for by methodological differences, different definitions of caseness and sample selection with some reflecting a clinical population.

The 6 month period prevalence of significant levels of psychopathology (defined as a score over the cut-off for psychiatric caseness on the DBC-A) decreased over the lifespan for both Indigenous and non-Indigenous participants, with 50% of younger Indigenous participants (43% of non-Indigenous) aged 16-18 years identified as cases, decreasing to rates of 14% for Indigenous and 15% for non-Indigenous people aged 55 years and older. This result is consistent with the findings of a longitudinal study of a representative sample of Australian young people with intellectual disability which reports a decline in psychopathology levels as the cohort moved from childhood to young adult life (Einfeld, et al., 2006). The same results of decline in levels of psychopathology with age are seen in the MIS, PIC and II scores. For example, the MIS of 16-19 year olds is more than twice that of those aged 55 and over (0.54 compared to 0.24 respectively). The reasons for this decline in mental health problems with age are not known. It has been suggested that an interaction of brain maturation, acquisition of daily living skills, treatment of emotional and behavioural problems in adult life and education might be an explanation (Einfeld, et al., 2006). It is also possible that some individuals with intellectual disability and serious behavioural and emotional problems do not survive to the age of 55.

When considering the caseness level of participants with different levels of intellectual disability, 34% of Indigenous participants with mild intellectual disability were identified as cases, reducing to 28% for those with moderate intellectual disability, and 26% for those with severe or profound intellectual disability. While the mean caseness levels of Indigenous participants in the moderate and severe/profound intellectual disability groups were similar to the non-Indigenous sample, they were more than double the levels for non-Indigenous people with mild intellectual disability (34% compared to 16%).

Although the caseness rates of non-Indigenous participants increased as the level of intellectual disability increased, the caseness rates of Indigenous participants did not. This contrasts with recent research which also found an increase in caseness between mild intellectual disability and profound intellectual disability (Cooper, et al., 2007), but is similar to other research (Borthwick-Duffy & Eyman, 1990) which found a lower prevalence of caseness at lower ability levels or the results of another study which found no relationship between ability level and caseness (Deb, Thomas, et al., 2001a). The reason for this increased rate in Indigenous people with mild intellectual disability is not known but individuals with mild intellectual disability generally merge into the wider community more readily therefore Indigenous people with mild intellectual disability may be prone to the same socio-cultural problems such as poverty, poor health, substance abuse and discrimination which create behavioural and mental health problems in the broader Indigenous communities (Australian Institute of Health and Welfare, 2009) whereas those with more severe levels of intellectual disability might be more likely to be identified and receive support and services. Another possible explanation for the finding of a higher rate of caseness in the Indigenous group compared to the non-Indigenous group with mild intellectual disability is that the assignment of mild intellectual disability for Indigenous participants is not accurate. Approximately 40% of the Indigenous participants did not have a formal IQ assessment, with a higher proportion in remote areas, compared to inner city and regional areas. It is possible that Indigenous individuals were initially referred to disability services due to their high behavioural support needs and were made administratively eligible for intellectual disability support even if they did not have an intellectual disability. However, there might also be some socio-cultural factors operating. Indigenous adults with mild intellectual disability may be more

likely than non-Indigenous adults with mild intellectual disability to have less access to education and services, perhaps a greater use of alcohol and other substances and have more involvement with the police and corrective services which would all add to increased risk of mental health problems.

How does the level of mental health problems amongst Indigenous adults with intellectual disability compare with the general Indigenous and non-Indigenous Australian population?

There is little specific and accurate data on the psychopathology of Indigenous people in Australia but in order to examine the different levels of psychological distress between Indigenous and non-Indigenous populations, results of the National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) (Australian Bureau of Statistics, 2006b) were compared with the National Health Survey (NHS) (Australian Bureau of Statistics, 2006c). This reveals that Indigenous adults were twice as likely as non-Indigenous adults to report high or very high levels of psychological distress (27% compared with 13%) (Australian Institute of Health and Welfare, 2009). This might suggest that the level of mental illness in Indigenous Australians with intellectual disability (29% cases) is similar to those without intellectual disability (27% high levels of psychological stress) and that intellectual disability might not confer an added burden in a population where mental health problems are already higher than the non-Indigenous population. For example, recent research on psychiatric emergency re-admission rates for Indigenous people with mental illness in the Top End of the Northern Territory indicate that nearly a quarter of those admitted to a mental health facility were readmitted within 28 days of discharge (Nagel & Thompson, 2006).

Further, in 2001-2005, Indigenous males were 5.8 times more likely, and Indigenous females 3.1 times more likely, to die as a result of the burden of mental and behavioural disorders than were their non-Indigenous counterparts (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008).

A regression analysis found that the probability of caseness declines with age, is not related to gender, is greater for people with moderate than mild intellectual disability (OR=1.7), greater for severe/profound vs. mild intellectual disability (OR=1.6) and is unrelated to Indigenous status after age gender and intellectual disability level are controlled for. Participants with moderate intellectual disability had higher MIS, PIC and II scores than those with mild (5% higher) or severe/profound intellectual disability (14% higher). Those with mild intellectual disability scored higher MIS and PIC than those with severe/profound intellectual disability, although the II scores between these two levels of intellectual disability were similar. This might suggest that underlying rates of mental health problems are similar in Indigenous and non-Indigenous populations with intellectual disability and decline with age, but being a younger Indigenous male with mild intellectual disability is associated with increased rates of psychopathology. It can be concluded that a priority in the delivery of mental health and disability services and support should be young adult males with intellectual disability.

6.3.2 REMOTENESS AND PSYCHOPATHOLOGY

The Mean Item Scores (MIS) for Indigenous participants increased according to the distance from a major city using the ASGC Remoteness Areas categories. The MIS of participants living in a city is .32, and this increased to .55 for those living in very remote areas. There is a similar increase in PIC, with city dwellers scoring a PIC of

.24 and those living in very remote areas scoring a PIC of .37. The intensity of item scored (IIS) also increases from .31 in the city, to .46 in very remote areas.

A comparison of the level of psychopathology in different regions may be made with results of the 2004-05 National Aboriginal and Torres Strait Islander Health Survey (Australian Bureau of Statistics, 2006b) and the 2004-05 National Health Survey (Australian Bureau of Statistics, 2006c), which reported on the levels of psychological distress experienced by Indigenous and non-Indigenous adults according to the remoteness of the region they lived in. This shows significant differences by Indigenous status across the three geographical categories (major cities, inner regional and outer regional). In all areas there was at least double the rates of high/very high psychological distress, with the largest difference being observed in the Outer Regional area, with 2.2 Indigenous adults reporting this level of distress for every one non-Indigenous adult who reported the same level of distress (Australian Institute of Health and Welfare, 2009). Higher levels of mental health problems in remote areas are probably linked to higher socioeconomic disadvantage, lack of services, increased risk of intellectual disability and poor educational opportunities. For example, the levels of educational attainment amongst Indigenous adults are lower in geographically remote areas. In 2006, almost one third (31%) of Indigenous people living in a city had completed Year 12 (the final year of high school) compared with 22% of Indigenous people living in regional areas, and only 14% in remote areas (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). It is also possible that non-Indigenous people with serious mental illness may choose not to live in remote areas or re-locate to urban areas which have more resources in terms of mental healthcare services. It can be concluded that remoteness is a factor in

increasing the risk of mental health problems which needs to be considered in the allocation of funding and service priorities.

6.3.3 NESB AND PSYCHOPATHOLOGY

The study found that Indigenous people with intellectual disability who identified as being from a NESB had higher rates of psychopathology than those who were not from a NESB. These results are comparable to recent research in Victoria which examined access rates of mental health services within the wider NESB community (Stolk, Minas, & Klimidis, 2008). The researchers analysed data from the 2001 Census (Australian Bureau of Statistics, 2001) and of Victorian community mental health and acute inpatient case registers for 2004/05. The Mental Health Branch (MHB) of the Victorian Department of Human Services provided mental health data from the Victorian Redevelopment of Acute and Psychiatric Information Directions (RAPID) database.

This study found lower prevalence rates of treated mental illness within the NESB population, compared to rates in the wider Australian population. However, higher rates of NESB clients were diagnosed with a serious mental illness such as psychosis (with significantly fewer being diagnosed with less severe mental illnesses) when they presented to a mental health service. People from a NESB also had higher rates of involuntary admissions, admissions to acute inpatient units, and longer admissions compared to the wider Australian population. The lower rates of treated mental illness, together with the finding of higher rates of serious mental illness in those from a NESB who presented to mental health services, suggests that this population group have lower rates of access to public community and inpatient mental health services due to a range of barriers and psychosocial factors, and present to services only after the mental health issue has become more serious. It may also be attributable to

mainstream services being considered culturally unsafe by NESB communities and issues relating to the stigma of a mental illness diagnosis. This would explain the disproportion in diagnoses of psychosis, involuntary admissions and longer stays in acute facilities. This finding is consistent with other research into mental illness within NESB populations across Australia (Bruxner, Burvill, Fazio, & Febbo, 1997; Klimidis, et al., 1999a, 1999b; McDonald & Steel, 1997; Nagel, 2005a; Stolk, 2005). The longer length of stay in mental health facilities was also recorded for Australian Indigenous people, with the mean occupied bed days for Indigenous clients being nearly three times higher than for all mental health clients (41.4 days, compared to 14.3 days), and over five times greater than English speaking clients (8.0 days). Stolk (Y. Stolk, personal communication, September 9, 2009), has stated that further research into mental illness within NESB communities is required in order to determine whether the differences in prevalence and nature of mental illness in the NESB population is due to barriers related to accessing mental health services, such as language and stigma, or whether the community prevalence is actually lower. Clearly the NESB Indigenous Australians with intellectual disability are a high risk group for mental health problems and require special consideration in the delivery of services.

6.3.4 SOCIAL CONTACT AND PSYCHOPATHOLOGY

There appears to be no evidence of any relationship between caseness and whether participants mixed with other people or not, or whether they had close relationships with anyone else. The only item that showed a significant relationship with caseness levels was whether a participant went on outings in their community, for example, going to the movies. Participants who did not go out had nearly double the level of caseness, compared to those who did (36% compared to 19%). This finding might suggest that effort should be made to encourage Indigenous people with intellectual

disability to go on outings and not become isolated as contact with other people and higher activity levels might promote mental health. It may also suggest that people with higher levels of mental disturbance are unable to go out as much as people with lower levels of disturbance.

6.3.5 LIFE EVENTS AND PSYCHOPATHOLOGY

Experiencing stressful Life Events (LEs) can have a significant negative effect on the mental health of adults with intellectual disability (Hulbert-Williams & Hastings, 2008), and are associated with the higher rates of emotional and behavioural problems in this population (Cooper, et al., 2007; Hamilton, Sutherland, & Iacono, 2005). People with intellectual disability are reported to experience a more frequent and a wider range of negative LEs, than those without a disability, and the deleterious effects of these LEs are cumulative (Hatton & Emerson, 2004).

Research also indicates a positive relationship between psychopathology and LEs experienced by adults with intellectual disability (Hamilton, et al., 2005; Hastings, Hatton, Taylor, & Maddison, 2004). Hamilton et al. (2005) found, in an Australian study, that the frequency of LEs is associated with DBC-A caseness status, with people who scored above the caseness threshold experiencing more LEs than those below caseness threshold (6.13 LEs compared to 4.42 LEs).

In the Lifespan study the highest rate of LEs occurred in younger participants and decreased with age. This confirms other research in the United Kingdom that also found younger people with intellectual disability were at increased risk of experiencing more LEs (Hastings, et al., 2004; Owen, et al., 2004).

Indigenous participants were reported to have higher rates than the non-Indigenous participants of most types of LEs, with approximately double the rate for the significant and negative LEs of serious illness or hospitalisation, death of a close

relative or family member, victim of crime or assault, and problems in the family and household. The rate of substance abuse was 11 times higher for Indigenous participants.

The higher rates of LEs found in this research study is consistent with the findings of another recent study in Indigenous families in WA which examined life stresses similar to those included in this research (Silburn, et al., 2006). Silburn et al. (2006) found that Indigenous families reported very high rates of life stress events (3.9 in the last 12 months), which was over three times the number of life stress events experienced by non-Indigenous families (Silburn, et al., 2006). The higher mean number of LEs for Indigenous participants (2.68), is also consistent with the findings of recent research into the social and emotional wellbeing of Indigenous people (Australian Institute of Health and Welfare, 2009), which found an average of 2.6 life stressors per person in the previous 12 months. Further, in this study, the carers of Indigenous participants indicated that 70% of all LEs selected caused *a moderate* or *a lot of stress*, compared with 60% of LEs for non-Indigenous participants.

Over 30% of Indigenous participants reported experiencing *the death of a close friend or relative*. This compares to the results of recent research conducted by the ABS, which found that 42% of Indigenous respondents reported experiencing the death of a family member or close relative in the previous 12 months (Australian Bureau of Statistics, 2006b). Both studies also indicate that Indigenous people were twice as likely as non-Indigenous people to have experienced a death of a family member or close relative. Further comparisons with the 2004- 2005 National Aboriginal and Torres Strait Islander Health Survey (NATSIHS) (Australian Bureau of Statistics, 2006b) results demonstrate similar findings in relation to other LEs. For example, NATSIHS found 28% of Indigenous people had a serious illness or disability

compared to 29.8% in this study. The NATSIHS found 19% of Indigenous people reported that a member of their family had been or was currently in jail, which compares with 14% of respondents in this study who reported trouble with police, court system or time spent in prison.

Indigenous participants with intellectual disability experienced nine times the rate of trouble with police or courts or time spent in prison compared to non-Indigenous participants. The Indigenous participants who had experienced trouble with police, contact with courts, or prison had six times the odds of having clinically significant mental health problems (DBC-A case) than those who answered "No" to the question, after age, gender and level of intellectual disability was accounted for. There was 2.7 times the level of DBC-A caseness for those Indigenous participants who answered in the affirmative to this question, compared to those who answered in the negative. This higher rate was similar to the non-Indigenous participant rate of 2.6 times.

People with mental illness are over-represented within the prison system in Australia, are more likely to be jailed for minor offences and are more likely to be remanded in custody and spend longer in custody awaiting sentencing, than people without a mental illness (Commonwealth of Australia, 2009). Indigenous people with mental health problems are also overrepresented within the prison system and consequently suffer a double disadvantage (Commonwealth of Australia, 2009).

This study confirms that also having an intellectual disability creates a triple disadvantage pointing to the urgent need for forensic services to provide coordinated Indigenous, mental health and disability services and support.

This research found that a higher proportion of Indigenous participants with any LEs were identified as meeting criteria for DBC-A caseness. This proportion with any LE was higher by .18 for both Indigenous and non-Indigenous participants, showing a

positive association between caseness and LEs. The odds of having any LE was 1.83 times higher for Indigenous participants, compared to non-Indigenous participants and the odds of having any LE was 2.41 times higher for Indigenous DBC-A cases than for Indigenous non-DBC-A cases.

Indigenous participants experienced:

- 1.1 more LEs than non-Indigenous participants

- Fewer LEs as the level of intellectual disability increased

- Fewer LEs as the age of participants increased.

Further, Indigenous participants who scored at or above the DBC-A caseness threshold, experienced over double the rate of LEs in the last 12 months (4.21) compared to non-cases (2.05). This higher rate of LEs being associated with psychopathology in Indigenous people is supported by other research which found that over one in five Indigenous children had experienced seven or more life stress events in the last 12 months and were five and a half times more likely to be at a higher risk of emotional or behavioural problems, compared to those children who experienced less stress events (Telethon Institute for Child Health Research, 2005).

Indigenous participants who identified that they had experienced a death of a close friend or relative in the last 12 months showed nearly double the rate of caseness than those Indigenous participants whose carers did not select the bereavement item (41% compared to 22%). The proportion of Indigenous participants who experienced a bereavement was higher than for non-Indigenous participants (26% compared to 20%). Therefore bereavement is likely to be a significant predictor of emotional or behavioural problems in Indigenous people with intellectual disability.

In summary, the experience of adverse Life Events is more likely in both people with intellectual disability and Indigenous people and is associated with an increased risk of mental health problems. Therefore this creates a situation of double jeopardy with an Indigenous person with intellectual disability being at even greater risk of suffering mental health problems associated with stressful Life Events.

There are prevention and mental health promotion implications because at least some of the stressful Life Events faced by Indigenous people are potentially preventable if poverty, disadvantage, poor health and neglect are more effectively tackled. Better crisis intervention and support services might also help to reduce the impact of negative Life Events.

6.3.6 DEPRESSION AND ANTISOCIAL BEHAVIOUR

Throughout the visits to various communities, when the family members were asked if they thought anything was the matter with the individual with an intellectual disability, it was commonly reported that the individual was "just depressed".

An examination of the profile of scores across the factors on the DBC-A showed that Indigenous participants have higher mean scores on the Depressive and Antisocial subscales than non-Indigenous people, together with a wider range and higher intensity of the items on both subscales.

Furthermore, regressions of MIS for the whole DBC-A and six factor-based subscales controlling for age, gender, level of intellectual disability and Indigenous status show that the Depressive and Antisocial subscales were significantly higher for Indigenous participants when these other variables are controlled for. The regressions also show that the presence of intellectual disability, rather than the level of intellectual disability, is the main determining factor in levels of psychopathology.

In addition to the findings on the subscales, further information on depression is provided by the frequency of selection of several individual DBC-A items that reflect low mood and depression in the Indigenous participants. For example, this may include item 32, *become more withdrawn*, and item 45, *lacks self-confidence and self-esteem*. Nearly double the number of Indigenous participants (37%, compared to 20% of non-Indigenous participants) responded positively to *become more withdrawn*, and half of the Indigenous participants (compared to 33% non-Indigenous) scored positively on *lacks self-confidence and self-esteem* item.

These results suggest that depression may also be a significant problem for Indigenous adults with intellectual disability. Depression within Indigenous communities throughout Australia has been recognised as a serious problem for decades (Kahn, Kennedy, & Cawte, 1978), and contributes to the increasing rates of admission to hospital for mental health problems, higher involuntary admissions and longer lengths of stay in mental health services (Minas, Lambert, Kostov, & Boranga, 1996; Nagel, 2005a; Stolk, et al., 2008).

Research conducted in the Northern Territory indicates that depression was the second most common reason for hospital admissions for Indigenous people in 2002-03(Nagel, 2005b). Nagel (2005b, p. 23) concludes that this is likely to represent only the "tip of the iceberg", considering the figures were based on hospital admissions and not a more comprehensive assessment of people throughout the community studied.

Several other items in the DBC-A also indicated significant differences between Indigenous and non-Indigenous scores and highlighted particular challenges that are facing Indigenous communities, such as high rates of suicidal behaviour and substance abuse (including illegal drugs, alcohol, petrol and other substances). These will be discussed later (see Sections 6.3.7 and 6.3.8).

6.3.7 INTENTIONAL SELF-HARM AND SUICIDE

There were two items in the DBC-A which indicated whether the individual displayed self injurious behaviour or suicidal tendencies. Item 36 asked whether the individual *Hits, bites or injures self* and one in four Indigenous participants (25%) responded in the affirmative to this question compared to 27% of the non-Indigenous participants. Item 91 asks whether the individual *Talks about or attempts suicide*, and 11% of the Indigenous participants (compared to 3% non-Indigenous) responded in the affirmative to this question.

The prevalence of suicide among populations of adults with intellectual disability is about one third of that of the general population, however, the risk factors for suicide are similar (Patja, Iivanainen, Raitasuo, & Lönnqvist, 2001). There has been no previously published research on the prevalence of suicide among Indigenous adults with intellectual disability.

There is a high rate of suicide and attempted suicide in Indigenous communities within the regions that were visited as part of the research project (Australian Bureau of Statistics, 2005), however data on the prevalence of suicide among Indigenous adults with intellectual disability was unavailable. On a visit to one community, a worker from the community family centre discussed several recent suicide attempts within the community and talked about the effect of these throughout the community. One of the attempts was successful. All were by young people living in the town (two had been sexually abused and included in the Mulligan enquiry into sexual abuse of children on the APY Lands (Mulligan, 2008) also released at the same time).

The worker said that one of the other people who attempted suicide would also have been successful if the person was not found in time and cut down from the rope. She spoke of how the community has not enough time to adequately deal with these events

because they are too frequent and come on top of other significant community concerns and issues, such as managing substance abuse.

In another community in the NT, similar stories of concern were relayed when talking with local residents. For example, when driving out of a community after meeting various families, the driver pointed out to the researcher several sites where flowers and stones were set up on the side of the road. Typically, these relate to someone dying from a vehicle accident. When a particular site was passed, the driver told the story of what happened. A close relative of the driver was fighting over a can of beer with others, and when he didn't get the can to drink, he climbed up the power pole and held two wires and fell down dead. She said that this only happened a few months before and that several young people have used this method of committing suicide, which seemed to be considered a new and effective method that has started to attract "copycat" incidents.

The worker said it is mainly the young men who are committing suicide. When asked why, she said that many young men are experiencing anger and grief associated with problems of not being able to see or visit their children, because, for example, there were legal restrictions on access to their child or their child has been taken to another community. It was noted that the young man mentioned above who committed suicide was 29 years old with three children who he had been unable to gain access to. On further discussion about the possible reasons for such high rates of suicides and attempted suicides, the worker said that the only community in this area without suicides was Hermannsburg, "because the stronger (older) men push the young ones into cultural activities and their spirits are stronger".

These results are consistent with research within Australia which points to a high prevalence of suicide amongst Indigenous Australians contributing to 16% of all

deaths which is almost three times that for non-Indigenous males for the 2001-2005 period (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). The largest differences occurred in the younger age groups. For example, Indigenous males aged 0–24 years and 25–34 years had three and four times the corresponding age-specific rates for non-Indigenous males respectively (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008).

The study found evidence of younger people attempting, and committing suicide in the various communities visited. In one community, three attempts by young people living there had occurred in the last month. In another community it was reported that it is mostly young men who are committing suicide.

Of all external causes for premature death reported for Indigenous people, which included accidents, intentional self-harm and assaults, premature death due to deliberate self-harm accounted for 33% of male deaths and 15% of female deaths (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). Further, the level of intentional self-harm is considered to be a key indicator of Indigenous disadvantage (Steering Committee for the Review of Government Service Provision, 2007).

Indigenous admissions to hospital for intentional self-harm were 2.3 times higher for Indigenous males and 1.5 times higher for Indigenous females than for their non-Indigenous counterparts (Steering Committee for the Review of Government Service Provision, 2007). Research has shown that the rates of self-harm in the Indigenous population are continuing to rise (Clough, et al., 2004). This study has produced some evidence to indicate that at least suicidal ideas are also more prevalent in Indigenous people with intellectual disability. Further study of this issue is required.

6.3.8 SUBSTANCE ABUSE

The DBC-A has two items that identify problems with substances (items 67 and 68).

Nearly one in four Indigenous participants (24%) were reported to have problems with

cigarettes, alcohol or caffeine (Item 67), compared to 6% of non-Indigenous

participants: A four-fold increase. In 8% of cases Indigenous participants were

reported to have problems with the illegal use of drugs (Item 68) compared to 1% of

the non-Indigenous group: An eight fold increase.

A further indication of the high level of substance use comes from the results from the

Life Events scale where 12.4% of Indigenous participants, compared to 1.1% non-

Indigenous participants were reported to have abused alcohol in the last 12 months.

This result is eleven times greater than non-Indigenous rates.

Substance abuse was found to be a significant area of concern for families supporting

a son/daughter with an intellectual disability. Substances such as petrol, glue, paint

and thinners, marijuana and other drugs (particularly in more recent years, the

introduction of methamphetamine ('ice') into Indigenous communities), were reported

to be having a negative effect within these communities. Petrol sniffing continues to

be an issue in some of the communities in far north SA and several family members

described how they thought petrol abuse from a young age contributed to brain injury,

and resulted in the intellectual disability of their son/daughter. One mother talked

about her young teenage daughter experimenting with petrol and marijuana in order to

fit in with her peers.

There was concern that young people who used to only use only marijuana ('gunga')

are now using methamphetamines with disastrous effects. In a discussion with a

community Cultural Liaison worker, a story was told about how four young people,

three males and one female, in this community had become addicted to ice recently.

"They've been helped to stop and are trying but it's too hard. These guys have been on ice for less than a year and it is causing a lot more trouble than ganga or grog ever has". The worker discussed how she was also a member of this community's governing committee and they discuss the effects of the abuse of drugs, particularly the recent arrival of ice, is having on their community and what strategies can be implemented to reduce the use of these drugs.

These results support research which shows the increased usage of substances and its detrimental effects on mental health within Indigenous communities (Hunter, 1988). Further, comparisons to the non-Indigenous populations show significant differences in prevalence in mortality from substance use. For example, the mortality rate due to psychoactive substance abuse is reported to be 14 times higher for Indigenous males aged 35-44 years than for non-Indigenous males in that age group and 12 times higher for Indigenous females in this age group, compared to their non-Indigenous counterparts (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008).

The findings from this study provide confirmation for the first time that there are similar patterns of excessive substance abuse within the population of Indigenous adults with intellectual disability, that are present within the broader Australian Indigenous community.

6.4 SOCIAL, CULTURAL, AND ENVIRONMENTAL CONTEXTS

6.4.1 ISSUES RELATED TO CONDUCTING THE RESEARCH

Every effort was made to ensure the project was conducted in a culturally sensitive, respectful and appropriate manner that aimed to maximise the value of the data collected. As the Lifespan research project within the Indigenous populations living in South Australia and Northern Territory progressed some special research issues emerged.

1. There was a tension between the absolute need to fully consult with the Indigenous community and the research funding timeline. Time is required to develop a working relationship with Indigenous communities in order to conduct research. The Lifespan research project had limited time available with 3 years of funding and a data collection period of around 18 months. Therefore consultation with Indigenous communities and services commenced early, extra work was done to ensure ongoing networking with a wide range of stakeholders throughout the project and the data collection period was extended to 2 years. With these strategies the crucial and effective collaboration with the Indigenous communities and services was achieved and the data collected.

2. The research needed to be conducted in a community focussed, inclusive and collaborative manner in order to ensure participation and in the hope that this would help to develop the capacity of the community and service providers to better support Indigenous adults with intellectual disability. This was achieved by intensive listening to stakeholders and shared learning. This included listening to the community's views and concerns about research, discussing the

challenges involved and then implementing agreed strategies that would support participation in the project.

3. In the process of data collection it became obvious that there was considerable mobility in this population, particularly movement across South Australian and Northern Territory borders and throughout the various regional and remote areas. This led to the inclusion of the lower and central desert region of the Northern Territory into the research project, in order to ensure the most representative sample of the Indigenous population.

4. Indigenous people are possibly the most researched in the world and are quite suspicious about being further researched. A key concern within the Indigenous community was to ensure that researchers work in sensitive and culturally appropriate ways (Donovan, 1997; Henderson, Simmons, Bourke, & Muir, 2002; Onemda VicHealth Koori Health Unit, 2008). Community members advised that unless the research was conducted in a culturally appropriate way, the participation rate would be very low and not representative of the Indigenous population. The initial forecasts of a low level of participation in the research project did not eventuate. The high level of participation (81% of all potential Indigenous adults with intellectual disability), indicates that the research was conducted within a culturally respectful framework and with an awareness of the special cultural issues in the regions. The high level of participation was possibly due to specific modifications to the data collection methodology and to the time spent on carefully establishing a respectful working relationship with Indigenous disability workers and the leaders of each community. As a consequence the study has provided a meaningful and representative sample of Indigenous

adults with intellectual disability living in South Australia and the Northern Territory. Modifications to the data collection methodology have been described earlier and included a personalised approach to contacting potential participants, and visits to all Indigenous communities identified in order to discuss the research project with them.

6.4.2 CULTURAL EXPLANATIONS AND RESPONSES TO INTELLECTUAL DISABILITY AND MENTAL ILLNESS

Internationally, there is limited data on the ways that Indigenous people perceive and respond to intellectual disability and mental illness (Connors & Donnellan, 1993). However, there remains a wide diversity of views and attitudes towards intellectual disability and mental illness amongst Indigenous communities and individuals (Glasson, et al., 2005; O'Neill, et al., 2004). An Indigenous elder from the Navajo Nation in North America was quoted as saying "Before the white man came, we were blind (to disabilities). You brought us the gift of sight. I think we were happier when we couldn't see" (in Connors & Donnellan, 1993, p. 279).

These views can range from people with intellectual disability or mental illness being considered to hold supernatural powers (both positive and negative), being seen as a 'gift', or they may be considered to be disabled as a result of some form of supernatural intervention such as sorcery (Maher, 1999b).

Traditional Indigenous cultural values such as a more 'holistic' view of life and a 'collective' or 'connected' view of personhood, attachment to one's family and their community are still shared today in Indigenous populations throughout the world, with children being considered particularly important and highly valued (Bennett & Blackstock, 2003; Mobbs, 1991).

Indigenous parents were wrongly considered to be unable to properly care for their son or daughter with a disability. As a result, limited services were provided to Indigenous parents to look after their children who had intellectual disability within their own community (Bostock, 1991; Milloy, 1999). Children with intellectual disabilities were also routinely removed from their community and placed into large institutions a long way away from their family with non-Indigenous people with intellectual disabilities. Due to the distances involved, familial connections became extremely limited, or typically severed, over time (Connors & Donnellan, 1993).

These past damaging policies and practices have understandably led to an ongoing fear that mainstream disability services may be involved in removing Indigenous children from their community.

This research aimed to further explore these issues and interviewed family carers of Indigenous adults with intellectual disability for this purpose. Below is a summary and discussion of key points from these interviews. Names and place details are altered to protect confidentiality and have been approved by Indigenous advisors to the study.

Indigenous Australians social and cultural experiences, beliefs and understandings about mental health are clearly acknowledged as different to those of the mainstream Australian community. For example, when talking about the past, Samantha said that "in the old times, people with a disability would have been left behind, as the community was always moving and strong. If someone is too old or weak, they were left under a tree or in a cave with food. This was the same with all the desert mobs" (tribes in the central Australia region). "Today, if you find them bones, you got to leave them there... some have found them and taken them away... it's no good".

When asked how this may influence perceptions today, she said that "anything to do with intellectual disability was always blamed on sorcery" and "it still goes on now". She emphasised that people today still hold these views of spiritual influence in disability and mental illness.

It was common for Indigenous people to report their own, and their communities, belief in spiritual influences and sorcery as a cause of intellectual disability and mental illness. This is supported by research which provides accounts from Indigenous people throughout Australia having encounters with spiritual beings, such as evil spirits and the spirits of relatives and friends who have died (Hunter, Reser, Baird, & Reser, 1999).

A number of syndromes present in Indigenous communities that are related to mental illness and may be 'culture bound' have been identified (Garvey, 2008). Examples of 'culture bound' syndromes include:

- Fear-of-sorcery syndrome (Eastwell, 1982)

- Hysterical trance states (Spencer, 1983)

- Longing for, crying for, or feeling sick for country (removal from country, place of dreaming, or spirit for a long time) (Westerman, 2003)

- Other culture bound syndromes have been identified such as pathological fear states

- Prolonged mutism (Reser, 1991)

- Psychopathology associated with being 'sung' by an aggrieved party

- Behaviours associated with rituals and 'sorry business' (Westerman, 2003).

Traditional Indigenous views of mental illness emphasise social and spiritual dysfunction as a key cause of illness (Maher, 1999a) and cultural explanations for causation of mental illness needs to be considered before treatment can be successful

Cawte, (in Reid & Trompf, 1992, p. 225). Supernatural phenomena play a very important role in the traditional health beliefs of Indigenous people and it may be the most accepted explanation for why a person became ill.

For example, when ill health occurs in Indigenous people, they are most likely to attribute this to some culturally based reason such as doing something wrong culturally (Sheldon, 2001; Vicary & Westerman, 2004) although the affected person is likely to be experiencing symptoms that are consistent with mental illness and follow the same clinical symptom profile (Sheldon, 2001; Vicary & Andrews, 2001). Activities aimed at influencing the social and emotional wellbeing of Indigenous people need to remain cognisant of the Indigenous terms of reference surrounding mental health and reflecting the Indigenous world view (Sherwood, 2005). Western health care systems have been slow to learn from Indigenous people that maintenance of wellness, not management of illness, should be the primary goal (van Holst Pellekaan & Clague, 2005).

It is important that mental health service providers focus on the maintenance of social and emotional wellness, as well as the management of mental illness in their work in Indigenous communities (Garvey, 2008).

Furthermore, in a recent study which explored Indigenous perceptions of mental illness, nearly 75% of respondents indicated that they believed that Indigenous people did not perceive depression as a state that could be addressed via treatment. Rather, depression was thought to be a characteristic of the individual concerned, or "that's just the way he is" (Vicary & Westerman, 2004, p. 6).

In other Indigenous cultures, concepts of mental illness and disability appear to be similar. For example, in the language of the Inuit nation from Northern Quebec in Canada, the term "Isumaqanngituq" can be translated to mean "he has no mind/brain",

"crazy", "doesn't know what's going on around him", "doesn't know what he's doing", or "acting strange"(Kirmayer, Fletcher, Corin, & Boothroyd, 1994, p. 31). "Isumaqanngituq" is a broad concept and may apply to a person who has mental health problems, intellectual disability or dementia (Kirmayer, et al., 1994).

A review of the DBC-A results for cultural specific issues shows that there were three items in the DBC-A that may be related to culture specific phenomena such as spirit visits and being 'sung'. The meaning of these items to specific communities requires further investigation in order to confirm any relationship. These items are:

- Distressed about being alone (Item 17)

- Nightmares/walks in sleep (Item 33)

- Hallucinations (Item 90).

Forty percent of Indigenous respondents identified that the person with intellectual disability was distressed about being alone at night, which was double the rate of non-Indigenous respondents. Twenty one percent of participants responded that they had nightmares/walks in sleep, compared to 6% non-Indigenous (over three times the rate of non-Indigenous responses), or to having hallucinations (nearly twice the rate of non-Indigenous responses, 14% compared to 6%). Indigenous people have been reported to experience hallucinations that are not due to any organic mental disorder, but are related to intense emotions experienced in traditional ceremonies (Sheldon, 2001).

6.4.3 REMOVAL FROM COMMUNITY AND CULTURE

A major negative influence on the lives of Indigenous people with intellectual disability and the experience of their family has been the effects of government

policies of removal of people with disabilities from their communities (National Disability Administrators, 2004).

These issues are considered to be linked to the historical efforts of assimilation in which family members with a disability were regularly removed from their family and community and placed into state care, usually many hundreds of kilometres away in cities (Human Rights and Equal Opportunities Commission, 1997).

Both historically and recently, children and young people with intellectual disability have been placed in institutions and environments that are culturally inappropriate because:

- The residential facilities are geographically isolated from the individuals family and home community (usually in major cities)

- The facilities are staffed by workers with little or no cultural awareness and knowledge of the individual's cultural background

- Indigenous people with intellectual disability in residential facilities have had limited or no access to cultural activities.

Parents, siblings and other community members reported that they do not feel welcome or comfortable in these places. This is consistent with findings from Indigenous families throughout Australia about the negative impact on them of individuals with intellectual disability being removed into western disability services (National Disability Administrators, 2004; O'Neill, et al., 2004).

When visiting families living in various communities throughout the data collection process, evidence was found of ongoing distress and other negative effects of the past removal of the individual with an intellectual disability from their family and community.

One such case was on older man who was born with a cleft palate and was removed from his Indigenous family with his siblings when he was a year old. When recalling the events of this removal and subsequent placement into an institution, his sister said that he was to have an operation to fix the cleft palate when he was about three years old, but instead of being returned to the orphanage where his siblings were after the operation, he was placed into Minda, a large institution in Adelaide at the age of four. From this age, until some years ago when his sister became aware of his location, he had been completely isolated from his family, who were unaware of his whereabouts, or whether in fact he was still alive.

Some parents reported that service agencies seemed to prefer to remove and place young children with intellectual disability into foster care and adoptive services instead of providing support to the family that would have enabled the child to remain cared for in the family home and community.

Observations were made on the negative effects of the multiple relocation of the individual with an intellectual disability between various community placements and family members whilst receiving limited support from agencies, and families struggling to care for their own children in difficult circumstances. The family members providing such support thought that it was preferable for the individual to be cared for "within our culture" rather than being removed to "white foster families". The desire to maintain care of one's own children was highlighted by a mother, who herself has an intellectual disability and a number of chronic health conditions such as high blood pressure, a kidney disorder and thyroid problems.

The mother is the sole carer of her daughter who has severe disabilities and who is wheelchair dependent. They live in a remote town and had moved in from a very

remote community in order to access schooling for the daughter and supports for the mother so she could continue to raise her daughter to the best of her ability.

She has not been able to find independent accommodation since arriving in the town and is living in a temporary hostel. This has required regular moves between dormitory and shared rooms with limited privacy and she relayed that she does not like sharing rooms with others, as they get angry with her because her daughter does not always sleep well at night. Fortunately, she has recently secured a wheelchair accessible room which she shares with her daughter until more suitable accommodation can be found but she is worried that she will lose this room and need to go back to one of the dormitories.

The number of Indigenous individuals with intellectual disability not living with their biological parents was higher compared to the non-Indigenous participants involved in the research project. Many have been placed into foster arrangements, some with other Indigenous families (which is considered preferable), but many individuals have been placed with non-Indigenous families.

An interview was conducted with a woman who has 10 Indigenous foster children with Fetal Alcohol Syndrome (FAS) aged from 17 to 25 currently living in her house. She had been providing foster support for Indigenous children with intellectual disability since 1973 and when asked how many children she has looked after over the years, she replied that "I stopped counting at 100". She said "these children have grown up without much positive Indigenous culture; rather they have seen the dangerous subculture of drugs and alcohol within their homes. There are a lot of mental health issues related to drugs and alcohol in the Indigenous community now. These mask depression and other mental illnesses".

6.4.4 SUPPORT AND SERVICES

In this study it was necessary to engage with and understand as far as possible the local cultural context of Indigenous communities and families in order to help carers describe their personal experiences of supporting someone with an intellectual disability and the factors contributing to the health and wellbeing of the person with an intellectual disability in their care.

There are significant differences in the structure of Indigenous and non-Indigenous families and communities which influence service utilisation and delivery (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008).   These include:

1. Indigenous families are typically larger, non-nuclear and more fluid in composition, with extensive kinship networks and greater mobility of family members moving between different households, particularly in remote areas (Morphy, 2006; Smith, 2000)

2. Indigenous households are three times more likely than non-Indigenous households to be a single-parent family with dependent children (30% compared to 10%) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008).

This is supported by the Lifespan project findings of 28% of Indigenous participants had moved in the last 12 months, which was more than double the rate of non-Indigenous participants who had moved in this time.

A comparison of Indigenous and non-Indigenous populations found that Indigenous people were more likely to be actively caring for another person with a disability (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). This was also a finding of this research. Indigenous carers were also found to be

younger than non-Indigenous carers by 10 years, and this age difference is similar to the age difference of Indigenous and non-Indigenous carers throughout Australia (12 years less) (Australian Bureau of Statistics & Australian Institute of Health and Welfare, 2008). Further stressors are also likely to be experienced by Indigenous carers. A recent finding from the Australian Institute of Health and Welfare (2008) was that Indigenous carers:

1. Were one and a half times less likely to be employed than non-Indigenous carers

2. Had a median weekly income equivalent to 42% of the median weekly income of non-Indigenous carers ($248 compared to $589)

3. Were four times more likely than non-Indigenous carers to be living in a household which earns less than $315 per week

4. Were between one and a half and three times more likely than non-Indigenous carers to need assistance with core activities, such as self-care, body movements or communication.

The Lifespan project found that although an Indigenous person may have been diagnosed as having an intellectual disability their family were more likely than non-Indigenous families to treat them as 'normal', rather than 'different'. This appears to be supported by research that explores the differences in Indigenous community concepts of, and responses to, disability and mental illness (Reser, 1991). Reser (1991) found that behaviours which may be defined as mental illness from a western psychiatry perspective, would typically have a non-psychiatric explanation for the majority of Indigenous people (Reser, 1991).

Similar explanations occur in other Indigenous cultures. In North America, the traditional beliefs of the Navajo people were that intellectual disability was caused by

witchcraft, incest, or offending a *Yei* (a Navajo spiritual god), and could be cured by conducting an appropriate ceremony. However, according to one Navajo medicine man, intellectual disability in the present day which is caused by substance abuse, accidents or western diseases such as spinal meningitis is understood to be different and cannot be cured by traditional ceremonies (Connors & Donnellan, 1993). Indigenous people are concerned that clinicians from outside the culture attempting to provide support and treatment for mental health problems within the Indigenous community do not adequately consider traditional Indigenous cultural beliefs and worldviews (Vicary & Westerman, 2004).

Throughout this project evidence was found that often the response to mental illness and intellectual disability within Indigenous communities are made more complex by the stigma and shame associated with mental illness and intellectual disability much as it does in the wider Australian population. As a consequence, families are hesitant to seek early support from disability and mental health services. Fear of the western mental health system is widely reported and results in families attempting to deal with this issue alone with limited support (Vicary & Westerman, 2004). This hesitancy to engage with services is then reinforced because the individual is more likely to be hospitalised and/or medicated (Vicary & Westerman, 2004).

In the Lifespan study the Indigenous participants had higher levels of behavioural and emotional problems compared to the non-Indigenous participants, but were less likely to seek professional help for these problems (6.9% Indigenous, compared to 20.5% non-Indigenous). In addition, it was found that Indigenous participants were more likely to be admitted to hospital for these problems than were non-Indigenous participants (21.3% compared to 12.7%) and of those who were admitted to hospital for emotional or behavioural problems, the Indigenous participants had higher DBC-A

scores and were much more likely to be detained under the Mental Health Act than were the non-Indigenous participants (22% compared to 6.2%). These results indicate that Indigenous people with intellectual disability and their carers are also reluctant to engage with mental health services, resulting in an increased severity of the emotional or behavioural problems when they eventually present to mental health services. There are a range of issues that appear to have led to an under-utilisation of disability services by Australian Indigenous people (O'Neill, et al., 2004). This includes:

- Differences between western and traditional Indigenous cultural values and perceptions of disability (Tipper & Dovey, 1991)

- Poor awareness of entitlements, service options, rights and advocacy options and confusion about which agency provides what services (National Disability Administrators, 2004)

- Incorrect assumptions and inappropriate procedures used by health service providers and other professionals (National Disability Advisory Council, 1999)

- Suspicious attitudes towards past government policies of separation and removal of people with a disability from their families and community (National Disability Administrators, 2004).

Family members were asked about the support they receive to look after their son, daughter or other family member and what would they like to see happen to improve this support.

An older mother who is widowed and looks after her son in a remote community said that she has asked for, but has not received any, respite residential support and there are no supported accommodation facilities on the APY Lands for people with a disability for her son to go to. She was very clear that she does not want her son to be

removed from his community to Port Augusta (a town over 700 kilometres away) to live in a 'white-fella' disability house.

Another primary carer in the same community reported that she does not receive any support for looking after her niece (such as carers payments or access to her niece's Disability Support Pension) to help with support and living expenses. In addition, her niece's Disability Support Payments appear to have lapsed, or has been 'breached' (discontinued due to a range of possible reasons) by Centrelink (Commonwealth government department responsible for administering pensions and benefits). This is likely to be because staff at Centrelink sent letters requesting contact from her niece, but the letters may have been sent to the wrong addresses and probably weren't understood by whoever read them.

A mother living in the Northern Territory reported that she is meant to receive 'support' from Red Cross, a service who are contracted to provide one hour of support each school morning to assist in getting her daughter prepared for school. The mother says that they never or rarely provide this support (maybe only one day a week) and she struggles with doing these jobs on her own most days as her daughter is "growing bigger and getting harder to lift".

When asked about her satisfaction with support services, the mother said that she is happy with "Susan's' mob" (HaCS Positive Behaviour Support Unit), but unhappy with Red Cross.

A carer looking after his step-son was particularly scathing of the NT 'welfare' and their 'support'. When he was initially approached at the front door of his house, he asked if the researcher had anything to do with the NT government department, and if so, he would "punch your lights out right here and now".

He said that he has previously tried to get more regular respite care for his step-son provided by the NT Department, but it hasn't worked out for a number of reasons. He says that he receives no support from the department and although he doesn't want to "become a millionaire" he struggles with the costs of providing for his family (he is a full-time carer and doesn't work). He said that the department does not have an understanding of providing culturally appropriate supports or flexible supports. He does not want his step-son to go into other accommodation, and feels that he is saving the government thousands of dollars and his role should be valued and recognised by the department.

A carer in a very remote community spoke of the lack of supports for people with a disability/mental illness. The community is on the border of South Australia/Western Australia and the Northern Territory. She gave an example of a young man with intellectual disability and also diagnosed with schizophrenia who regularly climbs to the top of the television tower and threatens to jump off if he doesn't get what he wants. There are no police in the community and these types of events usually require intervention from her husband or other men.

A carer in a remote community who is now the primary carer for her brother (as her mother, who was previously the main carer, recently died) said that her mother had spoken to her before she died about her fear of her son going into supported accommodation (her mother was a health worker for a long time in the community and witnessed "too many tablets and overdosing" of clients). She had said that, "You mob will need to look after him when I go" and it "meant a lot to mum that he didn't go into a 'home' and also that he was looked after by his family".

When asked about what supports would help her, she said they tried to live in a larger town about 80 kilometres away, but didn't like it. Her brother used to steal, so they

moved back to the more remote community. She said "We need help; we try to live in one house... it's no good. Maybe they can build another house for disability people in this community?" (the NT Department of Family and Communities has reported that there have been plans to do this for several years, but nothing has occurred as yet). "We would like some respite so we can go away sometimes back to our homelands to visit my husband's family – maybe my neighbour could look after him?"

An Indigenous Support worker said that there is a lack of Indigenous families wanting to look after non-related adults with a disability, although it is easier to place children. She felt that people should be looked after in their community and not taken off their land into the "white cities".

A mother in Adelaide reported that she was now receiving decreased access to support funding for her son. She said that although he attends a post school options program three days a week, it was initially five days a week, then four, and now three. This was due to funding being cut over the years because of his perceived "reduced support needs".

When asked about her community's traditional views of disability, she said that Indigenous people were advised to place their son or daughter into care if they had a disability. She said that the doctors advised them (when her son was little) to place him into Minda, as it was the "best place". There are parallels in the broader community, as advice such as, "doing the best thing for your son/daughter," has also historically been given to non-Indigenous families as well. She said that, "a lot of us mob did that". She said that it was the expected, 'right' thing to do. She said that she thought that less Indigenous families would be willing to do that now, as it's "better for them to be at home with their family and culture". Many parents didn't want to

give up their kids to be cared for in an institution and would rather access their extended family to provide support.

She finds it too overwhelming trying to not only deal with what's going on with the child with intellectual disability and their support needs, but also to trying to navigate through a system that she doesn't understand and doesn't think helps her very much. She feels it is all about going to meetings and talking (which makes her anxious), without getting any help at home. "Aunty can't cope with this", she said.

Another carer said that her relationship with DSSA (SA disability support department) is "very poor" and she doesn't want anything more to do with them. She spoke very strongly about the case workers being "idiots" who cut off her daughter's funding for after school care.

Improvements in accessibility of disability services, provision of disability supports within community, including respite, accommodation and similar culturally appropriate flexible care options, together with an easier to understand and navigate service system with a presence within communities are urgently required to in order improve the current situation for Indigenous adults with intellectual disability. Ensuring that all staff members employed within disability services have completed cultural competency education would also ensure that services are engaged with and considered culturally safe by clients and their families.

6.5 THE UTILITY OF THE DBC-A IN THE ASSESSMENT OF PSYCHOPATHOLOGY IN INDIGENOUS ADULTS WITH INTELLECTUAL DISABILITY

There are a range of potential challenges in attempting to accurately assess the psychopathology of people from another cultural group, such as clinician bias and unfamiliarity with cross-cultural presentations of mental illness (Stolk, et al., 2008). It is possible that the DBC-A also has some limitations in this regard. Although the DBC-A has been translated into 21 different languages its use had not been validated in an Indigenous group. However, the DBC-A has been shown to have good psychometric properties and is a reliable and valid instrument for describing psychopathology in adults with intellectual disability in the general Australian community (Einfeld & Tonge, 2002). Its use in the larger Lifespan project also provided invaluable contemporary data for comparison. If used clinically it should only form part of a comprehensive assessment of the psychopathology of an individual with an intellectual disability, and should not be relied upon solely to provide a diagnosis of mental illness (Einfeld & Tonge, 2002). This assessment should include an interview of the individual and their carer(s), observations of the individual's behaviour, an appropriate medical review and further investigations using a tool from a range of validated assessment instruments. Clearly a comprehensive assessment such as this was not feasible in the 161 participants studied.

It is possible that the carer who completes the DBC-A may be providing biased information on the emotional and behavioural wellbeing of the individual with an intellectual disability. Some checklist developers have recommended that screening checklists should be completed by two carers separately and the results compared (e.g. Reiss, 1988).

Only one carer was used to provide DBC-A information in this study, however, the DBC-A has been shown to have good inter-rater reliability in a previous study of paid carers and family carers (paid carers ICC= 0.7, family carers ICC= 0.72) (Mohr, et al., 2005). Further, each carer who completed the DBC-A and the Lifespan questionnaire, knew the individual with an intellectual disability very well (at least 12 months) and many carers had known the individual for their whole life. Many carers were themselves Indigenous, and most, if not all carers had a good understanding of Indigenous culture and the individual's support needs.

It is possible that there could be doubts about the responses to various items in the DBC-A due to:

- The questions being considered to be culturally insensitive

- Different cultural understandings of items or words used in DBC-A

- Limited literacy skills of the completer

- Not talking about items that may be 'shameful'

- A reluctance to talk about the business of someone from the other gender

- Asking too many questions at one sitting, or too quickly

- The carer being concerned that the DBC-A findings may be used to judge or disadvantage the person with intellectual disability, such as a fear that the results may reduce access to disability support funding or eligibility for services.

However, prior to data collection, meetings were conducted with the relevant Indigenous stakeholder bodies to review the Lifespan questionnaire and discuss the suitability of all questions that were to be asked. The researcher was informed that all questions in the DBC-A and Lifespan questionnaire were appropriate and would in fact provide important information about the support needs of Indigenous adults with

intellectual disability. Each DBC-A item was reviewed and none was considered culturally insensitive. Cultural advice was provided on the best ways to approach some of the questions with Indigenous carers, and the use of appropriate interpreters and cultural liaison workers in relevant areas, such as the remote communities where the local Indigenous languages predominate. It was noted that the results of certain DBC-A items may be influenced by cultural factors, such as Item 2, *Avoids eye contact*, and Item 86, *Shy*. It was suggested that avoiding eye contact may not be seen to be a symptom of psychopathology, but rather a culturally appropriate behaviour. The responses to this item showed 61% of Indigenous participants (compared to 45% of non-Indigenous participants) checked this item. Nearly double the rate of Indigenous participants checked *Shy* compared to the non-Indigenous participants (49% compared to 28%). It was considered that being shy was appropriate for many Indigenous people who may not choose not to speak out for the risk of being 'shamed'.

Further, all carers were informed of the confidentiality of all information provided and that no reporting of individual DBC-A results or of any discussion that identified individuals took place would be conveyed to Disability SA or others.

A DBC-A inter-rater reliability study of Indigenous adults with intellectual disability and its validation against a standard mental health assessment interview by an experienced culturally sensitive clinician is recommended to further assist in our understanding of any cultural bias and to ascertain the reliability and validity of the DBC-A in this population group. A follow-up study of the same participants may also be beneficial in order to further understand the nature of change over time in psychopathology in this population.

Despite of these reservations the study demonstrated that the DBC-A was an acceptable and feasible instrument to use, that it had face-validity and that many of the results obtained were in accord with the literature. Its use in further studies of Indigenous people with intellectual disability is therefore justified.

Finally, future research in this area should always aim to increase Indigenous engagement, participation and ownership that might assist in developing evidence based, culturally appropriate mental health promotion and treatment programs for individuals with intellectual disability in order to bring tangible benefits for the individuals, families and their communities.

6.6 LIMITATIONS OF THE STUDY

This research project may have a number of limitations which may bias, or influence the usefulness of the results. Possible limitations may be related to:

- The method of data collection

- The exclusion of related conditions occurring in adulthood (e.g. ABI, FAS) from the sample group

- The representativeness of the sample group

- The effectiveness of the DBC-A carer completed checklist to screen for psychopathology in an Indigenous group (which is discussed in 6.5).

6.6.1 DATA COLLECTION METHODOLOGY

It became apparent early in the project that in order to achieve high participation rates and a representative sample of this population, modifications were required to the broader Lifespan data collection methodology for the Indigenous participants including face to face meetings rather than mailing out a questionnaire booklet. However, a number of strategies were used which have been outlined earlier, to overcome those difficulties and which produced the high participation rate. These strategies included extensive meetings and networking with Indigenous disability services and community elders. The information gathered came from the principal carer and was not multi-informant, such as also obtaining information from a clinical assessment. However, the DBC has good inter-rater reliability and concurrent validity against other carer completed questionnaires and clinical assessments (Einfeld & Tonge, 2002).

Due to the widespread and mobile nature of the Indigenous population in the areas surveyed, extensive travelling was undertaken to make direct contact with all

participants on the client registers, wherever they lived in South Australia or the Northern Territory.

6.6.2 EXCLUSION OF RELATED CONDITIONS IN SAMPLE GROUP

As discussed above, this research involved using an administrative sample and may not have captured all Indigenous adults with intellectual disability in the catchment area. Every effort was made to remove individuals from the participant list if they were not eligible to receive intellectual disability services, or it could not be confirmed that they had an intellectual disability as their primary disability. In the course of doing this, people were removed from the list if they had a related condition such as Aspergers disorder, or an acquired brain injury, for example as a result of substance abuse, without a confirmed pre-existing intellectual disability (i.e. assessed as occurring before the age of 18 years). The support needs of people with related conditions may be similar to those with intellectual disability (and in many cases, individuals were being supported by the same Case Manager and service), however these individuals were not invited to participate in this study as they did not meet the requirements of having intellectual disability. The number of potential participants, particularly in the remote communities, would have been substantially higher if these groups had been included in the project.

Conditions such as Acquired or Traumatic Brain Injury (ABI or TBI) and the effects of substance abuse, have a debilitating effect on individuals, families and communities. Further research is urgently required into these conditions in Indigenous communities in order to better understand how to effectively respond to and support the individuals and communities affected. This may provide a better picture of the

prevalence and nature of psychopathology among Indigenous people with disabilities. In addition FAS is becoming a prominent issue and cause of intellectual disability within some Indigenous communities and requires urgent evidence based responses. It is possible that the DBC-A could be modified to create new screening factors and trialled in future studies for these conditions, and help screen for conditions such as FAS.

6.6.3 REPRESENTATIVENESS OF SAMPLE

As discussed previously, this sample consisted of only those who were registered as clients of the South Australian and Northern Territory intellectual disability services, not all Indigenous adults with intellectual disability may be listed on these registers. However, the agencies involved in the project provide their services across all of South Australia and the Northern Territory, with offices spread throughout all service regions. They both have admission and eligibility procedures applied by professionals who are experienced in assessing and diagnosing intellectual disability and are constantly working collaboratively with other service areas such as hospitals, community clinics, and the education system in order to identify any individual who may be eligible for intellectual disability services. This strong administrative sample, together with a high participation rate of 81% has provided this project with a sample that is much larger and therefore likely to be more representative than most studies investigating Indigenous populations.

The Indigenous sample was much younger than the non-Indigenous sample and it is possible that it is over-representative of younger people with intellectual disability. However, the age profile of the Indigenous participants matched closely with national population statistics which show that the Indigenous population is generally younger.

Lastly, there were a small number of Indigenous clients on the respective client registers who were unable to be located, probably because they had moved and lost contact with the disability support system. Future research may benefit from being able to also access other databases, such as Centrelink's Disability Support Pension (DSP) client register in order to locate those people.

6.6.4 SUMMARY AND CONCLUSIONS

The Lifespan project described the population of Indigenous adults with intellectual disability living in South Australia and the lower half of the Northern Territory and investigated their psychopathology. The major findings are higher levels of clinically significant mental health problems in Indigenous adults with intellectual disability compared to the non-Indigenous population of adults in South Australia. Further, these levels of mental health problems decrease over the lifespan for both Indigenous and non-Indigenous participants and increase the further people lived from major cities. There is double the rate of stressful Life Events among the Indigenous participants compared to the non-Indigenous participants, which in turn contributes to higher levels of caseness within this group. Similar patterns of substance abuse were found within the Indigenous participant group as is found within the broader Indigenous population.

The study also explored the support needs of Indigenous people with intellectual disability and their carers and found that traditional understandings and perceptions of intellectual disability and mental health problems continue to influence the way Indigenous people understand these concepts today.

Indigenous people with intellectual disability and/or mental health problems can experience similar stigma and marginalisation from their community as occurs in the broader Australian population. However, the project found that Indigenous carers and

family members are less likely to seek help on behalf of the Indigenous adult with intellectual disability.

This project recognises that the achievement of optimal individual outcomes for Indigenous people with intellectual disability depends on a strong evidence base, for example, the higher prevalence of mental health problems within this population compared to non-Indigenous adults with intellectual disability. However, at present, scientific knowledge about intellectual disability and psychopathology among Indigenous adults with intellectual disability is very limited but this project has added to this knowledge particularly describing and expanding understanding of the unique support needs of Indigenous adults with intellectual disability and their carers. Greater understanding has been achieved of the incidence and prevalence of psychopathology within this group and an improved understanding of the specific conditions, for example, the higher levels of depression and antisocial behaviour evident on the DBC-A subscales and higher levels of suicide ideation of the Indigenous participants, compared to the non-Indigenous participants. The findings are relevant to clinical and community services. Services should be both culturally safe and respectful and should incorporate Indigenous specific services, including community controlled services. For example, the findings suggest that carers of Indigenous adults with intellectual disability would prefer for the person with intellectual disability to be cared for within their community in services run by, or at least employing Indigenous people, rather than placed in accommodation services a long way from home and staffed exclusively by non-Indigenous employees.

Indigenous people face unique issues in terms of their wellbeing, and experience relatively higher rates of psychopathology than other Australians. Issues surrounding

mental illness and intellectual disability pose significant challenges in Indigenous communities, but they are also seen to be 'private business'.

Communities are trying their best to deal with relatively new concepts of western health without necessarily having a common understanding of, and language for the terms and concepts being used by western services and systems. For example the study found that many Indigenous people hold spiritual beliefs about the causation of mental health problems and intellectual disability. Further, while there are unique words in the various Indigenous languages to describe intellectual disability and mental illness, this research found that there was limited understanding of the differences between intellectual disability and mental illness.

Traditional culture and social laws continue to play an important role in contemporary Indigenous communities today and help foster the tremendous resilience demonstrated by Indigenous people in the face of unimaginable cultural destruction over the years since colonisation. Communities struggle with the ongoing burdens of dealing with dispossession from country, the trans-generational effects of grief and loss, the separation of families and children and the continual undermining of cultural and social traditions. For example the study found that the number of Indigenous people with intellectual disability not living with their biological parents was higher compared to the non-Indigenous participants and many of these people had been placed into foster arrangements with Indigenous and non-Indigenous families.

The findings in this study suggest that there are likely to be higher rates of depression for Indigenous adults with intellectual disability compared to non-Indigenous adults with intellectual disability, and reported that there was a common feeling in the community that the high level of alcohol, drugs and other substances were related to this.

There are appalling conditions of poverty, chronic health issues and high mortality rates, and poor access, particularly in remote areas, to adequate health services, housing and employment opportunities. The issues faced on a daily basis in relation to poverty, unemployment, suicide and dealing with illnesses such as diabetes, substance abuse, Fetal Alcohol Syndrome and other health disorders can overwhelm people with intellectual disability and their carers. It is essential that intellectual disability and mental health problems are acknowledged as a priority in planning services and a response to the issues that face Indigenous people today.

Similar problems are seen across many Indigenous groups throughout the world, where higher disability and mental illness rates prevail among similar socio-economic conditions and cultural challenges.

Despite the range of practical difficulties associated with the development of a better understanding of the mental health of Indigenous people with intellectual disability, this study demonstrated that the use of a culturally acceptable carer-completed questionnaire is feasible. Further research is required to gain a clearer insight into the nature of psychopathology in this population and improve our understanding and appreciation of disability support issues in order to accelerate the planning and implementation of suitable prevention and intervention strategies. Given the higher rates of intellectual disability and psychopathology among Indigenous Australians, this should be undertaken as a matter of priority. The findings from this research may also be useful for providing a greater understanding of issues related to mental health and intellectual disability and the delivery of better support services within other Indigenous and marginalised populations worldwide.

Indigenous people have distinctive rights to status and culture, self-determination and the land which is fundamental to their ongoing well-being. Closing the gap on

disadvantage and improving the mental well-being of Indigenous people in Australia will only be achieved if there is a mutual resolve to provide effective evidence based support and services that are respectful, culturally competent, flexible and responsive to the unique and changing needs of Indigenous Australians, the original inhabitants and custodians of this great land.

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APPENDICES

Appendix A. Lifespan Questionnaire booklet (incl.

Developmental Behaviour Checklist for Adults (DBC-A) &

Adaptive Behavior Assessment System – II (ABAS-II))

DBC-A

LifeSpan

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

Questionnaire Booklet

Thank you for agreeing to participate in this research. The *LifeSpan Project* is jointly being undertaken by the Centre for Developmental Psychiatry & Psychology, Monash University, Melbourne. In SA, the research partners are Disability Services SA, Minda Inc and Dept for Education and Children's Services, (DECS).

The results from the study will give us extremely valuable information for planning better services in the future for people who have both an intellectual disability and mental health problems. The research team needs as many people as possible to complete the survey.

To do so, please complete the questionnaire and return it in the reply paid envelope. It would be very helpful if you could do this as soon as possible.

Any information about your son/daughter or person for whom you are the guardian will remain confidential. The results of the study will be reported in such a way that it is not possible to identify any individual, and information about your son/daughter or person for whom you are the guardian will not be disclosed to anyone else without your written approval.

We will safeguard the confidentiality of all files. The questionnaires will be stored in a locked filing cabinet for fifteen years after the completion of the study, and then disposed of by shredding and file deletion. The research staff directly involved with data collection, are the only people who have access to these files. You may access the file containing information collected about your son/daughter or person for whom you are the guardian by contacting Professor Tonge on 03 9594 1354.

Please note that participation in this project is voluntary and you can withdraw from the study at any time. Whether you take part or not, it will not make any difference to the medical care or other professional services which your son/daughter or person for whom you are the guardian, yourself or your family receive.

Information regarding your involvement is attached. If you have any queries please contact Ann Rymill, *LifeSpan Project* Manager on 8348 6500 or the individual's case manager or support worker.

Part A

1A   Name of person with an intellectual disability (ID):

First name:	Family name:

2A   Date of Birth: _____   **Age:** _____

3A   Gender: Male ☐ 0   **Female** ☐ 1

4A   Is the person with ID an Aboriginal/Torres Strait Islander?

No ☐ 0   **Yes** ☐ 1

5A   Is the person with ID from a Non English speaking background?
No ☐ 0   **Yes** ☐ 1

Please specify _____

6A   Please identify the *primary* service provider for the person with ID:

Disability Services SA ☐ 1

Minda Incorporated ☐ 2

Dept of Education and Children's Services ☐ 3

Other (Please specify) ☐ 4

7A   Relationship of person completing questionnaire to the person with ID:

Mother ☐ 1

Father ☐ 2

Grandparent ☐ 3

Foster parent ☐ 4

Paid carer ☐ 5

Other *(please specify)* ☐ 6 _____

8A **Has the person had an formal IQ (intelligence) test?**   No ☐ 0   Yes ☐ 1   Don't know ☐ 2

9A If *Yes*, is the disability level.   ☐ 1 Mild   ☐ 2 Mod   ☐ 3 Severe/Pro   ☐ 4 Don't know

9B Has the person's IQ been estimated?   No ☐ 0   Yes ☐ 1   Don't know ☐ 2

9C If *Yes*, please indicate the profession of the person doing the estimation.   ☐

10A **Is the cause of the person's ID known?**   No ☐ 0   Yes ☐ 1   Don't know ☐ 2

11A If *Yes*, please describe
(eg Down syndrome, Fragile X, Autism etc)   ☐

		No	Somewhat	Yes
12A	**Is he/she able to see if wearing glasses?**	☐ 0	☐ 1	☐ 2
13A	**Is he/she able to hear?**	☐ 0	☐ 1	☐ 2
14A	**Is he/she able to use their arms to carry out day to day tasks?**	☐ 0	☐ 1	☐ 2
15A	**Is he/she able to use their legs to walk stand or mobilise?**	☐ 0	☐ 1	☐ 2
16A	**Is he/she able to speak?**	☐ 0	☐ 1	☐ 2

17A Does he/she use any of the following to communicate with others?
        (Tick all that apply)

Gestures   ☐ 1

Sign (e.g. Makaton)   ☐ 2

Assisted communication
(e.g. compic, photo system)   ☐ 3

Other *(please specify)*   ☐ 4   ☐

None of the above   ☐ 5

	Not at all well	Fairly well	Very Well

18A How well can other people understand what he/she communicates?
　　0　　　　1　　　　2

19A How well can the person understand what others say to him/her?
　　0　　　　1　　　　2

	No	Yes	Don't know

20A Does the person have any chronic medical/health problems?
　　0　　　　1　　　　2

21A If Yes, please describe (eg Diabetes, Epilepsy, Asthma, Thyroid, Heart etc)

22A Have you sought help for any behavioural or emotional problems for this person over the past six months?

No　☐　0 ⟶ Go to Q 27A

Yes　☐　1 ⟶ Go to Q 23A

23A From whom did you seek professional help for these behavioural and emotional problems? *(Tick __all__ that apply)*

Psychologist ☐ 1

Psychiatrist ☐ 2

Paediatrician ☐ 3

Community Mental Health Nurse ☐ 4

Caseworker/Developmental Educator ☐ 5

General Practitioner ☐ 6

Other *(please specify)* ☐ 7

Other – occupation not known ☐ 8

24A Does the person take any medication for these emotional/behavioural problems?
　　No　　Yes
　　0　　1

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25A **Has the person been admitted hospital for these emotional/ behavioural problems?**

No	Yes
☐	☐
0	1

26A **If *Yes*, was the person detained under the Mental Health Act?**

No	Yes
☐	☐
0	1

27A **Does the person have a *diagnosed* mental Illness?** *(eg depression, anxiety, schizophrenia, bipolar disorder, obsessive compulsive disorder)*

No	Yes
☐	☐
0	1

If *Yes*, please describe

☐

28A **Where does the person live now? (Tick *one* only)**

- ☐ 1 At home with both parents
- ☐ 2 At home with sole parent
- ☐ 3 Living with other relatives
- ☐ 4 Living with foster parents
- ☐ 5 Living in own home or unit
- ☐ 6 Living in Group Home (6 or less people)
- ☐ 7 Living in a supported residential facility
- ☐ 8 Large Residential Care facility (more than 6 people)
- ☐ 9 Aged care nursing home
- ☐ 10 Aged care hostel/unit
- ☐ 11 Living with spouse / partner
- ☐ 12 Living with friend(s)
- ☐ 13 No fixed address
- ☐ 14 Other *(describe below)*

☐

29A **If the person has moved in the last 12 months where was the previous residence (Tick *one* only)**

- ☐ 1 At home with both parents
- ☐ 2 At home with sole parent
- ☐ 3 Living with other relatives
- ☐ 4 Living with foster parents
- ☐ 5 Living in own home or unit
- ☐ 6 Living in Group Home (6 or less people)
- ☐ 7 Living in a supported residential facility
- ☐ 8 Large Residential Care facility (more than 6 people)
- ☐ 9 Aged care nursing home
- ☐ 10 Aged care hostel/unit
- ☐ 11 Living with spouse / partner
- ☐ 12 Living with friend(s)
- ☐ 13 No fixed address
- ☐ 14 Other *(describe below)*

☐

30A

What are his/her <u>usual</u> daytime activities now? *(Tick <u>all</u> that apply)*

Mainstream school class ☐

Special unit in a mainstream school ☐ 2

Special School ☐ 3

Other study, e.g. TAFE ☐ 4

Day activity/retirement programme ☐ 5

Supported workshop/employment ☐ 6

Working in open employment or Community development Employment programme ☐ 7

Home duties ☐ 8

No Organised daytime activity ☐ 9

Other (please describe) ☐ 10

☐

31A　How many hours per week does he/she spend in all of the activities ticked in Q30A combined? *(Tick <u>one</u> only)*

Less than 10 hours ☐ 1

10 - 20 hours ☐ 2

More than 20 hours ☐ 3

32A　What is his/her <u>main</u> daytime activity? *(Tick <u>one</u> only)?*

In a mainstream school class ☐ 1

Special unit in a mainstream school ☐ 2

In a Special School ☐ 3

Other study, e.g. TAFE ☐ 4

Day activity/retirement programme ☐ 5

Supported workshop/employment ☐ 6

Working in open employment or Community Development Employment Programme ☐ 7

No organised daytime activity ☐ 8

Other *(please describe)* ☐ 9

☐

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33A Does the person choose to mix with other people? *(Tick __one__ only)*

Not at all ☐ 0

A little ☐ 1

A lot ☐ 2

34A Where does he/she mix with other people? *(Tick __all__ that apply)*

At home – with the family ☐ 1

School / workplace ☐ 2

Visits to other families ☐ 3

Clubs, e.g. sports, church, social ☐ 4

Outings, e.g. going to movies ☐ 5

Neighbourhood, e.g shops, TAB, park café, pub ☐ 6

Internet ☐ 7

Other *(please describe)* ☐ 8

☐

35A Who does he/she have a close relationship with? *(Tick all that apply)*

Nobody in particular ☐ 0

Family member ☐ 1

Neighbourhood friend ☐ 2

School friend/workmate ☐ 3

Co-resident of group home ☐ 4

Sports, church or social club member ☐ 5

Volunteer / advocate ☐ 6

Boyfriend / girlfriend / partner / spouse ☐ 7

Staff member / case worker / other professional ☐ 8

Virtual relationships - telephone or internet only ☐ 9

Nobody in particular ☐ 10

Other *(please describe)* ☐ 11

☐

36A What does the person do best?

☐

37A What do other people like about him/her?

☐

38A What are his/her favourite activities?

☐

39A Is there anything you feel the person does as well as/better than others?

☐

40A **Have any of the following occurred in his/her life over the past year? If the event has occurred, tick YES and indicate how stressful you think the event was for the person.**

		No	Yes		Little Stress	Moderate Stress	A lot of Stress
1	Serious illness/ hospitalisation	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
2	Bereavement e.g. death of close relative or friend	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
3	Separation from parents or main carers	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
	If yes, for how long was the separation? ☐ mths						
4	Victim of crime/assault	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
5	Accident	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
6	Trouble with the police or courts/spent time in prison	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
7	Divorce or separation	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
8	Problems/changes in the family	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
9	Problems/changes in the household	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
10	Moved to new residence	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
11	Financial difficulty	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
12	Pregnancy/Parenthood	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
13	Began new job or entered new school	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
14	Having trouble with superiors at work or teachers at school	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
15	Moved from/lost contact with cultural/community group	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
16	Transition – school, work, unemployment, retirement	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3
17	Substance abuse	☐ 0	☐ 1	→	☐ 1	☐ 2	☐ 3

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	No	Yes		Little Stress	Moderate Stress	A lot of Stress
18 Any other major event *(please describe)*	☐	☐ →		☐	☐	☐
		1		1	2	3

(Please Describe)

19 Any other life event currently impacting on the person

(Please Describe)

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41A What is the year of birth or age range of the person's mother?

19 _____   Don't Know ☐ 0   *OR*

Age Range

Less than 30 ☐ 1   31-45 ☐ 2   46-60 ☐ 3   61-75 ☐ 4   Greater than 75 ☐ 5

Deceased ☐ 6

42A What is the year of birth or age range of the person's father?

19 _____   Don't Know ☐ 0   *OR*

Age Range

Less than 30 ☐ 1   31-45 ☐ 2   46-60 ☐ 3   61-75 ☐ 4   Greater than 75 ☐ 5

Deceased ☐ 6

Many of the following behaviours may not apply to the person in your care. For each item that does describe the person in your care, now or within the past six months, please circle the **2** if the item is **very true** or **often true**.   Circle **1** if the item is **somewhat or sometimes true** of the person. If the item is **not true** of the person circle the **0**.

0 = not true as far as you know   1 = somewhat or sometimes true   2 = very true or often true

If the person is unable to perform an item, circle the **0**. For example, if he/she has no speech, then for the item "Talks too much or too fast" circle the **0**

Office Use Only				**Please Circle**
1①⑥	0	1	2	Appears depressed, downcast or unhappy.
2	0	1	2	Avoids eye contact. Won't look you straight in the eye.
3③	0	1	2	Aloof, in her/his own world.
4①	0	1	2	Abusive. Swears at others.
5③	0	1	2	Arranges objects or routine in a strict order. Please describe: ....
6②	0	1	2	Bangs head.
7②①	0	1	2	Becomes over-excited.
8②	0	1	2	Bites others.
9	0	1	2	Bizarre speech. Please describe: ....
10	0	1	2	Cannot attend to one activity for any length of time, poor attention span.
11②	0	1	2	Chews or mouths objects, or body parts.
12①	0	1	2	Cries easily for no reason, or over small upsets.
13	0	1	2	Covers ears or is distressed when hears particular sounds. Please describe: ....
14③	0	1	2	Confuses the use of pronouns, eg uses "you" instead of "I".
15	0	1	2	Deliberately runs away.
16	0	1	2	Delusions: has a firmly held belief or idea that can't possibly be true. Please describe: ....
17	0	1	2	Distressed about being alone.
18	0	1	2	Doesn't show affection.
19②	0	1	2	Doesn't respond to others' feelings, eg shows no response if a close friend or family member is crying.
20③	0	1	2	Easily distracted from his/her task, eg by noises.
21③	0	1	2	Easily led into trouble by others.
22②	0	1	2	Eats non-food items, eg dirt, grass, soap.
23	0	1	2	Excessively distressed if separated from a familiar person.
24	0	1	2	Fears particular things or situations, eg the dark, insects or crowds. Please describe: ....
25②	0	1	2	Facial twitches or grimaces.
26③	0	1	2	Flicks, taps, twirls objects repeatedly.
27	0	1	2	Fussy eater or has food fads.
28②	0	1	2	Gorges food. Will do anything to get food, eg takes food out of garbage bins or steals food.
29	0	1	2	Gets obsessed with an idea or activity. Please describe: ……………………………………………
30②	0	1	2	Grinds teeth.
31⑥	0	1	2	Has become confused or forgetful.
32⑥	0	1	2	Has become more withdrawn.
33④	0	1	2	Has nightmares, night terrors or walks in sleep.
34①	0	1	2	Has temper tantrums, eg stamps feet, slams doors.
35④	0	1	2	Hides things.

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0 = not true as far as you know   1 = somewhat or sometimes true   2 = very true or often true

OfficeUse Only	Please Circle			
36	0	1	2	Hits, bites or injures self.
37②	0	1	2	Hums, whines, grunts, squeals or makes other non-speech noises.
38①	0	1	2	Impatient.
39④	0	1	2	Inappropriate sexual activity with another.
40	0	1	2	Increase in appetite.
41	0	1	2	Impulsive, acts before thinking.
42①	0	1	2	Irritable.
43①	0	1	2	Jealous.
44	0	1	2	Kicks, hits or injures others.
45	0	1	2	Lacks self-confidence, poor self-esteem.
46②	0	1	2	Laughs or giggles for no obvious reason.
47④	0	1	2	Lights fires.
48②	0	1	2	Likes to hold or play with an unusual object, eg string, twigs; overly fascinated with something, eg water. Please describe: ....
49⑥	0	1	2	Loss of appetite.
50⑥	0	1	2	Loss of enjoyment or interest in usual activities.
51⑥	0	1	2	Loss of self-care skills.
52④	0	1	2	Makes gloomy statements.
53④	0	1	2	Masturbates, or exposes self, in public.
54⑥	0	1	2	Mood changes rapidly for no apparent reason.
55⑥	0	1	2	Moves slowly, underactive, does little, eg only sits and watches others.
56②	0	1	2	Noisy or boisterous.
57⑥	0	1	2	Not communicating as much as usual.
58②③	0	1	2	Overactive, restless, unable to sit still.
59③	0	1	2	Overaffectionate.
60	0	1	2	Overbreathes, vomits, has headaches or complains of being sick for no physical reason.
61①	0	1	2	Overly attention-seeking.
62	0	1	2	Overly interested in looking at, listening to or dismantling mechanical things, eg lawnmower, vacuum cleaner.
63④	0	1	2	Panics. Sweats, flushes, trembles.
64④*	0	1	2	Poor sense of danger.
65⑤	0	1	2	Prefers to do things on his/her own. Tends to be a loner.
66	0	1	2	Preoccupied with only one or two particular interests. Please describe: ....
67	0	1	2	Problems with cigarettes, alcohol or caffeine.
68	0	1	2	Problems with the illegal use of drugs.
69①	0	1	2	Refuses to go to college, activity centre or workplace.
70②	0	1	2	Repeated movements of hands, body, head or face, eg handflapping or rocking.
71⑤	0	1	2	Resists being cuddled, touched or held by close friends or family.
72③	0	1	2	Repeats back what others say like an echo.
73	0	1	2	Repeats the same word or phrase over and over.
74②	0	1	2	Smells, tastes, or licks objects.

LifeSpan Project   *Confidential 2006*

0 = not true as far as you know   1 = somewhat or sometimes true   2 = very true or often true

OfficeUse Only	Please Circle	
75②	0 1 2	Scratches or picks her/his skin.
76	0 1 2	Screams a lot.
77	0 1 2	Sleeps too little. Disrupted sleep.
78②	0 1 2	Stares at lights or spinning objects.
79	0 1 2	Sleeps too much or overly drowsy.
80②	0 1 2	Soils outside toilet though toilet trained. Smears or plays with faeces.
81	0 1 2	Speaks in whispers, high pitched voice, or other unusual tone or rhythm.
82②	0 1 2	Spits.
83②	0 1 2	Switches lights on and off, pours water over and over; or similar repetitive activity. Please describe: ....
84④	0 1 2	Steals.
85①	0 1 2	Stubborn, disobedient or unco-operative.
86③	0 1 2	Shy.
87②	0 1 2	Strips off clothes or throws away clothes.
8③	0 1 2	Says he/she can do things that he/she is not capable of.
89③	0 1 2	Stands too close to others.
90③	0 1 2	Sees, hears, something which isn't there. Hallucinations. Please describe: ....
91	0 1 2	Talks about or attempts suicide.
92③	0 1 2	Talks too much or too fast.
93③	0 1 2	Talks to self or imaginary people or objects.
94②*③	0 1 2	Tells lies.
95③	0 1 2	Thoughts are unconnected. Different ideas are jumbled together with meaning difficult to follow.
96①	0 1 2	Tense, anxious, worried.
97①	0 1 2	Throws or breaks objects.
98①	0 1 2	Tries to manipulate or provoke others.
99	0 1 2	Underreacts to pain.
100	0 1 2	Unrealistically happy or elated.
101	0 1 2	Unusual body movements, posture, or way of walking. Please describe: ....
102①⑤	0 1 2	Upset and distressed over small changes in routine or environment. Please describe: ....
103②	0 1 2	Urinates outside toilet, although toilet trained.
104①	0 1 2	Very bossy.
105	0 1 2	Wanders aimlessly.
106①	0 1 2	Whines or complains a lot.
		Please write in any problems she/he has that were not listed above.
	0 1 2	....
	0 1 2	....
107	0 1 2	Overall, do you feel the person has problems with feelings or behaviour, in addition to problems with development? If not, please circle the 0. If so, but they're minor, please circle the 1. If they're major problems, please circle the 2.

Please be sure you have answered all items

Are there any other comments you would like to make?

....

....

You have now completed the DBC-A.

The final part of the questionnaire is the completion of the ABAS-II.

You will note the ABAS-II has a different scoring method than the DBC-A and is more detailed.
.
To assist you with the scoring there is a loose sheet containing the rating scale which can be easily used as you work through the questionnaire sections.

ABAS–II ADULT (Ages 16–89))

The following table is provided to further assist you in filling out this form.

Rating	The individual:
0 Is Not Able	• cannot perform the behavior; • is too young to have tried the behavior; or • has a physical condition that prevents the behavior.
1 Never or Almost Never When Needed	**has the ability to perform the behavior, but** • never or almost never does it when needed; or • never or almost never does it on his/her own without being reminded.
2 Sometimes When Needed	**has the ability to perform the behavior, and** • only does it sometimes when needed; • sometimes does it without help, but sometimes needs help; or • sometimes does it on his/her own, but sometimes needs to be reminded.
3 Always or Almost Always When Needed	**has the ability to perform the behavior, and** • displays the behavior most or all of the time without being reminded; or • displayed the behavior at a younger age, but has now outgrown it.

Column	Check this column if:
Check If You Guessed	• your rating was an estimate. • you have never seen the individual in a situation in which the behavior is needed. • the individual has not had the opportunity to perform the behavior.
Comments	• you do not understand an item.* • you feel it would be helpful to discuss an item with the assessment professional.*

* You may make a brief note of your concerns in the Notes box on page 10 of this Rating Form.

Communication	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1. Says the names of other people, for example, "Mama," "Daddy," or friends' names.	0	1	2	3	☐	○
2. Says "Hello" and "Good-bye" to others.	0	1	2	3	☐	○
3. States his/her own telephone number.	0	1	2	3	☐	○
4. Uses sentences with a noun and a verb.	0	1	2	3	☐	○
5. States home address, including zip code.	0	1	2	3	☐	○
6. Answers the telephone appropriately.	0	1	2	3	☐	○
7. Names 20 or more familiar objects.	0	1	2	3	☐	○
8. Places local telephone calls.	0	1	2	3	☐	○
9. Speaks clearly and distinctly.	0	1	2	3	☐	○
10. Gives verbal instructions that involve two or more steps or activities.	0	1	2	3	☐	○
11. Looks at others' faces when they are talking.	0	1	2	3	☐	○
12. Shakes head or says "yes" or "no" in response to a simple question, for example, "Do you want something to drink?"	0	1	2	3	☐	○
13. Ends conversations appropriately.	0	1	2	3	☐	○
14. Tells parents, friends, or others about his/her favorite activities.	0	1	2	3	☐	○
15. Says irregular plural nouns, for example, *knives* or *mice*.	0	1	2	3	☐	○
16. Listens closely for at least five minutes when people talk.	0	1	2	3	☐	○

continued

ABAS–II ADULT (Ages 16–89)

Communication *continued*	Is Not Able	BEHAVIOR FREQUENCY			Check If You Guessed	Comments
		Never When Needed	Sometimes When Needed	Always When Needed		
17. Pays attention during family or group discussions for as long as needed.	0	1	2	3	☐	○
18. Nods or smiles to encourage others when they are talking.	0	1	2	3	☐	○
19. Uses up-to-date information to discuss current events.	0	1	2	3	☐	○
20. Starts conversations on topics of interest to others.	0	1	2	3	☐	○
21. Repeats stories or jokes after hearing them from others.	0	1	2	3	☐	○
22. Waits for a pause in a conversation before expressing his/her own ideas.	0	1	2	3	☐	○
23. Answers complex questions that require careful thoughts and opinions, for example, questions about politics or current events.	0	1	2	3	☐	○
24. Talks about realistic future educational or career goals.	0	1	2	3	☐	○
25. Takes turns talking during conversations with people (is not too talkative or too quiet).	0	1	2	3	☐	○

	Total	/75	Total Guessed

Community Use

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1. Orders his/her own meals when eating out.	0	1	2	3	☐	○
2. Finds the restrooms in public places.	0	1	2	3	☐	○
3. Looks both ways before crossing a street or parking lot.	0	1	2	3	☐	○
4. Carries enough money to make small purchases, for example, a soft drink.	0	1	2	3	☐	○
5. Carries personal identification when traveling to nearby places in the community.	0	1	2	3	☐	○
6. Finds a specific department in a store or business, for example, customer service department in a bank or laundry supplies in a store.	0	1	2	3	☐	○
7. Relies on himself/herself for travel in the community, for example, walks or uses public transportation, a bicycle, or a car.	0	1	2	3	☐	○
8. Packs his/her own clothing and supplies for overnight trips.	0	1	2	3	☐	○
9. Mails letters at the postal box or local post office.	0	1	2	3	☐	○
10. States general address of a travel destination, for example, "On Washington Avenue, near Lake Street."	0	1	2	3	☐	○
11. Follows another's directions to nearby places.	0	1	2	3	☐	○
12. Finds and uses a pay phone.	0	1	2	3	☐	○
13. Asks store clerk for help if an item cannot be found.	0	1	2	3	☐	○
14. Tells others about a store's hours of operation, for example, "10 a.m. to 9 p.m."	0	1	2	3	☐	○
15. Walks alone to friends' houses in the neighborhood.	0	1	2	3	☐	○
16. Calls a doctor or hospital when ill or hurt.	0	1	2	3	☐	○
17. Calls to find out if a repair or order is ready.	0	1	2	3	☐	○
18. Calls a repairperson if, for example, the air conditioner or heater is not working.	0	1	2	3	☐	○
19. Takes other people on trips to nearby places, for example, takes a child or family member to a park.	0	1	2	3	☐	○
20. Asks other people's advice on where to shop.	0	1	2	3	☐	○
21. Shops for friends and family who may be unable to shop.	0	1	2	3	☐	○
22. Walks or rides bike alone to locations within a one-mile or five-block radius of home or work.	0	1	2	3	☐	○
23. Uses the local library to check out books, use reference materials, or for other purposes.	0	1	2	3	☐	○
24. Asks store clerk for product information before buying an item.	0	1	2	3	☐	○

	Total	/72	Total Guessed

ABAS–II ADULT (Ages 16–89)

Functional Academics

		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
			BEHAVIOR FREQUENCY				
1.	Writes his/her own first and last name.	0	1	2	3	☐	○
2.	Reads his/her own written name.	0	1	2	3	☐	○
3.	States the days of the week in order.	0	1	2	3	☐	○
4.	Tells time correctly, using a watch or a clock with hands.	0	1	2	3	☐	○
5.	Gives clerk the necessary amount of money when purchasing items.	0	1	2	3	☐	○
6.	Writes his/her own address, including zip code.	0	1	2	3	☐	○
7.	Reads and obeys common signs, for example, *Do Not Enter*, *Exit*, or *Stop*.	0	1	2	3	☐	○
8.	Reads menus at restaurants.	0	1	2	3	☐	○
9.	Finds somebody's telephone number in the phone book.	0	1	2	3	☐	○
10.	States time and day of favorite television shows.	0	1	2	3	☐	○
11.	Reads and follows a daily work or other type of schedule.	0	1	2	3	☐	○
12.	Locates important dates on a calendar, for example, birthdays or holidays.	0	1	2	3	☐	○
13.	Weighs himself/herself or other objects correctly using a scale.	0	1	2	3	☐	○
14.	Measures length and height.	0	1	2	3	☐	○
15.	Finds name and phone number in telephone book for repair service or business.	0	1	2	3	☐	○
16.	Checks for correct change after buying an item.	0	1	2	3	☐	○
17.	Follows a favorite interest or current event by reading newspapers, books, or other materials.	0	1	2	3	☐	○
18.	Keeps score when playing games.	0	1	2	3	☐	○
19.	Uses a dictionary or encyclopedia to find information.	0	1	2	3	☐	○
20.	Reads and follows instructions to assemble new purchases.	0	1	2	3	☐	○
21.	Writes letters, notes, or e-mails.	0	1	2	3	☐	○
22.	Makes reminder notes or lists.	0	1	2	3	☐	○
23.	Completes forms for businesses or services, for example, obtains a lease.	0	1	2	3	☐	○
24.	Reads important documents, for example, credit card applications or rental agreements.	0	1	2	3	☐	○
25.	Budgets money to cover expenses for at least one week.	0	1	2	3	☐	○
26.	Reads classified ads for purchases and services.	0	1	2	3	☐	○
27.	Balances checkbook.	0	1	2	3	☐	○

Total ___ / 81 Total Guessed

Home Living

		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1.	Operates a microwave oven.	0	1	2	3	☐	○
2.	Uses small electrical appliances, for example, a can opener or blender.	0	1	2	3	☐	○
3.	Cooks simple foods on a stove, for example, eggs or canned soup.	0	1	2	3	☐	○
4.	Makes simple meals that require no cooking, for example, sandwiches or salads.	0	1	2	3	☐	○
5.	Wipes up spills at home.	0	1	2	3	☐	○
6.	Places dirty clothes in the proper place, for example, a hamper or clothesbasket.	0	1	2	3	☐	○
7.	Wipes wet or dirty shoes before entering a building.	0	1	2	3	☐	○
8.	Washes dishes either by hand or by placing them in a dishwasher.	0	1	2	3	☐	○
9.	Uses a clothes dryer.	0	1	2	3	☐	○

continued

ABAS—II ADULT (Ages 16–89)

Home Living continued

		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed
10.	Uses a washing machine to wash clothes.	0	1	2	3	☐
11.	Assists in big clean-up projects at home or work, for example, spring cleaning or cleaning storage rooms.	0	1	2	3	☐
12.	Folds clean clothes.	0	1	2	3	☐
13.	Takes out trash when can is full.	0	1	2	3	☐
14.	Clears the table completely after a meal.	0	1	2	3	☐
15.	Makes his/her own bed.	0	1	2	3	☐
16.	Makes minor repairs to personal possessions, for example, bikes or clothes.	0	1	2	3	☐
17.	Puts things in their proper place when finished using them.	0	1	2	3	☐
18.	Sweeps floor.	0	1	2	3	☐
19.	Cleans room or living quarters regularly.	0	1	2	3	☐
20.	Cleans bathroom with proper cleaning supplies.	0	1	2	3	☐
21.	Mixes and cooks fairly complex foods on a stove or oven, for example, cake or brownies.	0	1	2	3	☐
22.	Dusts furniture until it is clean.	0	1	2	3	☐
23.	Follows a maintenance schedule for home or car, for example, changes the oil in the car or changes the air conditioning filter.	0	1	2	3	☐

Total   / 69   Total Guessed

Health and Safety

		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed
1.	Swallows liquid medicines if needed for illness.	0	1	2	3	☐
2.	Shows caution around hot or dangerous items.	0	1	2	3	☐
3.	Uses electrical outlets or sockets safely.	0	1	2	3	☐
4.	Goes to another place when too hot or too cold, for example, finds shade if too hot, goes indoors when too cold.	0	1	2	3	☐
5.	Carries breakable objects safely and carefully.	0	1	2	3	☐
6.	Follows general safety rules at home.	0	1	2	3	☐
7.	Follows safety rules for fire or weather alarms at home or work.	0	1	2	3	☐
8.	Follows general safety regulations at work or other public places.	0	1	2	3	☐
9.	Takes prescription medicines by himself/herself.	0	1	2	3	☐
10.	Cares for his/her minor injuries, for example, paper cuts, knee scrapes or nosebleeds.	0	1	2	3	☐
11.	Tests hot foods before eating them.	0	1	2	3	☐
12.	Carries scissors safely.	0	1	2	3	☐
13.	Follows safety rules at park or playground.	0	1	2	3	☐
14.	Buckles his/her seat belt in a car.	0	1	2	3	☐
15.	Obeys traffic signals when riding a bike or driving a car.	0	1	2	3	☐
16.	Buys over-the-counter medications when needed for illness.	0	1	2	3	☐
17.	Stores poisonous substances or dangerous objects out of the reach of children.	0	1	2	3	☐
18.	Helps children cross the street by taking their hands.	0	1	2	3	☐
19.	Takes temperature with a thermometer when feeling sick.	0	1	2	3	☐
20.	Plans meals in order to get necessary nutrition.	0	1	2	3	☐

Total   / 60   Total Guessed

ABAS-II ADULT (Ages 16–89)

Leisure

		Is Not Able	BEHAVIOR FREQUENCY			Check If You Guessed	Comments
			Never When Needed	Sometimes When Needed	Always When Needed		
1.	Waits for his/her turn in games and other fun activities.	0	1	2	3	☐	◯
2.	Selects television programs or videotapes to keep up with an area of interest, for example, sports, music, or nature.	0	1	2	3	☒	◯
3.	Follows the rules in games and other fun activities.	0	1	2	3	☐	◯
4.	Listens to music for fun and relaxation.	0	1	2	3	☒	◯
5.	Looks at pictures or reads books or magazines during free time.	0	1	2	3	☐	◯
6.	Invites others to join him/her in playing games and other fun activities.	0	1	2	3	☒	◯
7.	Attends fun activities at another's home.	0	1	2	3	☐	◯
8.	Plays with toys, games, or other fun items with other people.	0	1	2	3	☒	◯
9.	Tells others when he/she needs free time to relax alone.	0	1	2	3	☐	◯
10.	Attends fun community activities with others, for example, a movie or concert.	0	1	2	3	☒	◯
11.	Decides alone to participate with others playing a game or other group activity.	0	1	2	3	☐	◯
12.	Plans ahead for play or fun activities on free days or afternoons.	0	1	2	3	☒	◯
13.	Initiates games or selects TV programs liked by friends or family members.	0	1	2	3	☐	◯
14.	Participates in a specific fun activity on a routine basis, for example, listening to a certain type of music or playing a computer game.	0	1	2	3	☒	◯
15.	Plans ahead for leisure activities during work, school breaks, or vacations.	0	1	2	3	☐	◯
16.	Plays alone with toys, games, or other fun activities.	0	1	2	3	☒	◯
17.	Invites others home for a fun activity.	0	1	2	3	☐	◯
18.	Organizes a game or other fun activity for a group of friends without help from others.	0	1	2	3	☒	◯
19.	Tries a new activity to learn about something new.	0	1	2	3	☐	◯
20.	Has a hobby or creative activity that requires making or building something, for example, sewing, carpentry, or gardening.	0	1	2	3	☒	◯
21.	Reserves tickets in advance for activities, for example, concerts or sports events.	0	1	2	3	☐	◯
22.	Decides alone to join an organized group, for example, a club, sports team, or musical group.	0	1	2	3	☒	◯
23.	Participates in an organized program for a sport or hobby, for example, takes a music class or practices basketball.	0	1	2	3	☐	◯

Total ____/69 Total Guessed

Self-Care

		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1.	Puts shoes on correct feet.	0	1	2	3	☒	◯
2.	Blows and wipes nose with tissue or handkerchief.	0	1	2	3	☐	◯
3.	Buttons his/her own clothing.	0	1	2	3	☒	◯
4.	Dresses himself/herself.	0	1	2	3	☐	◯
5.	Uses restroom at home without help.	0	1	2	3	☒	◯
6.	Washes hands with soap.	0	1	2	3	☐	◯
7.	Uses a fork to eat solid food.	0	1	2	3	☒	◯
8.	Ties his/her own shoes.	0	1	2	3	☐	◯
9.	Combines hot and cold water for shower or bath.	0	1	2	3	☒	◯
10.	Closes and locks door before using public restrooms.	0	1	2	3	☐	◯

continued

Self-Care continued

	Is Not Able	BEHAVIOR FREQUENCY			Check If You Guessed
		Never When Needed	Sometimes When Needed	Always When Needed	
11. Uses public restroom alone.	0	1	2	3	☐
12. Washes his/her own hair.	0	1	2	3	☐
13. Fastens and straightens clothing before leaving restroom.	0	1	2	3	☐
14. Selects correct clothes for cold or warm days.	0	1	2	3	☐
15. Cleans or brushes himself/herself off if muddy or dirty.	0	1	2	3	☐
16. Brushes teeth before leaving for work or appointments.	0	1	2	3	☐
17. Bathes daily.	0	1	2	3	☐
18. Keeps hair neat during the day by brushing or combing.	0	1	2	3	☐
19. Cuts meats or other foods into bite size pieces.	0	1	2	3	☐
20. Cleans under fingernails.	0	1	2	3	☐
21. Gets out of bed on time by himself/herself.	0	1	2	3	☐
22. Cuts or files his/her own fingernails and toenails on a regular basis.	0	1	2	3	☐
23. Has pleasant breath.	0	1	2	3	☐
24. Washes and rinses sink after brushing teeth.	0	1	2	3	☐
25. Gets hair cut.	0	1	2	3	☐

Total /75 Total Guessed

Self-Direction

	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed
1. Keeps spending money in pocket, purse, or other safe place.	0	1	2	3	☐
2. Works independently and asks for help only when necessary.	0	1	2	3	☐
3. Works on one home activity for at least 15 minutes.	0	1	2	3	☐
4. Goes out alone in daytime.	0	1	2	3	☐
5. Avoids situations at home or in the neighborhood that are likely to result in trouble.	0	1	2	3	☐
6. Stops a fun activity, without complaints, when time is up.	0	1	2	3	☐
7. Personally calls work or other places if absent.	0	1	2	3	☐
8. Completes routine household tasks within a reasonable amount of time.	0	1	2	3	☐
9. Controls anger when another person breaks the rules in games and other fun activities.	0	1	2	3	☐
10. Refrains from telling a lie to escape punishment.	0	1	2	3	☐
11. Routinely arrives at places on time.	0	1	2	3	☐
12. Controls disappointment when a favorite activity is canceled.	0	1	2	3	☐
13. Controls temper when disagreeing with friends.	0	1	2	3	☐
14. Keeps working on hard tasks without becoming discouraged or quitting.	0	1	2	3	☐
15. Saves money to buy something special, for example, a birthday present or special clothes.	0	1	2	3	☐
16. Cancels fun activity if something more important comes up.	0	1	2	3	☐
17. Returns on time when requested to be back in one hour.	0	1	2	3	☐
18. When leaving home, informs others of destination and return time.	0	1	2	3	☐
19. Controls feelings when not getting his/her own way.	0	1	2	3	☐

ABAS–II ADULT (Ages 16–89)

Self-Direction continued

		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
20.	Puts work or school over leisure activities.	0	1	2	3	☐	○
21.	Plans ahead to allow enough time to complete big projects.	0	1	2	3	☐	○
22.	Makes plans for home projects in logical steps.	0	1	2	3	☐	○
23.	Gathers all supplies needed before beginning a cleaning or maintenance project at home.	0	1	2	3	☐	○
24.	Calls family or others when late.	0	1	2	3	☐	○
25.	Completes large home projects on time.	0	1	2	3	☐	○

Total ____ /75 Total Guessed

Social

|		Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed	Comments
1.	Says "Thank you" when given a gift.	0	1	2	3	☐	○
2.	Has one or more friends.	0	1	2	3	☐	○
3.	Laughs in response to funny comments or jokes.	0	1	2	3	☐	○
4.	Stands a comfortable distance from others during conversations (not too close).	0	1	2	3	☐	○
5.	Moves out of another person's way without being asked.	0	1	2	3	☐	○
6.	Offers assistance to others.	0	1	2	3	☐	○
7.	Congratulates others when something good happens to them.	0	1	2	3	☐	○
8.	Keeps a stable group of friends.	0	1	2	3	☐	○
9.	Seeks friendships with others in his/her age group.	0	1	2	3	☐	○
10.	Has good relationships with family members.	0	1	2	3	☐	○
11.	Shows sympathy for others when they are sad or upset.	0	1	2	3	☐	○
12.	Places reasonable demands on friends, for example, does not become upset when a friend goes out with another friend.	0	1	2	3	☐	○
13.	Offers guests food or beverages.	0	1	2	3	☐	○
14.	Shows good judgment in selecting friends.	0	1	2	3	☐	○
15.	Listens to friends or family members who need to talk about problems.	0	1	2	3	☐	○
16.	Offers to lend belongings to others, for example, clothes or tools.	0	1	2	3	☐	○
17.	Apologizes if he/she hurts the feelings of others.	0	1	2	3	☐	○
18.	Compliments others for good deeds or behavior, for example, honesty or kindness.	0	1	2	3	☐	○
19.	Tries to please others by doing something special or giving them a surprise.	0	1	2	3	☐	○
20.	States when others seem happy, sad, scared, or angry.	0	1	2	3	☐	○
21.	Refrains from saying something that might embarrass or hurt others.	0	1	2	3	☐	○
22.	Personally makes or buys gifts for family members on birthdays or major holidays.	0	1	2	3	☐	○
23.	Says when he/she feels happy, sad, scared, or angry.	0	1	2	3	☐	○

Total ____ /69 Total Guessed

ABAS—II ADULT (Ages 16–89)

Work

Complete the **Work** skill area if the individual being rated holds a part-time or full-time job.

	BEHAVIOR FREQUENCY				
	Is Not Able	Never When Needed	Sometimes When Needed	Always When Needed	Check If You Guessed
1. Respects the property and rights of other workers.	0	1	2	3	☐
2. Attends work regularly.	0	1	2	3	☐
3. Follows daily work schedule without reminders from supervisor.	0	1	2	3	☐
4. Behaves safely at work so that no one will be harmed.	0	1	2	3	☐
5. Performs tasks at work neatly.	0	1	2	3	☐
6. Cares properly for work supplies and equipment.	0	1	2	3	☐
7. Works faster on the job as needed, for example, to keep on schedule or meet a deadline.	0	1	2	3	☐
8. Cleans up area after completing work.	0	1	2	3	☐
9. Returns tools and other work-related items to their proper location after their use.	0	1	2	3	☐
10. Completes work assignments in required time limits.	0	1	2	3	☑
11. Starts back to work willingly after taking a break or lunch.	0	1	2	3	☐
12. Chooses work consistent with his/her own skills and abilities.	0	1	2	3	☐
13. Works quietly and does not disrupt or disturb the work of others.	0	1	2	3	☐
14. Changes from one job-related task to another without special instructions from supervisor.	0	1	2	3	☐
15. Checks his/her own work to determine if improvements are needed.	0	1	2	3	☐
16. Finds full-time or part-time jobs for himself/herself.	0	1	2	3	☐
17. Performs extra work on the job willingly.	0	1	2	3	☐
18. Asks for directions, as needed, before beginning work tasks.	0	1	2	3	☐
19. Keeps working quickly and accurately, even with loud noises or distractions.	0	1	2	3	☐
20. Follows supervisor's suggestions to improve work.	0	1	2	3	☐
21. Helps other workers with their work without interfering with his/her own work.	0	1	2	3	☐
22. Seeks help from supervisor, as needed, when work-related problems or questions arise.	0	1	2	3	☐
23. Shows positive attitude towards job.	0	1	2	3	☐
24. Lives on his/her own earnings.	0	1	2	3	☑

Total _____ / 72   Total Guessed

Notes:

ABAS II
Adaptive Behavior Assessment System®
SECOND EDITION
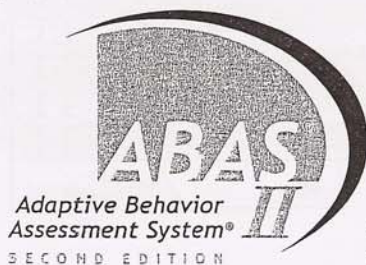
Patti L. Harrison
Thomas Oakland

Adult Form
Ages 16–89

Ⓟ **PsychCorp**™
To order, call 1-800-211-8378

Future Contact

To understand people's development over time, we may need to contact the parent/guardian again in the future. Therefore, it would be useful to have the name, address and contact number of several close family members or friends who could help us contact them, in case the parent or guardian have moved.

We would only make use of such contact information if we were unable to contact the parent /guardian personally, and we would not provide anyone with information about any member of the family that has been given to us as part of LifeSpan study.

Contact persons who would be able to get in touch with the parent/guardian if they have moved:

1   **Name**

Address

Telephone

2   **Name**

Address

Telephone

THANK YOU

THANK YOU FOR YOUR Time in completing this questionnaire. Your input is VALUABLE to THIS RESEARCH PROJECT.

Please return the completed questionnaire in the reply paid envelope.

Appendix B. Ethics approval – Monash Standing Committee on Ethics in Research Involving Humans

MONASH University

Standing Committee on Ethics in Research Involving Humans
Research Grants and Ethics Branch

16 December 2004

Prof Bruce Tonge
Department of Psychological Medicine
Monash Medical Centre

Dr Caroline Mohr
Department of Psychological Medicine
Monash Medical Centre

2004/977MC - Normative study of a checklist of emotional and behavioural disturbance in adults with intellectual disability

The above research project has been considered by the Standing Committee on Ethics in Research Involving Humans and approval has been given. This approval will be ratified at meeting A1/2005 on 1 February 2005. It is possible that issues may be raised by the Committee at that meeting. If you do not hear anything further you may assume that approval for the project is confirmed.

Terms of approval
1. This project is approved from 16 December 2004 to 15 September 2007 and this approval is only valid whilst you hold a position at Monash University.
2. It is the responsibility of the Chief Investigator to ensure that all information that is pending is forwarded to SCERH. You will then receive a letter from SCERH confirming that we have received a letter from each organisation.
3. It is the responsibility of the Chief Investigator to ensure that all investigators are aware of the terms of approval and to ensure the project is conducted as approved by SCERH.
4. You should notify SCERH immediately of any serious or unexpected adverse effects on participants or unforeseen events affecting the ethical acceptability of the project.
5. **Amendments to the approved project:** Changes to any aspect of the project require the submission of a Request for Amendment form to SCERH and must not begin without written approval from SCERH. Substantial variations may require a new application.
6. **Future correspondence:** Please quote the project number and project title above in any further correspondence.
7. **Annual reports:** Continued approval of this project is dependent on the submission of an Annual Report. Please provide the Committee with an Annual Report determined by the date of your letter of approval.
8. **Final report:** A Final Report should be provided at the conclusion of the project. SCERH should be notified if the project is discontinued before the expected date of completion.
9. **Monitoring:** Projects may be subject to an audit or any other form of monitoring by SCERH at any time.
10. **Retention and storage of data:** The Chief Investigator is responsible for the storage and retention of original data pertaining to a project for a minimum period of five years.

All forms can be accessed at our website www.monash.edu.au/resgrant/human-ethics

We wish you well with your research.

Dr Andrea Lines
Human Ethics Officer (on behalf of SCERH)

Appendix C. Ethics approval – South Australian Department of Health: Human Research Ethics Committee

Department of Health

Government
South Australia

STRATEGIC PLANNING
& RESEARCH

Citi Centre Building
11 Hindmarsh Square
Adelaide SA 5000

PO Box 287, Rundle Mall
Adelaide SA 5000
DX 243

www.health.sa.gov.au

T (08) 8226 6064
F (08) 8226 7088

www.health.sa.gov.au

ABN 976 433 565 90

Human Research Ethics Committee

Professor Bruce Tonge
Monash University's Centre for Developmental
Psychiatry and Psychology
Monash Medical Centre
246 Clayton Road
CLAYTON VICTORIA 3168

Dear Professor Tonge,

**Re: Normative study of a checklist of emotional and behavioural
disturbance in adults with intellectual disability.**

Thank you for responding to the issues raised by the Department of Health
Human Research Ethics Committee in relation to the above project.

I am pleased to inform you that the HREC have given ethics approval to your
project at its meeting on the 15th September 2004, subject to the following
conditions:

> Please forward details of your application to the Aboriginal Health
> Research Ethics Committee (AHREC) for approval. The Executive
> Officer can be contacted on (08) 8132 6700.

> In response to question one about collection of data from other
> sources, how will you protect against 'double dipping' as many adults
> with intellectual disability attend more than one organisation.

> The question in the DBC-A which asks participants to tick a box to
> identify their ethnicity, has answers which are a mixture of citizenship
> and ethnicity. This question needs to be modified so that people
> answering it are clear which box they need to tick.

> In the participant information sheet, paragraph 5 should be revised to
> state: *Sometimes we publish these results. If we publish the results of*

your questions, we will take your name out so that your name remains private.

➢ The third paragraph of the participant consent form could be simplified to state: *I also understand that whether or not I take part is up to me. I can withdraw at any stage of the project without being disadvantaged in any way.*

➢ The third sentence of the parent/guardian information sheet is quite complex. You may be able to say the same thing in a simplified way.

➢ It is not necessary to include the statement "Drugs are not used" in the last paragraph of the parent/guardian information sheet.

➢ In the confidentiality section of the parent/guardian information sheet, you state that *Project staff are required by law to report any situations of abuse or neglect.* The Committee would appreciate an indication as to why this statement is in the sheet. Members have questioned whether in fact it could be deleted.

➢ Will family members receive a copy of a written report regarding the outcomes of the clinical interview and the cognitive assessment?

A response to the above issues would be appreciated. Please forward this to Sarah Lawson, Executive Officer of the HREC, at your earliest convenience. The Committee would particularly like to see a copy of the revised plain language statements and consent forms.

Please note that ethics approval is also given subject to the following NHMRC conditions:

➢ The research being conducted in accordance with the 'National Statement on Ethical Conduct in Research Involving Humans.'

➢ Provision of a final report when the project is completed.

➢ Immediate notification to HREC of any adverse events involving participants.

➢ Immediate notification of any unforeseen events that might affect continued ethical acceptability of the project.

➢ Submission of any significant changes to the original proposal. Such changes should be approved by the HREC before they are implemented.

➢ Immediate advice, giving reasons, if the project is discontinued before its completion.

Approval is given for a period of three (3) years only, and if the research is more prolonged than this, a new submission will be required.

Should you have any questions or concerns, please contact Sarah Lawson, Executive Officer of the HREC, Tel 8226 6367 or E-mail sarah.lawson@dhs.sa.gov.au.

We wish you wish you all the best with the *"Normative study of a checklist of emotional and behavioural disturbance in adults with intellectual disability."* project.

Yours sincerely,
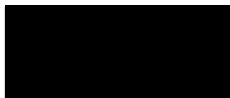
Professor Ian Olver
A/CHAIRPERSON
HUMAN RESEARCH ETHICS COMMITTEE

/09/2004

Appendix D. Ethics approval – South Australian Department of Education and Children's Services

Government of South Australia

Department of Education and
Children's Services

Office of Strategic
Policy & Planning
Education Centre
Level 8/31 Flinders
Street Adelaide 5000
South Australia

GPO Box 1152
Adelaide 5001
Tel: 8226 0119
Fax: 8226 8890

DECS CS/06/0108-2.7

07 September 2006

Professor Bruce Tonge
Locked Bag 29
Monash University
CLAYTON VIC 3800

Dear Professor Tonge

Thank you for your letter requesting approval for your project *"Investigating the Mental Health of People with Intellectual Disability across the Lifespan"*.

Your project has been reviewed by a senior DECS consultant with respect to protection from harm, informed consent, confidentiality and suitability of arrangements. Subsequently, I am pleased to advise you that after careful consideration your project has been **approved**.

Please find below some comments made by the reviewer for your information along with the reviewer's contact details in order for you to clarify any queries or comments made.

"DECS is a collaborative partner in this project: this application is fully supported."

Ms Debra Kay, Manager – Interagency Health Care, DECS. Ph: 8226 0974.

Please supply the department with an electronic copy of the final report, which will be circulated to interested staff and then made available to DECS educators for future reference.

I wish you well with your project.

Lexie Mincham
MANAGER, POLICY AND RESEARCH
INTER-GOVERNMENT RELATIONS

Appendix E. Ethics approval – Aboriginal Health Council of South Australia: Aboriginal Health Research Ethics Committee

ABORIGINAL HEALTH RESEARCH ETHICS COMMITTEE

Professor Bruce Tonge
Centre for Developmental Psychiatry & Psychology
Department of Child & Adolescent Psychiatry
Monash Medical Centre
246 Clayton Road
Clayton VIC
3168

3rd December 2004

Dear Bruce

Thank you for submitting your research project, Normative study of a checklist of emotional and behavioural disturbance in adults with intellectual disability, on the 24th November 2004 for ethical consideration.

At our last meeting your application was assessed and I am pleased to inform you that this proposal has met with support and that the committee has decided that your application be recommended.

In accordance with the NH&MRC guidelines, *National Statement on Ethical Conduct in Research Involving Humans*, we require at regular periods, at least annually, reports from principle researchers.

If you require any further information please do not hesitate to contact the Executive Officer or myself.

We wish you well with the project and look forward to receiving a copy of your report.

Sincerely yours
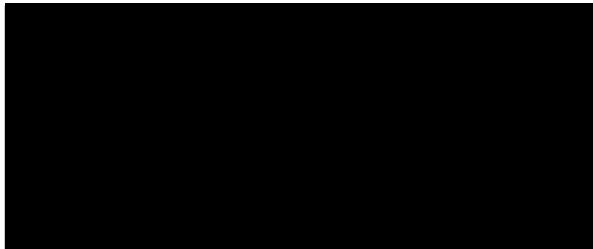
DR SUZI HUTCHINGS
CHAIRPERSON
Ref: Approval/Proposal/3December04

Aboriginal Health Council
of South Australia Inc.

AHREC is a sub-committee of AHCSA

78 Fullarton Road Norwood SA 5067   PO Box 787 Kent Town SA 5067
Tel: (08) 8132 6700 Fax: (08) 8132 6799 Email: alwin.chong@ahcsa.org.au Website: www.ahcsa.org.au

Appendix F. Amendment 1: Aboriginal Health Council of South Australia: Aboriginal Health Research Ethics Committee

LifeSpan

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

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

Dr Suzi Hutchins
Chairperson
Aboriginal Health Research Ethics Committee
PO Box 787
KENT TOWN
SA 5067

**Re: Normative study of a checklist of Emotional and Behavioural
Disturbance in Adults with an intellectual disability – Notice of Amendment**

Dear Suzi,

I am pleased to report that the research project is progressing well and receiving
positive support and participation from families of Indigenous people with an
intellectual disability.

Now that the data collection stage of the project is underway, I continue to seek
and receive valuable feedback from those involved in completing the
questionnaire on different aspects of their participation in the research.

A topic that has been mentioned numerous times is that of reimbursement for
families in recognition of the expenses incurred in completing the questionnaire.
I have discussed ways in which this may occur with the Lifespan research team,
my two Monash supervisors, Aboriginal advisors, Alwin Chong (AHCSA), and
the Aboriginal Disability Network of South Australia.

With support from the above groups, it is proposed to provide a $30 Woolworths
voucher to the carer/parent/guardian who completes the questionnaire (or cash
equivalent where there are no Woolworths in the town/community) in recognition
of the expenses incurred in participating in this research. Naturally, in order to
ensure equity for all participants, parents/carers/ guardians who have already
participated in the research will receive the same amount. The vouchers will be
funded through the existing Lifespan budget.

I am seeking the Ethics Committee's approval on this proposal amendment to
the research procedures. If you require any further information, please do not
hesitate to contact me on 0416 182 577 or phil.flint@med.monash.edu.au

Yours sincerely,

Phil Flint
Higher Degree Research Candidate
LifeSpan Project
Centre for Developmental Psychiatry and Psychology
Department of Psychological Medicine
Monash University

Appendix G. Amendment 2: Aboriginal Health Council of South Australia: Aboriginal Health Research Ethics Committee

LifeSpan

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

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

Dr Suzi Hutchins
Chairperson
Aboriginal Health Research Ethics Committe
PO Box 787
KENT TOWN
SA 5067

15th August 2007

**Re: Normative study of a checklist of Emotional and Behavioural Disturbance
in Adults with an intellectual disability –Additional Notice of Amendment**

Dear Suzi,

Please find attached an additional list of interview questions that I wish to include in
the LifeSpan research project. The interview will enquire into four key areas that
possibly have a relationship with the emotional and behavioural wellbeing of
Indigenous people with an intellectual disability. These areas are:
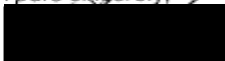
➢ **Perceptions of Intellectual Disability & Mental Health**
➢ **Disability support issues**
➢ **Service satisfaction**
➢ **The individual's contribution to community and valued roles**

The opportunity to participate in the interview will be offered to all Indigenous
research participants who have already completed the main LifeSpan questionnaire.
It is envisaged that there will be no more than 10 interviews with carers and
individuals with a disability.

As with the previous amendment, it is proposed to provide an additional $30
Woolworths voucher to the carer/parent/guardian and each individual with an
intellectual disability who agrees to participate in this interview (or cash equivalent
where there are no Woolworths in the town/community) in recognition of the
expenses incurred. The vouchers will again be funded through the existing Lifespan
budget.

I am seeking the Ethics Committee's approval on this proposal additional
amendment to the research procedures. It is considered that this will be the final
amendment to the Research project. If you require any further information, please
do not hesitate to contact me on 0416 182 577 or phil.flint@med.monash.edu.au

Yours sincerely,

Phil Flint
Higher Degree Research Candidate
LifeSpan Project
Monash University

Appendix H. Lifespan newsletters

Autumn 2006

LifeSpan

DBC-A

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

Welcome to the very first issue of the LifeSpan Project Newsletter.

The LifeSpan Project is a South Australian based research project studying the mental health of adults with an intellectual disability.

The **Project aims** to:
- Provide vital information regarding the mental health status of those adults with an intellectual disability.
- Provide information about the prevalence and nature of mental illness.
- Consider the mental health problems and needs amongst specific groups such as indigenous Australians and older people with an intellectual disability.
- Investigate mental health problems in late adolescents with an intellectual disability in their transition from school life into adult services.

This project will result in a number of benefits for carers and/or service providers. These include:
- Improved assessment, diagnosis and treatment of mental illness for adults with intellectual disability.
- Increased understanding of the prevalence, nature and development of mental illness in adults with an intellectual disability, including risk and protective factors.
- Increased knowledge to assist in policy development, resource allocation and service planning for adults with an intellectual disability and mental illness.
- Improved resources and increased access to training for carers/staff working with adults with an intellectual disability and mental illness.

INSIDE THIS ISSUE
- Welcome
- Background History
- Launch Headline
- Team Profile
- Info Box/Upcoming Events
- Contact details

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 upcoming events.

LifeSpan Project

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

Background to the LifeSpan Project

Industry Partners

The LifeSpan Project is a collaborative research project between The Centre of Developmental Psychiatry and Psychology - Monash University, IDSC, Minda Inc and DECS.

Industry Partner meetings are held quarterly and following people attend:

Prof Bruce Tonge
Prof Stewart Einfeld
Dr Caroline Mohr
Centre of Developmental Psychiatry and Psychology – Monash University

Richard Bruggemann – IDSC
Janice Clark – IDSC
Phil Martin – Minda Inc
Dorothy O'Brien – Minda Inc
Deb Kay - DECS
Ann Rymill – IDSC

♦ Prevalence

Mental illness is 2-3 times more prevalent in people with an intellectual disability than in the general community. Problems related to mental illness often cause distress to the individual and their family/carers, exacerbate their disability and add to the costs of caring, as well as disrupting the individual's developmental, educational and occupational progress. Unfortunately, mental illness in this population often goes undetected and therefore untreated. One of the greatest obstacles is that instruments used to assess and assist in diagnosis of mental illness in the general community are not suitable for use with individuals with an intellectual disability.

♦ ACAD

The Centre for Developmental Psychiatry and Psychology – Monash University, have conducted an internationally unique longitudinal study (Australian Child to Adult Development Study; ACAD) **investigating behavioural and emotional disturbances in a large representative sample of children, adolescents and adults with intellectual disability.** The LifeSpan Project has emerged from the work conducted on the ACAD project that has led to the development and use of the Developmental Behaviour Checklist (DBC).

♦ DBC

Using the Developmental Behaviour Checklist – Adults (DBC-A) the **LifeSpan Project team will assess emotional and behavioural disturbances in adults who have an intellectual disability.** The results will contribute to the largest and most comprehensive research in this area, both on a national and international level.

OFFICIAL LAUNCH

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

On Tuesday 7th February 2006, the Minister, the Hon Jay Weatherill, launched the Lifespan Project, a collaborative research project between Monash University's Centre for Developmental Psychiatry and Psychology, IDSC, Minda and the Department of Education and Children's Services (DECS).

The launch was well attended by many people who work in the field of Intellectual Disability, and included opening speeches from the Minister, Professor Bruce Tonge (Monash University), Richard Bruggemann (CEO-IDSC), Phil Martin (CEO-Minda Inc) and Deb Kay (Manager Interagency Health Care - DECS).

Special thanks must go to IDSC for the In-kind contribution of organising and catering for the event, and to DECS for the In-Kind contribution of the venue (Raggat House, Australian Education Union).

L to R: Phil Flint, Caroline Mohr, Bruce Tonge, Barbara Pennington, Sharon Stinson, Rafaela Karas. *Insert* Ann Rymill

"The outcomes of the project will be very important to people with intellectual disability. They will provide evidence on which to base future interventions, and will enable us to look at not only the prevalence of mental illness amongst people with intellectual disability, but also special programs that might be needed to meet needs, particularly when traditional treatment programs require a degree of cognitive ability. " *Richard Bruggemann LifeSpan Launch*

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.

LifeSpan Project

Information and Upcoming Events

IDSC Conference – The LifeSpan Team will be at the IDSC conference on May 30th, Lakes Resort Hotel-look out for our display. Professor Bruce Tonge is an invited keynote speaker and will provide information on the LifeSpan Project at 1.45pm-2.45pm.

Information Packs – containing information about the Project and details about your involvement with the research can be obtained from the address below and will be available at the conference.

Contact Details

Ann Rymill
LifeSpan Project
PO Box 34
Ferryden Park SA 5010
Ph: 83486500   Fax: 83486599
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

Higher Degree Research Students
- ❖ Barbara Pennington
  barbara.pennington@med.monash.edu.au

- ❖ Phil Flint
  phil.flint@med.monash.edu.au

Research Officers
- ❖ Sharon Stinson
  sharon.stinson@med.monash.edu.au

- ❖ Rafaela Karas (Melbourne Office)
  rafaela.karas@med.monash.edu.au

Spring 08

LifeSpan

DBC-A

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

Welcome to the Final Issue of the LifeSpan Project Newsletter.

INSIDE THIS ISSUE

♦ Data Analysis Update

♦ IASSID Conference 2008

♦ Disability Expo 2008

♦ LifeSpan Events

♦ Project Manager

♦ Mental Health of Older People with ID

♦ Mental Health of Aboriginal and Torres Strait Islanders people with ID

♦ Information: Industry Partners Final Meeting

♦ Research Team & Contact Details

This will be the final issue of the LifeSpan Newsletter. We hope the newsletters have been a useful and informative way of keeping you up to date with the progress of the project over the past three years.

DATA ANALYSIS UPDATE

The data analysis from over 1,600 questionnaires for the norming study, older people and ATSI people is well underway. Apart from the main outcome of creating norms for the Developmental Behaviour Checklist - Adults (DBC-A) the information collected will hopefully assist in a number of other critical areas such as, support and treatment; individual and organisational planning; policy development and service planning; and future research.

Some preliminary findings include:

- 21% screened positively for psychopathology on the DBC-A

- 42% reported to have a diagnosed mental illness

- 35% sought help for emotional & behavioural disturbances

- 42% take medication for behavioural & emotional disturbances

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.

IASSID Conference 2008

Caroline Mohr presenting on LifeSpan at the IASSID conference in South Africa. The presentation included an overview of the project together with some preliminary findings.

Disability Expo 2008

On Friday 24th October the team participated in the Disability Expo. As well as presenting a broad range of preliminary findings in poster format other information was also available on the day including; newsletters, general project information and information on dual disability. There was a good level of interest from university students, parents and people working in the disability field, some of whom had participated in the project and were pleased to see the results of their hard work .

LifeSpan Events

Conference Attendance & Presentations

Various members of the team have attended and presented papers at a number of conferences including:

- Presented at the IASSID Conference in Capetown South Africa, Aug 2008
- Disability Expo, October 24th 2008
- UNI SA Indigenous Psychology conference in Adelaide in July
- The RANZCP "Creating Futures: Research, Practice and Policy for Indigenous, Rural and Remote and Island Peoples" conference in Cairns and Yarrabah in September
- Presented a project update and initial results to the Aboriginal Disability Network of South Australia in October

Upcoming Conference Presentations

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

- The ASSID Conference in Melbourne, November, 2008.
- Disability SA Conference "Shifting the Paradigms" in Adelaide, November 2008

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LifeSpan Project

A Last Word from the Project Manager- Ann Rymill

I really cannot believe that 3 years has passed since we were first discussing how we were going to tackle this seemingly enormous task and now we are nearly at an end. WOW. This has been due to the efforts of all those involved who were willing to give up their precious time to provide the data we needed.

WE THANK YOU.

But I also want to thank the research team both past and present, here and in Melbourne as without their dedication this project would not have got the great outcomes

The Mental Health of ATSI People

Well now that the collection of data for the Aboriginal and Torres Strait Islander (ATSI) study is over, I've been busy starting to analyse and write it all up. Below are some initial results:

❖ ATSI were over 9 years younger than the Non ATSI and 40% were from Non English Speaking Background
❖ 29% screen positively for psychopathology (compared to 21% Non ATSI)
❖ 10% have been admitted to hospital for emotional/behavioural problems (Double Non ATSI rate)
❖ 50% of those admitted to hospital were detained under the Mental Health Act (Double Non ATSI rate of 25%)
❖ 65% reported chronic health conditions
❖ Double the level of hearing loss of Non ATSI (3.75% compared to 1.7%)

There will be much more information to share over the coming months.

The Mental Health of Older People

Firstly I would like to thank all those who assisted in the data collection process. Our participation rate of about 91% is a reflection of the goodwill and effort of carers.

We have a large amount of data on 322 people aged 55-86yrs: a first for Australia! The preliminary results reveal a picture showing they face similar issues to older people who do not have an ID. Prevalence of psychopathology is less than in younger people but about 80% have chronic medical problems, mostly age related. About 6.7% screen positively for dementia.

They suffer less stress than younger people from life events suggesting that their longevity may have resulted in some emotional resilience. Many have little or no social network and they spend less time in daytime activities. 28% are still able to be supported in small community homes, 8% live in their own home or with family. Nearly 25% live in nursing homes while 30% are still living in larger facilities.

There is a tsunami wave of older people who will require aged care services on the horizon, with the largest group (>70%) being in the 55-64yr age group. Services need to be prepared and hopefully the knowledge we have gained will be of benefit to all.

LifeSpan Project

Information

Industry Partners Final Meeting (IPM) -
The final IPM was held on October 27th which included a presentation by Caroline Mohr. The presentation included an overview of the DBC-A and a range of preliminary findings. Further analysis of data still needs to occur and once this happens these findings and the overall outcomes of the research will be presented. The preference of industry partners for the dissemination of information was through individual agency forums, which will happen early 2009 so stay tuned for further updates for details in the new year.

Ongoing project information
Although the project will officially come to a close at the end of 2008 there is still work being done on the publishing and broader dissemination of the results and outcomes. To ensure that this information is accessible the LifeSpan website will continue to be maintained.

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LifeSpan Project

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barbara.pennington@med.monash.edu.au

❖ Phil Flint
phil.flint@med.monash.edu.au

Research Officers
❖ Debbie Collins (Adelaide)
debra.collins@med.monash.edu.au

❖ Caroline Keating (Melbourne)
caroline.keating@med.monash.edu.au

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.

Appendix I. Lifespan information sheets

LifeSpan

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

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

RESEARCH TEAM:	INFORMATION SHEET 1

CHIEF INVESTIGATORS:

- **Professor Bruce Tonge.** *MBBS, MD, DPM, MRC Psych, FRANZCP, RANZCP,*

  Prof Tonge is an academic Child and Adolescent Psychiatrist, who is head of the Centre for Development Psychiatry and Chairperson of the Division of Psychiatry at Monash Medical Centre, Melbourne.

  He has a distinguished record of teaching and research in child psychiatry. He established and directs the internationally recognised Monash University Centre for Developmental Psychiatry and Psychology. He has research and teaching interests in the area of developmental psychiatry with a particular focus in the areas of Autism Spectrum Disorders and behavioural and emotional disturbance in children and adolescents with intellectual disability and treatment outcome studies in childhood anxiety and depressive disorders.

  Prof Tonge is the co-author of the Developmental Behaviour Checklist, an instrument which assesses behavioural and emotional problems in children and adolescents with intellectual disability. This instrument is widely used in clinical and research settings in both Australia and internationally.

- **Professor Stewart Einfeld.** *MBBS, MD, DCH, FRANZCP, MRACMA, Grad Cert Man*

  Prof Einfeld is the Chair of Mental Health, Faculty of Health Sciences, Brain and Mind Research Institute, University of Sydney, and is the Director of Child and Adolescent Psychiatry Programs, South Eastern Sydney Area Health Service. He is also a visiting professor at Monash University and a Consultant Psychiatrist for the Royal Alexandra Hospital for Children, Westmead.

  Prof Einfeld is co-developer of the Developmental Behaviour Checklist. This instrument is widely used in clinical and research settings both within Australia and internationally, and has been translated into 18 languages.

- **Dr Caroline Mohr, PhD**

  Dr Caroline Mohr is a clinical psychologist and researcher in the field of mental health care for people with an intellectual disability. Following 20 years experience in psychiatry and intellectual disability services she completed a PhD in 2003, which developed the Developmental Behaviour Checklist for Adults. The DBC-A is a carer completed checklist of emotional and behavioural problems for adults with intellectual disability.

  Caroline lives in Christchurch, NZ where she works in a mental health service for people with ID. As one of the Chief Investigators on the LifeSpan Project, she regularly travels to SA to work with the project team and supervise the higher degree students whose studies are supported by the funding package in the research programme.

RESEARCH TEAM:

♦ **Ann Rymill, Project Manager,**

After working for a number of years as a social worker in both IDSC and in Mental Health Services, Ann took up the position as Snr Practitioner within the Dual Disability Programme, SISS. Within that programme she has been involved with clinical consultations, training , research and development of interagency cooperation

♦ **Barbara Pennington, PhD Candidate**

Barbara has more than 18 years experience working as a psychologist with people who have an intellectual disability and complex needs related to dual diagnosis, ageing and/or behavioural/emotional problems. She has managed multidisciplinary specialist teams. Barbara is an accredited trainer having both developed and delivered training courses at Certificate and Graduate levels. She has participated in research, and policy/programme development. Barbara also currently works as a Psychologist in her own private practice.

♦ **Sharon Stinson, Research Officer, (Adelaide)**

Sharon has more than 18 years experience working with people who have an intellectual disability, as carer, work trainer, educator, and psychologist. She is an accredited trainer, and delivers training to Community Service Workers at certificate II, III, and IV levels in the areas of disability and mental health. Sharon also works in private practice offering psychology services to people with depressive and anxiety disorders.

♦ **Phil Flint, PhD Candidate**

Phil has a degree in Disability Studies and has worked across a broad range of disability services over the last 12 years including Open Employment, Respite, and Supported Living. After spending the last 5 years in the Top End managing an accommodation for people with a disability, he has returned to Adelaide with his wife and 3 children to undertake this study, with particular focus on the mental health of indigenous people with an intellectual disability. He has been more recently employed as Disability Program Coordinator within the NT Department of Health and Community Services for people with a disability involved in the justice system in the Top End of the NT prior to being awarded an Australian Research Council Scholarship to undertake this study.

♦ **Caroline Keating, Research Officer, (Melbourne)**

Caroline has an honours degree in Psychology. She is working at the Monash University Centre for Developmental Psychiatry and Psychology. Caroline has been appointed to work on the LifeSpan project as she is interested in the areas of intellectual disability and mental health.

LifeSpan Project, PO Box 34, Ferryden Park SA 5010. Ph +61 8 83486500, Fax +61 8 8348599
ann.rymill@med.monash.edu.au
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LifeSpan

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

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

BENEFITS OF THE PROJECT: INFORMATION SHEET 3

👍 **BENEFITS FOR ASSESSMENT AND DIAGNOSIS:**
The Developmental Behaviour Checklist –Adult version (DBC-A) is a carer completed instrument that will lead to a *more accurate assessment and diagnosis of mental health issues* in people who have an intellectual disability. It only takes about 15 to 20 minutes to complete.

👍 **BENEFITS FOR SUPPORT AND TREATMENT:**
The DBC-A will assist with *targeting interventions and monitoring their effectiveness based on an accurate diagnosis.* This information will result in
- Appropriate approach/interactions and expectations of the individual
- Improved peer, family, carer relationships
- Better community options/integration and increased opportunities for development
- Improved quality of life for the individual
- A reduced burden to the individual and carer.

👍 **BENEFITS FOR INDIVIDUAL PLANNING:**

Information obtained from the DBC-A will assist in *improved individual planning and service delivery* for individuals by:
- Informing person centred planning.
- Informing planning during critical periods of life transitions
- Identifying and maximising the use of appropriate resources to suit the individual's needs.

👍 **BENEFITS FOR ORGANISATIONS**

Information obtained from the DBC-A will assist agencies to provide *improved service delivery* for individuals by:

- Improving the quality of information on agency database/register.
- Increasing opportunities for staff/carer training in relation to mental health issues and intellectual disability.
- Improving staff/carer understanding and awareness of assessment, interventions, and monitoring of outcomes.
- Improving communication between carers/staff/specialist services (eg mental health services, GP's etc)
- Improving access to specialist and generic services/resources
- Improving staff recruitment, retention rates, reducing staff turnover, burn out/stress.
- Assisting in service planning and delivery of targeted models of service.
- Contributing to the quality service delivery.

👍 **BENEFITS FOR RESEARCH, POLICY DEVELOPMENT AND SERVICE PLANNING**

Information obtained from the DBC-A will assist in *policy development and service planning* by:

- Raising awareness and understanding of prevalence and nature of issues related to mental health issues and intellectual disability.
- Informing national research priorities and Mental Health Strategies
- Improving inter-sectorial communication.
- Informing the sectors relevant to:
  - Older people with intellectual disability and mental health issues
  - Indigenous people with intellectual disability and mental health issues
  - Young people with intellectual disability in transition from school
- Identifying gaps in service planning and delivery
- Identifying further research opportunities and inform graduate training
- Informing policy and planning at all levels of decision making
- Generate and inform the debate around resource allocation and policy development.
- Providing information to assist in funding submissions and resource allocation.
- Contributing to the promotion of mental health in people with intellectual disability by identifying risk and protective factors.

LifeSpan Project, PO Box 34, Ferryden Park SA 5010. Ph +61 8 83486500, Fax +61 8 8348599
ann.rymill@med.monash.edu.au
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Investigating the Mental Health of people
with Intellectual Disability across the LifeSpan

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

SELECTED BIBLIOGRAPHY: INFORMATION SHEET 4

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LifeSpan Project, PO Box 34, Ferryden Park SA 5010. Ph +61 8 83486500, Fax +61 8 8348599
ann.rymill@med.monash.edu.au
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Enquiries regarding the use of the instrument or purchase of materials can be directed to:

Centre for Developmental Psychiatry
Monash Medical Centre
246 Clayton Rd, Clayton
VICTORIA 3168, AUSTRALIA

Phone: +61 (0)3 9594 7728
Fax: +61 (0)3 9594 6333
Email: DBC@med.monash.edu.au

Please note: The DBC is a non-profit enterprise. All income from the sale of DBC material is devoted to disability research.

LifeSpan Project, PO Box 34, Ferryden Park SA 5010. Ph +61 8 83486500, Fax +61 8 8348599
ann.rymill@med.monash.edu.au
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Investigating the Mental Health of people
with Intellectual Disability across the LifeSpan

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

INDIGENOUS RESEARCH: INFORMATION SHEET 9

There is a very limited amount of information and research in the area of intellectual disability and mental illness within the Australian Aboriginal and Torres Strait population. However, a study by the West Australian Disability Services Commission found that there are approximately double the expected rates of intellectual disability within the Aboriginal and Torres Strait population (4% compared with 2% for all Australians) *(Glasson, Sullivan et al.2005)*.

It is nationally recognised that there is an under-representation of Aboriginal and Torres Strait Islanders with an intellectual disability in health-care data.

Intellectual disability is a relatively new concept within the Aboriginal and Torres Strait Islander population and there is no word in various indigenous languages for intellectual disability. In the context of other impacting factors, disability is not a high priority *(Smeaton, 1998)*.

Mental illness within the Aboriginal and Torres Strait Islander population is also difficult to describe as mental health concepts refer to the social, emotional and cultural wellbeing of the whole community *(Swan & Raphael, 1995)*. A further and recent West Australian study into social and emotional wellbeing found 1:4 Aboriginal and Torres Strait Islanders with mental health issues, compared with 1:6 in Australian population.

Research Aims:

- To increase understanding of the prevalence and nature of mental illness and potential risk and resilience factors of Aboriginal and Torres Strait Islander adults with an intellectual disability in South Australia. Data will be collected will in urban, regional and remote communities throughout SA in collaboration with Aboriginal people in each area to develop with them an approach to research that is inclusive and sensitive to their needs.

- To assist in obtaining standardisation data for the Developmental Behaviour Checklist for Adults (DBC-A) within the broader study of psychopathology in adults with intellectual disability being conducted in South Australia, and compare the rates of psychopathology in the Aboriginal population to a control sample, a large community cohort of adults with intellectual disability.

- To assist in policy development, resource allocation and service planning for Aboriginal and Torres Strait Islander adults with intellectual disability and mental illness by making the project data available to agencies working in the field.

- To assist in improving the accurate assessment, diagnosis and treatment of mental illness for Aboriginal and Torres Strait Islander adults with intellectual disability by ensuring that the DBC-A is used appropriately with Aboriginal and Torres Strait Islander people. The DBC-A may also be modified (language and/or structure) to enhance its utility and relevance to this population

LifeSpan Project, PO Box 34, Ferryden Park SA 5010. Ph +61 8 83486500, Fax +61 8 8348599
ann.rymill@med.monash.edu.au
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Methodology: A personalised approach is being adopted with the research using:
- Demographic information;
- Developmental Behaviour Checklist-Adults (DBC-A);
- Disability/impairment/health status;
- Life events scale;
- Adaptive Behaviour Assessment Scale (ABAS-11 Adult form)

Activities and Strategies: During the course of the research close consultation and collaboration will be maintained with the;
- Aboriginal Disability Unit
- Aboriginal Disability Network - South Australia
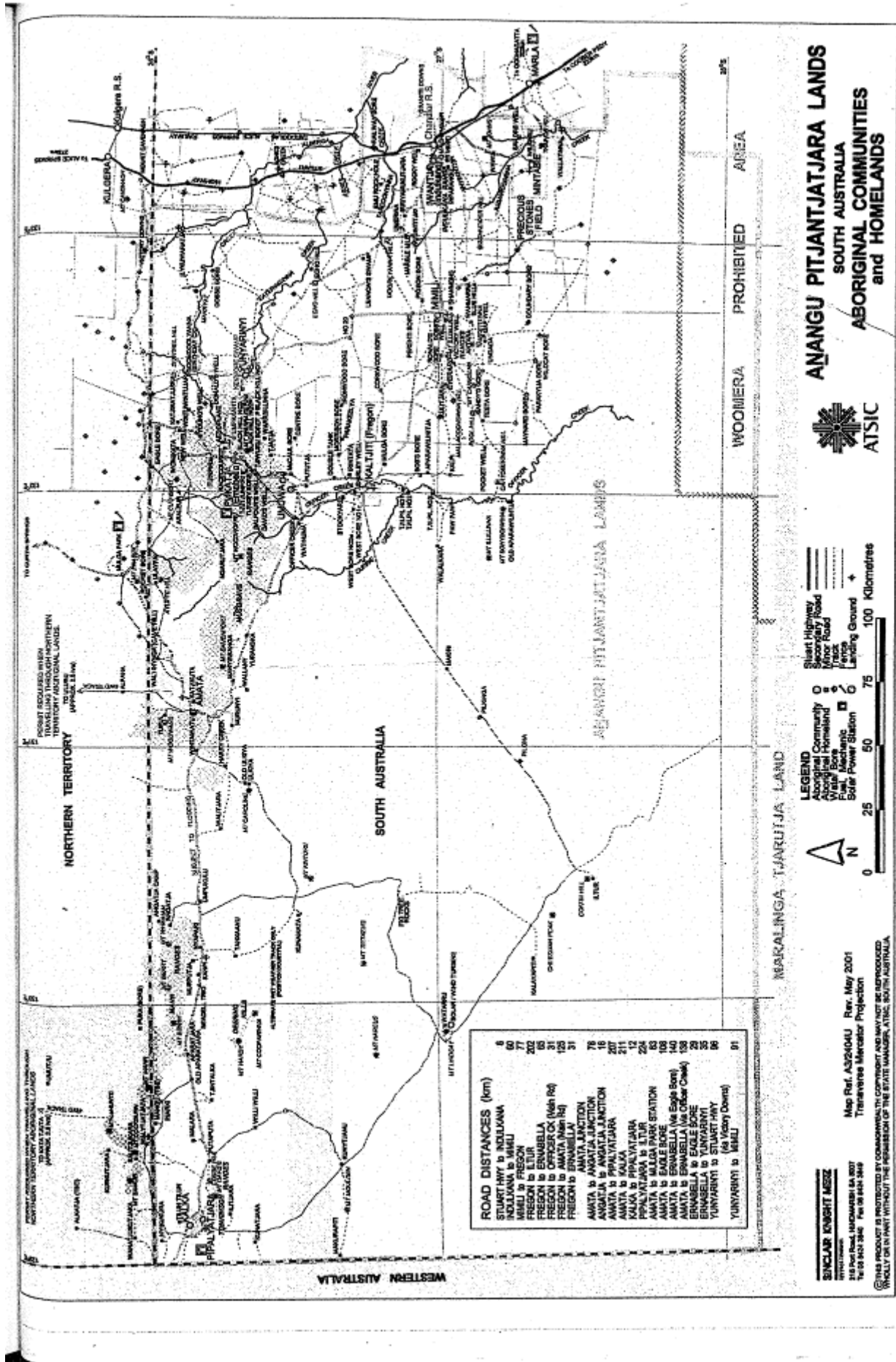- South Australian Aboriginal Health Council
- DSA, DECS, Minda Inc

Participants: All Aboriginal and Torres Strait Islander adults in SA who are registered with Disability South Australia (DSA), Minda Inc. and Department of Education and Children's Services (DECS) will be offered an opportunity to participate in the research.

Predicted Outcomes:
- Increased understanding of the determinants of mental health within the Aboriginal and Torres Strait Islander population with an intellectual disability across the life span.

- Developing more culturally sensitive services including a greater understanding of cultural explanations for causation of mental health/disability issues.

- Improved assessment, diagnosis and treatment of mental illness for Aboriginal and Torres Strait Islander adults with intellectual disability.

- Improved resources and increased access to training for carers/staff working with Aboriginal and Torres Strait Islander adults with an intellectual disability and mental illness.

- Increased knowledge to assist in policy development, resource allocation and service planning for Aboriginal and Torres Strait Islander adults with intellectual disability and mental illness.

- Increased understanding of prevalence, nature & development of mental illness, including protective and risk factors.

If you would like more information about this research please contact
Phil Flint PhD Research Candidate,
Faculty of Medicine, Nursing and Health Sciences, Monash University
phil.flint@med.monash.edu.au
phone 08 8348 6500

LifeSpan Project, PO Box 34, Ferryden Park   SA 5010. Ph +61 8 83486500, Fax +61 8 8348599
ann.rymill@med.monash.edu.au
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Appendix J. Map of APY Lands

ANANGU PITJANTJATJARA LANDS
SOUTH AUSTRALIA
ABORIGINAL COMMUNITIES
and HOMELANDS

Appendix K. Lifespan data collection travel diary

Dates	Place
19th March 07	Murray Bridge, Tailem Bend
28 - 30th Mar 07	Yorke Peninsula, Port Augusta, Whyalla
(2 nights)	
10th April 07	Fleurieu Peninsula, Victor Harbour, Goolwa
12-15 June 07	Ceduna, Yalata, Port Lincoln, Eyre Peninsula
(3 nights)	
27-28 June 07	Riverland (Barmera, Berri, Renmark, Loxton)
(1 night)	
	Northern Territory trip -1
27th August 07 to	Coober Pedy, Marla, Alice Springs and region, Ti Tree,
10th October 07	Tennant Creek, Katherine, Nardirri, Peppimenarti, Nauiyu, Darwin
(44 nights)	
	APY and Northern Territory Central Desert trip -2
13th April 08	APY Lands -(Marla, Umuwa, Pipalyatjara, Pukatja,
to	Amata, Mimili, Fregon, Indulkana, Kalka, Wallatinna)
24th April 08	Central Desert (Alice Springs, Santa Theresa)
(11 nights)	

Appendix L. Lifespan project information, consent form and plain language form

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

PARENT/GUARDIAN INFORMATION SHEET

Background:

Mental illness is 2-3 times more common in people with intellectual disability. Unfortunately their mental health disorders often go undetected and untreated. Questionnaires completed by carers are an effective and inexpensive method of gathering important information about the mental health of the person in their care. However, questionnaires used in the general community to assist in the diagnosis and monitoring of mental illness are often not suitable for use with people with intellectual disability.

Aims:

This study aims to further develop the Developmental Behaviour Checklist for Adults. This checklist is used to assess behavioural and emotional problems in adults with intellectual disability.

Specifically, this project aims to collect Developmental Behaviour Checklist scores from a large representative population of adults with intellectual disability. This will help health professional make more informed decisions as it will be possible for them to compare an individual's score on the Developmental Behaviour Checklist against average scores from a representative population of adults with intellectual disability. Through this comparison health professionals will be able to determine the severity of the individual's behaviour. Information about the person's daily support needs will also be collected as a measure of the degree of his/her disability.

We aim to study every person with an Intellectual Disability over 16 years in South Australia, this is why we are approaching you and your son/daughter or person for whom you are the guardian. The Chief Investigators are Prof Bruce Tonge, Prof Stewart Einfeld and Dr Caroline Mohr.

If your son/daughter or person for whom you are the guardian is over 55 years of age we are, in addition to the above, seeking to gather information to further develop a checklist (the Broadscreen Checklist of Change) which may be useful in identifying and tracking age related changes in abilities and behaviour.

Demands/Risk:

We cannot guarantee that you, or your son/daughter, or person for whom you are the guardian will receive any direct benefits from this study. However, information may be of use to you and any professional helping your son/daughter or person for whom you are the guardian, and upon request to the researchers you are welcome to have a report of the questionnaire results as well as a copy of the questionnaire.

We are not aware of any risks arising from participation. If in talking to you or members of your family any concerns are raised for which you or they may want further assistance, we will arrange a referral to an appropriate clinician or services.

If you agree to take part, can you *please complete the Parent/Guardian consent form* and return it to the researchers in the reply paid envelope.

If your son/daughter or person for whom you are the guardian is not living with you, we would like to ask you to give written consent for their carer (or a person who has contact with them on a daily basis) to complete the questionnaires.

Following receipt of consent we will contact you and send the questionnaires to the relevant person to be completed. The questionnaires will take up to an hour to complete and can be returned to the researchers in a reply paid envelope.

Confidentiality:

Any information about your son/daughter or person for whom you are the guardian will remain confidential. The results of the study will be reported in such a way that it is not possible to identify any individual, and information about your son/daughter or person for whom you are the guardian will not be disclosed to anyone else without your written approval.

We will safeguard the confidentiality of all files. The questionnaires will be stored in a locked filing cabinet for fifteen years after the completion of the study, and then disposed of by shredding and file deletion. The research staff directly involved with data collection, are the only people who have access to these files. You may access the file containing information collected about your son/daughter or person for whom you are the guardian by contacting Professor Tonge.

Project staff are required by law to report any situations of abuse or neglect.

Voluntary Participation:

Please note that participation in this project is voluntary and you can withdraw from the study at any time. Whether you take part or not, it will not make any difference to the medical care or other professional services which your son/daughter or person for whom you are the guardian, yourself or your family receive. If you agree to take part, you can withdraw at any time by writing or talking to the researcher. Your son/daughter or person for whom you are the guardian may decline to participate in this study. In this case this person's wishes override consent provided by their legal guardian.

Ethical Guidelines:

This project will be carried out according to the National Statement on Ethical Conduct in Research Involving Humans (1999) produced by the National Health and Medical Research Council of Australia. This research project has been approved by SA Department of Health, Human Research Ethics Committee, and the Standing Committee on Ethics in Research Involving Humans (SCERH) Monash University, Clayton.

Contacts:
If you have any questions or concerns regarding this study, please do not hesitate to contact:

      Professor Bruce Tonge
      Centre for Developmental Psychiatry and Psychology
      Monash Medical Centre
      246 Clayton Rd
      Clayton VIC 3168
      Tel: (03) 9594 1354.

Complaints:

You can complain about the study if you don't like something about it. To complain about the study, you need to phone 03 9905 2052. You can then ask to speak to the secretary of the Human Ethics Committee and tell him or her that the number of the project 2004/977MC. You could also write to the secretary. The address is

      The Secretary, The Standing Committee on Ethics in Research Involving Humans
      PO Box No 3A
      Monash University VIC 3800
      Telephone: +61 3 9905 2052   Fax: +61 3 9905 1420
      Email: SCERH@adm.monash.edu.au

LifeSpan

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

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

PARENT/GUARDIAN CONSENT FORM

I

(Please Print)

of

Address

Contact number

have been asked that my son/daughter or the person for whom I am a guardian participate in the research project entitled 'LifeSpan; Investigating the Mental Health of People with Intellectual Disability across the LifeSpan' being conducted by Prof Bruce Tonge, Prof Stewart Einfeld and Dr Caroline Mohr.

Name of Person with an Intellectual Disability

Date of Birth

I give voluntary consent for my son/daughter or the person for whom I am guardian to participate in the LifeSpan Project. I have had the Project explained to me, and I have read the Parent/Guardian Information Sheet, which I can keep for my records. I understand that the research study will be carried out in a manner conforming with the principles set out by the National Statement on Ethical Conduct in Research Involving Humans, and further that:

1. I understand the general purposes, methods, demands and benefits and possible risks, inconveniences and discomforts of the study as outlined in the *'Parent/Guardian Information Sheet'* that has been given to me or the person for whom I am a guardian.

2. Although I understand that the purpose of this research project is to improve the quality of care, it has also been explained that my involvement may not be of any personal benefit to me.

3. My participation in the research study is voluntary, and I am free to withdraw at any time, and to continue receiving appropriate treatment for the person for whom I am a guardian, as will be the case if I do not volunteer to enter the study.

4. I have received information and explanations about the study and I understand that I will be given the opportunity to ask questions and seek clarification as required.

5. I understand that any information I provide is confidential, and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other party.

Page 3 of 4

C:\Users\phil\Documents\Lifespan\a PhD Research Project\Thesis\MASTER THESIS\Appendixes\appendix 14 Parent info & consent form.doc

Parent/Guardian Signature:

Date

As my son/daughter or person for whom I am guardian does not live with me, I consent to carers completing and retaining a copy of the questionnaires.

Support Agency Details:

Agency:

Contact Person:

Phone

Fax

Mailing address

Parent/Guardian Signature:

Date

LifeSpan

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

A Monash University Centre for Developmental Psychiatry & Psychology Research Project

EASY ENGLISH INFORMATION SHEET
(You can keep this form for your information)

Everybody can have problems with how they feel and behave sometimes. This can make them and their families sad and upset. It is sometimes very hard for people to tell other people about how they are feeling. Staff and doctors can find it to hard to work out what the problem is so they can help the person.
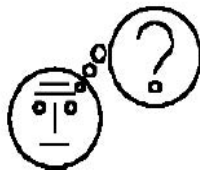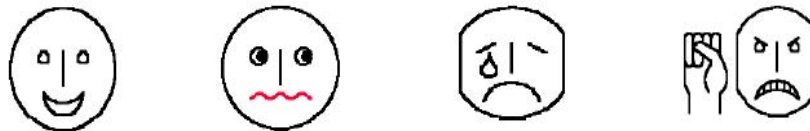
We have some questions (called the DBC-A) that we want to ask people or their helpers about feelings and behaviour. The answers we get then help us to work out how many people are having problems, what sort of problems they are having and how we might help.

We want to know these things because we are trying to find better ways of helping people in the future. Our project is called the LifeSpan Project because we are trying to find ways of helping people no matter how old they are.

We can do this work because we have been given money from the Australian Research Council, Minda, IDSC and DECS. You may not have heard of them but they are organisations that help people with disabilities.

We want to ask you or your helper about what you do and how you feel. We are going to be asking the same questions about lots of people.
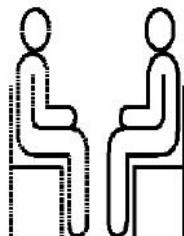
We will not ask your helper any questions if you do not want us to.

If you or your helper tells us something which means that you might need some more help now we will arrange for you to see someone who can help you, if you want to.

What we find out about you is PRIVATE, that is, it is just between you, us and your helper.   What you or your helper tells us will not be given to or seen by anyone but the people working on the project.
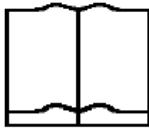
Sometimes the things we find out get written in a book or magazine. If this happens, we will take your name out so that it remains PRIVATE. No one will know that the answers to the questions were about you. After fifteen years, we will destroy all of these answers.
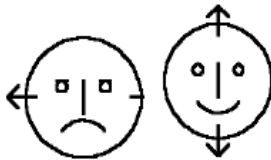
If you do not want to help with this project, that is OK. You will still get help whether you answer these questions or not.

If you change your mind and don't want to finish the questions, that is OK too. If you want to stop, you will still get help with whatever you need.

If you have any questions, please call Ann, on 83486500 who will be happy to answer them. You can keep this form.

Barbara Pennington, Ann Rymill, (back) Rafaela Karas & Sharon Stinson (front)

Phil Flint, Caroline Mohr & Bruce Tonge

Here are some pictures of the people working on the project.

They have all worked for many years trying to find ways to help people with an intellectual disability.

Complaints: if you don't like something about what we do or say you can complain. You or your helper can phone 03 9905 2052.   Ask to speak to the secretary of the Human Ethics Committee and tell him or her that the number of the project is ID LPO561542. You could also write to the secretary. That person's address is;

> *The Secretary*
> *The Standing Committee on Ethics in Research Involving Humans*
> *PO Box No 3A*
> *Monash University VIC 3800*
> *Telephone: +61 3 9905 2052   Fax: +61 3 9905 1420*
> *Email: SCERH@adm.monash.edu.au*

PARTICIPANT CONSENT

> **If you agree to participate, please sign and return this form to us.**

- I agree to take part in the LifeSpan Project. I have had the project explained to me, and I have read the Participant Information Sheet, which I can keep for my records.

- I understand that any information that I provide is confidential and that no information that could lead to the identification of any individual will be disclosed in any reports on the project, or to any other person outside the research team.

- I also understand that whether or not I take part is up to me. I can withdraw at any stage of the project without being disadvantaged in any way.

My Name:

Date of Birth:

My Signature:

My Address:

Witness: I

of

(Please Print)

as an independent witness, confirm that the aims and procedures of the study and any risks involved have been explained to the person consenting, whose signatures I witness. In opinion, he/she is acting rationally and voluntarily.

Signature   **Date**

Thank you for helping us with our study.

Appendix M. Descriptions of other chronic medical/health problems

Table M.1

Medical/health problems

Medical/Health problems	Indigenous N (%)	
Marfans syndrome	2	(33.3)
Alcohol dependency	3	(50.0)
Significant burns	1	(16.7)
Total	6	(100)

Appendix N. Life Events

Table N.1

Life Events: Regression

Number of LEs	Coef.	Std. Err.	t	P>t	95% Conf. Interval
Age	-.032	.00	-10.12	0.00	-0.04 – 0.03
Female	.048	.09	0.6	0.56	-0.13 – 0.23
Not City	.091	.12	0.46	0.46	-0.15 – 0.33
Indigenous	1.05	.16	6.52	0.00	0.73 - 1.36
Cons	2.67	.15	17.33	0.00	2.37 – 2.97

Appendix O. Caseness and mixing with others

Table O.1

Proportion of DBC-A Caseness among mixing levels

| Choose to mix with others?	Case		No Case		Total
	N	(%)	N	(%)	N
Not at all	6	(35.3)	11	(64.7)	17
A little	27	(30.0)	63	(70.0)	90
A lot	14	(26.4)	39	(73.6)	53
Total	47	(29.4)	113	(70.6)	160

Pearson chi2(2) = 0.5279 Pr = 0.768

Table O.2

Individual results on "Mixing with others" question

Where do they mix?	Yes/No	Case No. (%)		No Case No. (%)		Pearson chi2 (1)	Pr
At home (with family)	Yes	27	(27.3)	72	(72.7)	0.22	0.64
	No	14	(31.1)	31	(68.9)		
School/ workplace	Yes	15	(40.5)	22	(59.5)	2.07	0.15
	No	28	(27.7)	73	(72.3)		
Visits to other families	Yes	13	(27.7)	34	(72.3)	0.1	0.76
	No	26	(30.2)	60	(69.8)		
Clubs e.g. Sports, social	Yes	12	(23.5)	39	(76.5)	1.4	0.02
	No	30	(33.0)	61	(67.0)		
Outings e.g. Movies	Yes	11	(18.6)	48	(81.4)	4.92	0.03
	No	29	(35.8)	52	(64.2)		
Neighbourhood visits	Yes	22	(32.8)	45	(67.2)	0.61	0.44
	No	19	(26.8)	52	(73.2)		
Internet	Yes	1	(50.0)	1	(50.0)	0.36	0.55
	No	38	(30.4)	87	(69.6)		
Other	Yes	12	(25.0)	36	(75.0)	0.93	0.33
	No	29	(32.9)	59	(67.1)		

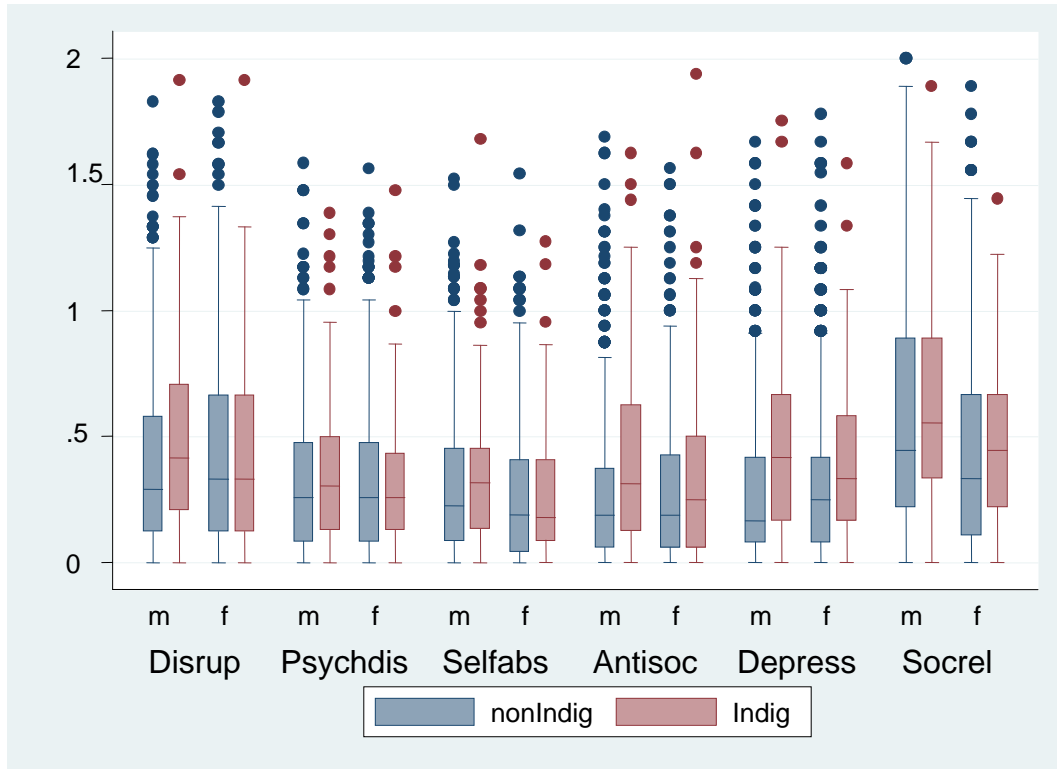## Appendix P. DBC-A subscale scores

Figure P.1

Indigenous vs non-Indigenous on the subscales
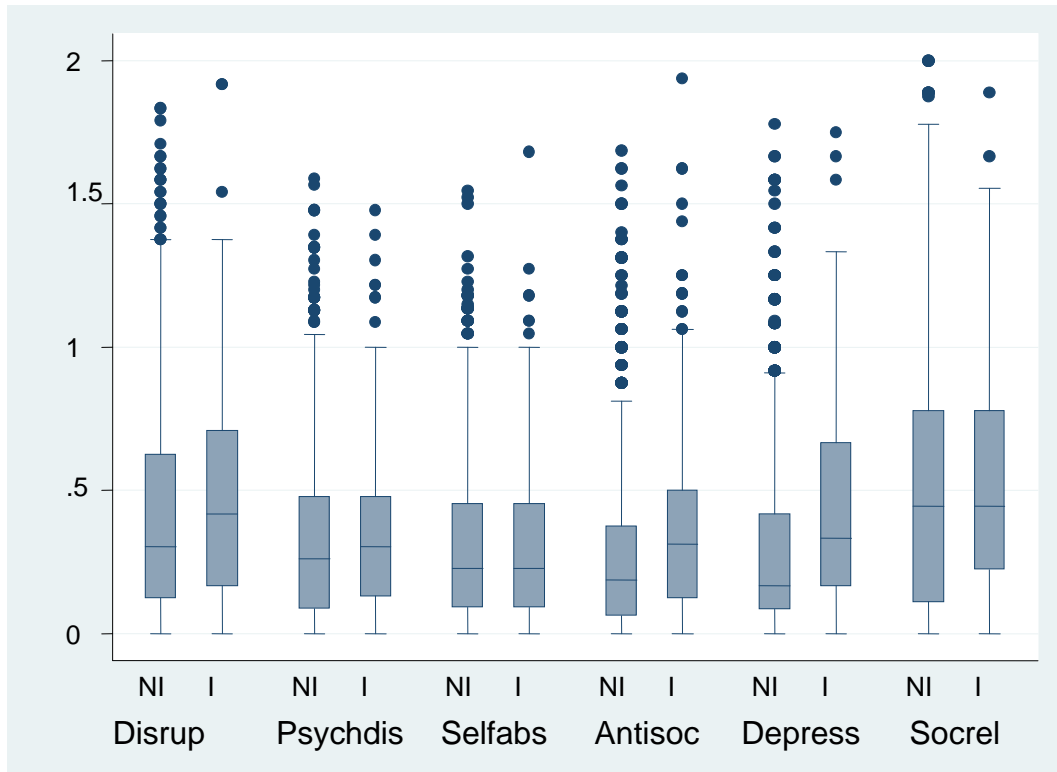
Disrup= Disruptive, Psychdis= Psychological Disturbance, Selfabs= Self Absorbed,

Antisoc= Antisocial, Depress= Depressive, Socrel= Social Relating
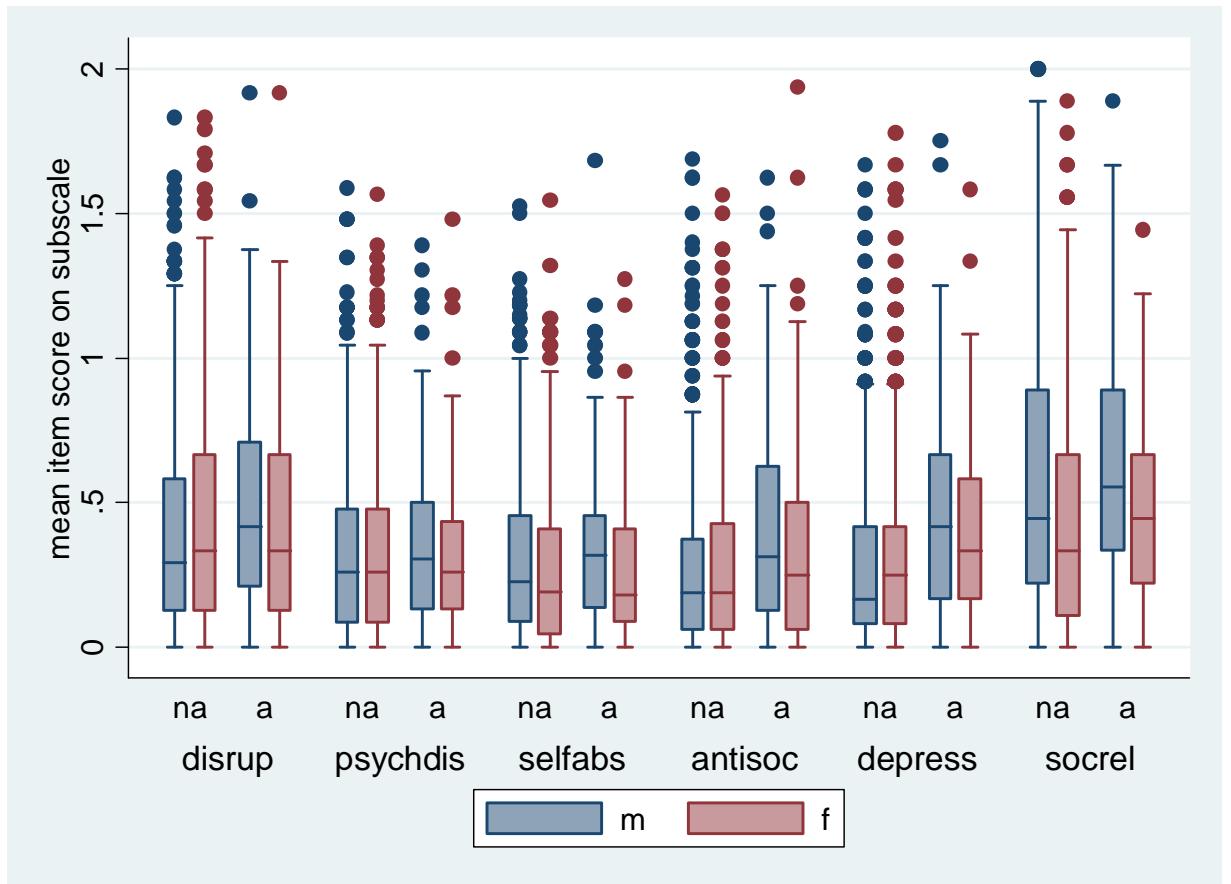
Figure P.2

Indigenous and gender on subscales – version 1

Disrup= Disruptive, Psychdis= Psychological Disturbance, Selfabs= Self Absorbed, Antisoc= Antisocial, Depress= Depressive, Socrel= Social Relating
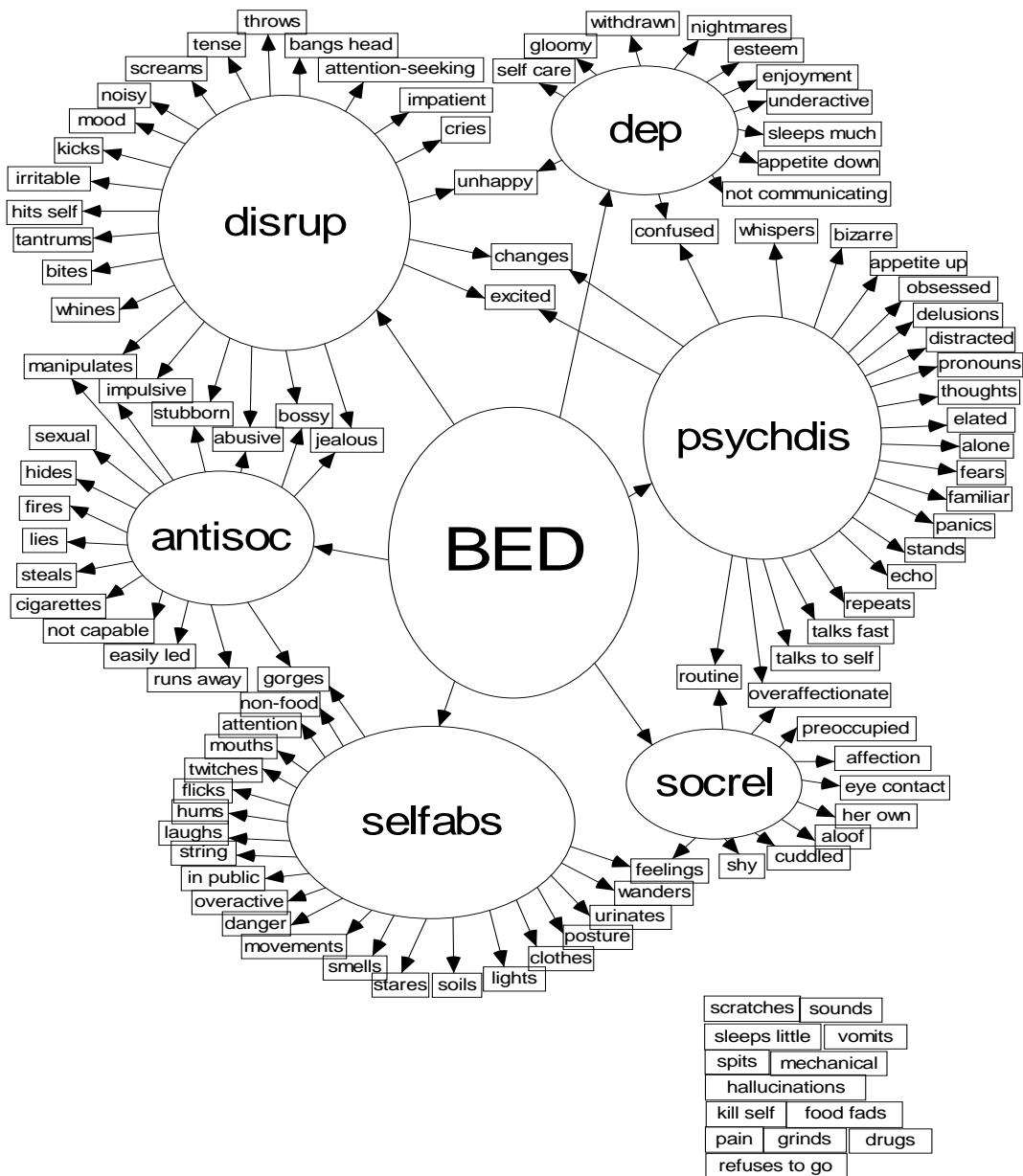
Figure P.3

Indigenous and gender on subscales – version 2

Disrup= Disruptive, Psychdis= Psychological Disturbance, Selfabs= Self Absorbed,

Antisoc= Antisocial, Depress= Depressive, Socrel= Social Relating

Figure P.4

Lifespan sample factor-based subscales of the DBC-A


BED	behavioural and emotional disturbance
Disrup	Disruptive
Dep	Depressive
Antisoc	Antisocial
Psychdis	Psychological Disturbance
Selfabs	Self Absorbed
Socrel	Social Relating

Items not part of the factor solution appear at the lower right

Appendix Q. Aboriginal Australia Map (Horton, 2000)

Figure Q.1

Distribution of Aboriginal language groups in Australia
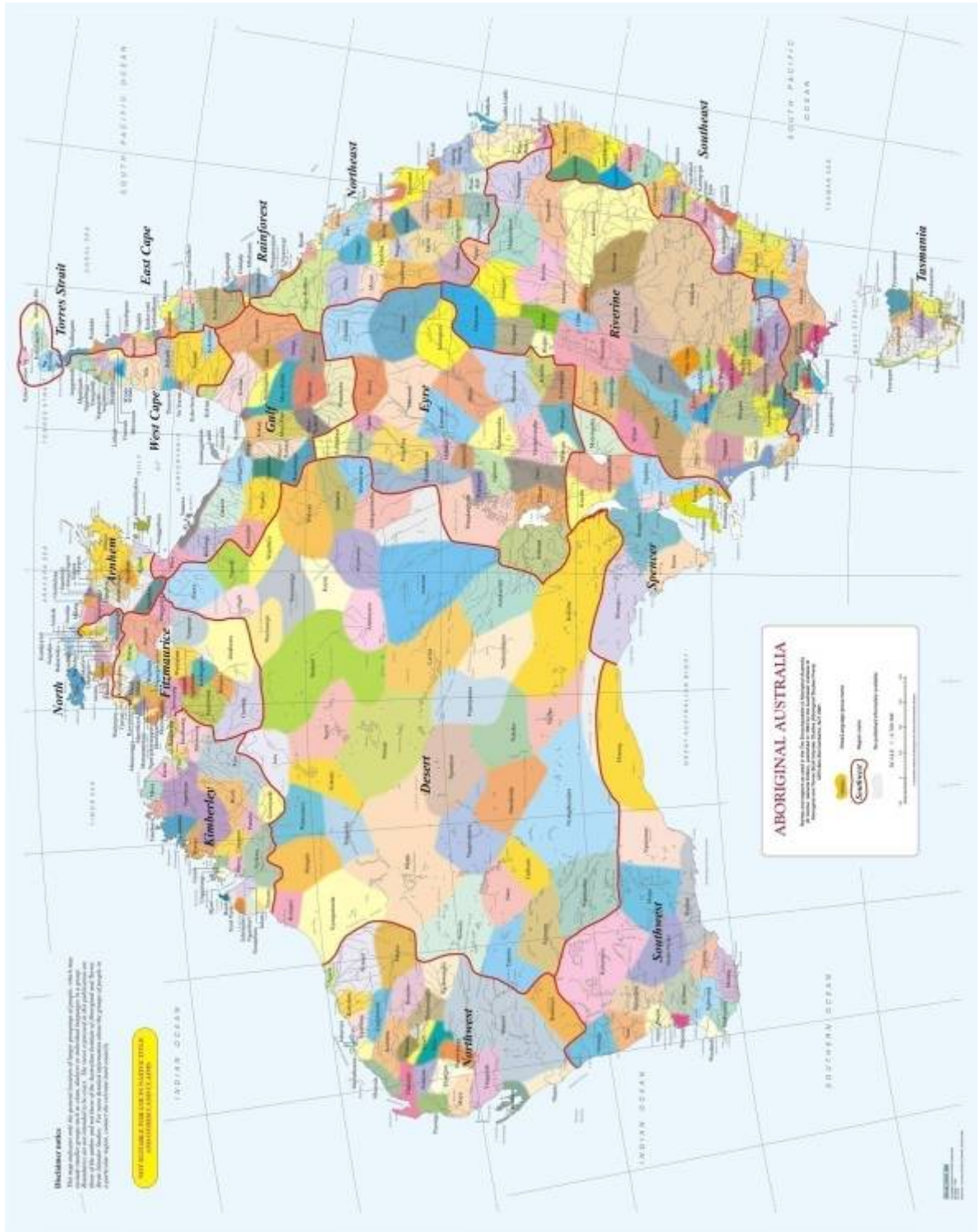
GLOSSARY

LIST OF ACRONYMS

ABAS-II	Adaptive Behavior Assessment System, Second edition
ABC	Aberrant Behavior Checklist
ABI	Acquired Brain Injury
ADAMS	Anxiety Depression and Mood Scale
ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
ADNSA	Aboriginal Disability Network of South Australia
APY	Anangu Pitjantjatjara Yankunytjatjara
ARIA	Accessibility/Remoteness Index of Australia
ASGC	Australian Standard Geographical Classification
ATSI	Aboriginal and/or Torres Strait Islander
CD	Collection Districts
CDI	Children's Depression Inventory
CSTDA MDS	Commonwealth State/Territory Disability Agreement National Minimum Data Set
DASH-II	Diagnostic Assessment Schedule for Severely Handicapped, Second edition
DBC	Developmental Behaviour Checklist
DBC-A	Developmental Behaviour Checklist for Adults
DBC-ASA	Developmental Behaviour Checklist Autism Screening Algorithm
DBC-ES	Developmental Behaviour Checklist Early Screen
DBC-P	Developmental Behaviour Checklist Primary Carer Version
DBC-T	Developmental Behaviour Checklist Teacher Version
DC-LD	Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/ Mental Retardation
DM-ID	Diagnostic Manual - Intellectual Disability
DRU	Disabilities Research Unit
DSM-III	Diagnostic and Statistical Manual of Mental Disorders, Third edition
DSM-III-R	Diagnostic and Statistical Manual of Mental Disorders, Third edition, Revised
DSM-IV	Diagnostic and Statistical Manual of Mental Disorders, Fourth edition

DSM-IV-TR	Diagnostic and Statistical Manual of Mental Disorders, Fourth edition, Text Revision
DSP	Disability Support Pension
D-START	Disability, Support, Training and Resource Tool
FAHRU	Flinders University Aboriginal Health Research Unit
FAS	Fetal Alcohol Syndrome
GSS	General Social Survey
ICC	Intraclass Correlation Coefficient
ICD-10	International Classification of Diseases, Tenth edition
ICD-9	International Classification of Diseases, Ninth edition
ID	Intellectual Disability
II	Item Intensity
IQ	Intelligence Quotient
LE	Life Event
MIS	Mean Item Scored
NATSIHS	National Aboriginal and Torres Strait Islander Health Survey
NATSISS	National Aboriginal and Torres Strait Islander Social Survey
NESB	non-English speaking background
NHS	National Health Survey
OR	Odds Ratio
PAS-ADD	Psychiatric Assessment Schedule for Adults with Developmental Disabilities Checklist
PDD	Pervasive Developmental Disorder
PIC	Proportion of items positively checked
PIMRA	Psychopathology Instrument for Mentally Retarded Adults
RA	Remoteness Areas
RAPID	Redevelopment of Acute and Psychiatric Information Directions
ROC	Receiver Operating Characteristics
RSMB	Reiss Screen for Maladaptive Behavior
SB5	Stanford-Binet Intelligence Scale, Fifth edition
SRDQ	Self Report Depression Questionnaire
TBI	Traumatic Brain Injury
TBPS	Total Behaviour Problem Score
VABS-II	Vineland Adaptive Behavior Scales, Second edition
WAACHS	Western Australian Aboriginal Child Health Survey
WAIS-III	Wechsler Adult Intelligence Scale, Third edition

WAIS-IV	Wechsler Adult Intelligence Scale, Fourth edition
WISC-III	Wechsler Intelligence Scale for Children, Third edition
WMS-III	Wechsler Memory Scale, Third edition
WPPSI-III	Wechsler Preschool & Primary Scale of Intelligence, Third edition