

SUMMER
FOUNDATION



Productivity Commission **Disability Care and Support**

Response to Draft Report

Submission prepared by
Summer Foundation Ltd | April 2011

The Summer Foundation commends the Productivity Commission on the Draft Report into Disability Care and Support. The Summer Foundation believes that the Commission's comprehensive assessment of the current status of disability services accurately reflects the experience of young people in nursing homes and their families.

It is also our view that the recommendations provided will mitigate against the barriers to the social inclusion experienced by people with disability and that the emerging evidence base, theoretical frameworks and standards inherent in the recommendations will foster quality service provision. We welcome the identification of young people in nursing homes and people with newly acquired disabilities as priority groups and the National Injury Insurance Scheme (NIIS) and conclude that the Disability Care and Support Scheme will provide the structural change necessary to build a good service system and resolve the issue of young people in nursing homes.

As Building Better Lives Ambassador Jason Anderson has stated:

"If the NDIS had existed when I was first diagnosed with multiple sclerosis I would not have had to wait and save up for home renovations or equipment. I would have received personal care support, which would have helped ease the pressure and stress on me and my young family. I would have also received therapy much earlier - maybe it could have helped me stay in a job, maybe it could have somehow helped delay the progress of my disability. What this scheme would mean for me now is that I would be more independent, I could choose where to live, who I live with, and also have a place where my kids could stay over - that would mean everything to me."

The Summer Foundation therefore supports the key recommendations of the Productivity Commission Draft Report Disability Care and Support.

For the group that is young people in nursing homes the scheme would:

- Build capabilities and provide resources which will see people learn, work, engage and have a voice
- Provide security and enable proactive planning with knowledge that funding will be available rather than having people competing for rationed resources and on wait lists

- Be a positive investment in the lives of people with disability which would enable them to realise individual potential and contribute to the development of society
- Enable people with disability to maintain valued life roles such as mothers, fathers, brothers, sisters, daughters and sons
- Have significant cost benefits through maximising abilities and independence and decreasing life time care costs
- Reduce the time, emotional and financial burden on families/carers which can contribute to their social exclusion
- Ensure equity in access to services
- Have significant cost benefits related to long stays in hospital (throughput) or hospital readmissions (due to secondary complications)
- Reduce demand for nursing home beds.

The following submission provides additional information regarding monitoring and assessment, staff knowledge, skills and attitude, capacity building in indigenous communities and the implementation of a pilot scheme in Victoria.

Individual Assessment

Assessment needs to be flexible, person-centered and participation-focused. A semi-structured interview which elicits information about the individual's pre-injury lifestyle (if relevant), daily activities and routines, life roles and satisfaction, personal achievements, perceived level of community integration and coping strategies is a starting point. While employing a participation and strength focus, the semi-structured interview also gathers information about the barriers and impairments that negatively impact upon role performance (Sloan, Winkler, & Callaway, 2004).

In 2006 Australian federal and state governments commenced a five-year, \$244 million national program called Younger People with Disabilities in Residential Aged Care (YPIRAC). This program aims to reduce the total number of people under 50 years living in aged care from 1000 to less than 400. This initiative is one of the largest to be undertaken internationally and therefore provides a unique research opportunity. In Victoria this program is called *my future my choice* and has funded the development of 22 new shared supported accommodation services for young people either living in aged care or at risk of entry.

The assessment and planning framework developed by the Summer Foundation (Winkler, Sloan, & Callaway, 2007a) for *my future my choice* was developed for people with a range of disabilities. This framework incorporated planning for individuals with the aggregation of quantitative data to inform statewide service planning and development. Some of the quantitative data obtained during this process is also being utilised as a baseline measure for an evaluation that will measure the quality of life outcomes for people receiving services through this program. The *my future my choice* assessment and planning framework includes the following life areas and instruments:

- Community integration – Community Integration Questionnaire (CIQ) (Willer, Rosenthal, Kreutzer, Gordon, & Rempel, 1993)
- Social inclusion
- Health
- Mental health – Health of the Nations Scale–ABI (HoNOS) (Fleminger et al., 2005)
- Challenging Behaviour – Overt Behaviour Scale (OBS) (Kelly, Todd, Simpson, Kremer, & Martin, 2006)
- Life roles and interests – Role Checklist (Oakley, Kielhofner, Barris, & Reichler, 1986)
- Choice and control – The Choice Scale (Hatton, Robertson, Emerson, Gregory, & Kessissoglou, 1999)
- Accommodation and support history
- Support required for everyday activities – Care and Needs Scale (CANS) (Tate, 2004)

Given that this is an extensive list of life areas, such a thorough assessment could become a huge impost on people with a disability and their families. It is unrealistic for assessors to expect to obtain a detailed understanding of the person and their particular circumstances in every aspect of their life. While assessment should obtain a broad understanding of the person's function in all areas of life, the assessment process should be flexible and enable the assessor to conduct a more detailed assessment related to the life roles or areas of participation that are a high priority for the individual (Sloan et al., 2004). For example, if the individual's highest priorities are related to their role as a parent and independence in personal care, the assessment process would obtain a detailed understanding of their current participation in these life areas as well as any strengths, barriers, opportunities and natural supports that are relevant to fostering full participation.

Monitoring

There are considerable structural, technical and operational resources available to Victorians to support and set the benchmark of disability service provision, and by extension inform the monitoring and review of the insurance scheme. These include: The Victorian Charter of Human Rights; The Disability Act, 2006 (principles and practice implications); Quality Framework for Disability Services in Victoria (2007); Standards for Disability Services; Industry Standards for Disability Services; The Disability State Plan 2002- 2012; the National Disability Strategy (2010); and the United Nations Convention on the Rights of Persons with Disabilities (2007).

In our previous submission two targeted interventions – the ABI:STR Program and the *my future my choice* program – were discussed. Both qualitative and quantitative research indicates positive outcomes for young people in nursing homes who have been recipients of these programs (Sloan, 2008; Winkler, Farnworth, Sloan, & Brown, 2009). Both of these programs provide the benchmark for service delivery and individual outcome standards against Victorian legislation and associated policy, and provide, given the programs' longevity, comprehensive examples of how this can work. It is argued therefore that the approach to monitoring and review undertaken by these programs be utilised to inform the Disability Long Term Care and Support for people with catastrophic brain injuries.

The Summer Foundation notes also that people with catastrophic brain injuries may, depending on cause of the injury, receive services from either the NDIS or the NIS. Given that the impact of a catastrophic injury is as implied catastrophic, regardless of cause we would expect services provided from the parallel schemes to be equitable necessitating comparable systems and outcomes benchmarking.

A strong culture of advocacy will be required to ensure that people with disability have representative input into monitoring and review processes. Advocacy services should comprise entities separate to service providers and be sufficiently remunerated to meet potential demand. Advocacy providers should have the requisite skills and knowledge base to undertake the role.

In summary good service system and monitoring and review would comply with disability legislation, policy and practice and the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007).

The availability of valid and reliable instruments to monitor the social inclusion and full participation of people with a disability is limited. Ideally these instruments should be used to:

1. Evaluate the social inclusion and participation outcomes for people with disability
2. Evaluate the efficacy of the NDIS and NIIS
3. Identify systemic barriers (e.g. infrastructure, transport, health, housing, rehabilitation etc.) that limit the social inclusion and full participation of people with disability

Following is a list of questions that these tools should address based on the United Nations Convention on the Rights of Persons with Disabilities (United Nations, 2007).

Evaluation of outcomes for individuals

- Does the individual experience full inclusion and active participation in society?
- Is the person supported to live as independently as possible and participate fully in all aspects of life?
- What are the barriers (physical, attitudinal, financial etc.) to their social inclusion and participation in meaningful life roles?
- Does the individual have the freedom to make his/her own choice?
- Does the individual have the accessible information required to make an informed choice about equipment, assistive technologies and services?
- Does the individual get to choose their place of residence and where and with whom they live?
- Does the individual live in a residence which is segregated from the rest of the community?
- Is the individual supported to access an inclusive, quality and free education?
- How frequently does the individual participate with others in recreational, leisure and sporting activities?
- Does the individual have a range of recreational, leisure and sporting activities to choose from?
- Are these activities segregated or mainstream?

Systemic barriers

What is the general public's attitude towards people with a disability?

Do the general public respect for the rights and dignity of people with a disability?

Do people with a disability fully participate in political and public life?

The Summer Foundation is currently utilising the tools on the following page to evaluate the quality of life of people receiving services through the *my future my choice* program in Victoria.

Domain	Variable	Tool
Community Inclusion		
	Community integration	Community Integration Questionnaire (CIQ)(Willer et al., 1993)
	Frequency of social contact	1 item from my future my choice planning tool (Winkler, Sloan, & Callaway, 2007b)
	Frequency of community access	1 item from my future my choice planning tool (Winkler et al., 2007b)
	Frequency of going outside	1 item from my future my choice planning tool (Winkler et al., 2007b)
	Life Roles	Life Roles Checklist (Part 1)(Oakley et al., 1986)
Choice		
	Choice	Resident Choice Scale (13 items) (Hatton et al., 2004)
Health		
	Complex care needs	Simplified checklist of health issues section on my future my choice planning tool
	Weight range	Body mass index
	Neuropsychiatric sequelae	Select items from the Health of the Nations Scale (Fleminger et al., 2005)
	Challenging behaviour	Checklist – presence of behaviours defined on the Overt Behaviour Scale (Kelly et al., 2006)
Factors		
	Level of awareness	Rating by observation
	Additional services received	Semi-structured interview
	Staff turnover	Semi-structured interview
Families		
	Quality of Life	Personal Wellbeing Index (PWI) (R.A. Cummins, 1997)
	Impact of injury or illness on the family	Family Outcome Measure (FOM) (Simpson & Winstanley, 2009) & semi-structured interview
Service providers		
	Changes observed as a result of move or package or any ongoing concerns	Semi-structured interview
	Number of staff providing direct support, staff turnover, additional services received.	Semi-structured interview

At the end of this evaluation the Summer Foundation plans to collaborate with the providers of shared supported accommodation for this target group to determine which instruments are useful for the ongoing evaluation of the quality of the service provided to residents.

Specialist Responses

In our previous submission we cited outcomes from a comprehensive review of both national and international research regarding the provision of rehabilitation programs to people with catastrophic brain injuries for the ABI: Slow to Recover Program Southern Health (Sloan, 2008). The findings included:

- In order to provide a comprehensive continuum of care, the systematic availability of slow stream rehabilitation across the entire lifetime following catastrophic brain injury is required
- Individuals in minimally conscious or vegetative states may pass through various phases of consciousness at varying points post injury. As such, the timing and nature of rehabilitation intervention will be influenced by an understanding of the level of consciousness of the individual
- Functions and skills can emerge many years after catastrophic brain injury, highlighting the importance of long-term intervention and the importance of minimising secondary complications that may otherwise hinder future progress
- The brain's recovery potential is influenced by the physical and social environment to which the individual is exposed. This points to the need for environmental stimulation, opportunities for learning, minimisation of the experience of pain and stress and early intervention
- Optimal recovery can be promoted by minimising secondary health complications such a neurological, musculoskeletal, skin, respiratory and digestive issues
- Skill development is encouraged by providing consistent and repeated opportunities for contextualised practice of personally meaningful activities
- Disability management plans require that skills and routines which are developed in active rehabilitation phases are maintained over time when therapy input is reduced

- Better health status and functional outcomes are seen following specialist ABI rather than generic programs, indicating that expert knowledge and experience in working with catastrophically brain-injured individuals is crucial to outcome
- Progress towards role participation is an overarching long term goal following catastrophic brain injury and requires a level of resources and rehabilitation input to achieve
- The individual's changing level of insight and readiness to benefit from therapy necessitates monitoring as well as long-term, flexible funding and dynamic intervention
- Given high levels of family and carer distress, provision of education and training and support for caregivers is an essential component of ABI rehabilitation (Sloan, 2008).

It is argued that to effectively implement the knowledge, skills and attitudes identified above, in addition to generic disability support with a focus on social inclusion, a specialised and highly trained workforce is required.

Capacity Building | Indigenous Communities

The Summer Foundation supports the Productivity Commission contention that additional strategies will be required to ensure access to disability services for Aboriginal and Torres Strait Islander people. In 2010 the Summer Foundation joined with the Rumbalara Aboriginal Cooperative (RAC) Aged Care and Disability Services to provide an evidence base and framework to assist RAC Aged Care and Disability Services and the Department of Human Services (DHS), Disability Services Hume Region to progress access to disability services for Aboriginal and Torres Strait Islander (ATSI) people with a range of disabilities residing in the Hume Region. Key outcomes of the project include:

- An analysis of the nature and causes of disadvantage and exclusion of ATSI people with disabilities in the current project has found multiple disadvantage and multiple barriers across all dimensions of the social inclusion/exclusion paradigm. In the current project this is reflected in the underrepresentation of ATSI people with disabilities accessing disability services and associated unmet need.

- A number of protective factors with the potential to reduce risk were found. One of the strengths of the community is that ATSI people with disabilities are not excluded within their own community, they are community members, are valued and considered 'special', and their problems are community problems. RAC Aged Care and Disability Services has an extensive and impressive history of service provision to their community, they have the experience, connections and know the stories. RAC Aged Care and Disability Services has demonstrated, a capacity to develop tailored services using locational approaches, with preservation of family, kinship and culture at the fore, in response to the presenting needs of community members including those community members with disability.
- The partners have a mutual understanding that there are no simple solutions and that new approaches to community problem solving are needed. Many opportunities to build capacity, drawing on the respective partners' individual, community and organisational strengths have been identified. This includes: professional development opportunities where expertise is shared, to increase the capabilities of RAC staff to assess eligibility, in compliance with State government disability legislation and associated policy; and DHS staff to implement effective cultural practice and the engagement of RAC Aged Care and Disability Services in a meaningful partnership.

A copy of the report is attached (Appendix A).

Implementation of a pilot National Injury Insurance scheme (NIIS) in Victoria

The case for a separate, but parallel scheme to support those with catastrophic life-long injuries is well stated. In our original submission we put forward that Victoria is well placed to develop a good service system for people with severe to profound disabilities, by building on the existing infrastructure, expertise and the good work undertaken across the Victorian acquired brain injury compensable, non-compensable, and generic disability service systems. In Victoria there are many examples across the sector of positive practice and innovation to build on. Notably the work here is characterised by collaboration and partnerships, research, the application of evidence and integrated data to inform policy, the sharing of practice wisdom across health, rehabilitation and disability sectors, planning for sustainability and building joined-up services and whole-of-government solutions. This provides significant capacity for expansion and therefore the integration of a Disability Long Term Care and Support Scheme and in particular the NIIS.

Michelle Newland demonstrates the potential of young people in nursing homes and the value of investing in them. Michelle was 19 years old when she suffered a near-fatal asthma attack, which resulted in a severe brain injury. Michelle spent 18 months in a nursing home, most of her time spent lying in bed because there was so little to do.

In Australia today we have a grossly unfair system that can mean a dramatically different outcome for anyone that has an acquired brain injury. Through her hard work and the tenacity and support of her parents, Michelle has regained her continence, re-learned to talk, swallow, read, dress, walk and swim. She would never have realised her potential languishing in a nursing home and she hasn't finished yet. Michelle has recently documented her story in a 5 minute video clip which is available to view here http://www.youtube.com/watch?v=QxLpJh_FGtw. A National Disability Long Term Care and Support Scheme would address this inequity.

Conclusion

Over 250 people under 50 are admitted to nursing homes each year in Australia. Young people end up in nursing homes because the existing disability service system has failed them.

Without a commitment to increase resources and implement responses to address housing and support needs and systemic change, this group will once again become lost to the system. The Summer Foundation believes that a National Disability Long Term Care and Support Scheme is an essential reform and strongly supports the recommendations contained in the Productivity Commission Draft Report.

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Enabling Indigenous Access to Disability Services

Final Report | March 2010

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Executive Summary

The following report is the outcome of a joint project of Rumbalara Aboriginal Cooperative (RAC), Aged Care and Disability Services and Summer Foundation Ltd. The overall aim of the project is to provide an evidence base and framework which will assist RAC Aged Care and Disability Services and the Department of Human Services (DHS), Disability Services Hume Region to progress access to disability services for Aboriginal and Torres Strait Islander (ATSI) people with a range of disabilities residing in the Hume Region.

To achieve these aims a literature review was completed and a series of individual interviews, focus groups and attendance at scheduled interviews were undertaken. Consultations took place with community members, staff from mainstream services and staff from RAC services. Interviews comprised an overview of the project and a series of questions designed in response to the project aims.

The Australian Government's definition of social inclusion –

“people have the resources (skills and assets, including good health, opportunities and capabilities) they need to: Learn participate in education and training; Work participate in employment, unpaid or voluntary work including family and carer responsibilities; Engage connect with people, use local services and participate in local, cultural, civic and recreational activities; and have a voice influence decisions that affect them” (Social Inclusion Unit, 2009) and the *Australian Public Service Social Inclusion and Policy Design and Delivery Toolkit* (2009): *“building partnerships with key stakeholders; developing tailored services; giving a high priority to early intervention; building joined-up services; using an evidence-based approach; using local approaches; planning for sustainability and building on individual and community strengths”* (2009, page 1)

– provides a methodology which aims to influence policy design and delivery ensuring better outcomes for disadvantaged individuals and groups. The definition of social inclusion and supporting methodology is based on evidence derived from a decade of application in Europe and more recently in Australia regarding communities experiencing concentrations of disadvantage and exclusion. The key areas of disadvantage identified by the Social Inclusion Unit (2009) include: homeless people; people with disabilities; indigenous Australians; communities experiencing concentrations of disadvantage and exclusion; and jobless families with children. The definition and supporting policy were utilised to code qualitative data into meaningful themes and develop recommendations, given the high degree of relevance to the current project.

Learnings from the literature and the current project validate the Australian Government targeting of people with disabilities and ATSI people as social inclusion

priority groups. An analysis of the nature and causes of disadvantage and exclusion of ATSI people with disabilities in the current project has found multiple disadvantage and multiple barriers across all dimensions of the social inclusion/exclusion paradigm. In the current project this is reflected in the underrepresentation of ATSI people with disabilities accessing disability services and associated unmet need.

A number of protective factors with the potential to reduce risk were found. ATSI people with disabilities in the current project are not excluded within their own community; they are community members, are valued and considered 'special', and their problems are community problems. RAC Aged Care and Disability Services has an extensive and impressive history of service provision to their community; they have the experience, connections and know the stories; to access existing social and health programs you need only identify as ATSI. RAC Aged Care and Disability Services has demonstrated, a capacity to develop tailored services using locational approaches, with preservation of family, kinship and culture at the fore, in response to the presenting needs of community members including those community members with disability. This is not meant to suggest that the organisation does not see a need for disability specific responses. Unmet need resulting in the denial of opportunities and capabilities needed to participate within their own community, and the wider community have been identified. The organisation recognises the valuable professional development opportunities available to staff and tangible benefits to community members with disabilities arising from partnerships with 'experts' in the disability sector.

Both RAC Aged Care and Disability Services and DHS Disability Services Hume Region have demonstrated a commitment to the progression of this initiative. The partners have a mutual understanding that there are no simple solutions and that new approaches to community problem solving are needed. Many opportunities to build capacity, drawing on the respective partners' individual, community and organisational strengths have been identified. This includes: professional development opportunities where expertise is shared, to increase the capabilities of RAC staff to assess eligibility, in compliance with State government disability legislation and associated policy; and DHS staff to implement effective cultural practice and the engagement of RAC Aged Care and Disability Services in a meaningful partnership. In recognition of the obvious benefits hope was expressed that the partnership will continue, strengthen and grow, and an undertaking was made to work together and construct the partnerships necessary to progress this initiative.

Project Management

Project Partners

The project and this report is the result of a partnership between Summer Foundation Ltd and Rumbalara Aboriginal Cooperative.

- Equity | Each partner has an equal right to be at the table
- Transparency | Each partner will demonstrate openness and honesty in the working relationship
- Mutual Benefit | The partnership will work towards achieving specific benefits for each partner over and above the common benefits

Rumbalara Aboriginal Cooperative (RAC)

Rumbalara was established from the Maloga and Cummeragunja missions. These missions were located on both sides of the Murray River near Barmah in NSW.

Rumbalara means *at the end of the rainbow*, and identifies the ATSI community in the Goulburn Valley area of Victoria, located between Shepparton and Mooroopna. Rumbalara started as a shanty town on the river flats in the 1940s. In 1958 Rumbalara was developed as a transitional housing estate for aboriginal people which operated until the 1960s.

In the early 1970s it became the administrative centre for Rumbalara Aboriginal Cooperative, which runs the community's health, social and cultural heritage programs. It also became the central point for the political aspirations and policy development for ATSI people in the Goulburn Valley. The expansion of Rumbalara Aboriginal Cooperative over the years has seen it become a major provider of primary health care and community services to the Aboriginal community. Most members of the Rumbalara community are descendents from the Yorta Yorta people, the traditional owners of the Goulburn Valley area, which is home to the largest ATSI population outside of Melbourne.

RAC is an Aboriginal Community Controlled organisation, governed by a Board of Directors, elected from the community, by the community. RAC provides proactive, transparent services aimed at reducing the inequities in health and socioeconomic status of the ATSI community for over 27 years. RAC's provides services in the areas of: finance, aged care and disability, families, justice and well-being and health. RAC Aged care and Disability Services has been operating for over 21 years,

supporting people to live in their home environment for as long as possible. Geographically the services cover 43% of Victoria from Corryong to Mildura, down to Macedon, and across to Wallan and from Albury to Wentworth in NSW. The service encompasses ATSI family kinship networks which cross various geographical/funding boundaries.

Summer Foundation Ltd

The Summer Foundation was founded in January 2006 and is dedicated to overcoming the concerns of a section of our community, which is overlooked, namely young people living in residential aged care. The Foundation focuses on practical research and seeks to provide workable solutions to improve the health and wellbeing of this group. The Foundation has completed a number of projects, which demonstrate a significant understanding and knowledge of participants in the *my future my choice* initiative.

Service development

Rumbalara Aboriginal Cooperative (RAC)

- Home and Community Care for over 21 years, in the Greater Goulburn Valley Area
- Community Aged Care Packages in Hume and Loddon Mallee Regions in Victoria and Southern Riverina Murray Region in New South Wales
- Extended Aged Care at Home (EACH) in Southern Orana Far West and Southern Riverina Murray
- EACH Dementia Loddon Mallee and Southern Riverina Murray
- Indigenous Respite Program (NRCP) – in Hume and Loddon Mallee
- The Galnya Maya Program – respite program for younger people with moderate to profound disabilities, in Shepparton area.

Summer Foundation Ltd

- The publication of DVD and Booklet: *From a home to their homes*
- The publication of *Younger People in Residential Aged Care: Support needs, preferences and future directions* my future my choice

- The implementation workshops focusing on transition
- The Summer Foundation Knowledge Network
- Research which examines the outcomes of transition from RAC to the community

Project Methodology

The overall aim of the project is to provide an evidence base and framework which will assist RAC Aged Care and Disability Services and the DHS, Disability Services Hume Region to progress access to disability services for Aboriginal and Torres Strait Islander (ATSI) people with a range of disabilities residing in the Hume Region. The project commenced in August 2009 and was completed in February 2010. Project outcomes include:

- a report documenting demographics and disability, support needs and barriers to service access
- pathways and partnerships and strategies for working in culturally appropriate ways
- strategies to support initiative sustainability and build capacity including training and mentoring support to RAC staff
- recommendations to inform an action plan

To achieve this aim a literature review was completed and a series of individual interviews, focus groups, and attendance at scheduled meetings were undertaken. Consultations took place with community members, staff from mainstream disability services and mainstream services for example Centrelink, and staff from RAC services. Interviews comprised an overview of the project and a series of questions designed in response to the project aims.

The Australian Government's definition of social inclusion –

“people have the resources (skills and assets, including good health, opportunities and capabilities) they need to: Learn participate in education and training; Work participate in employment, unpaid or voluntary work including family and carer responsibilities; Engage connect with people, use local services and participate in local, cultural, civic and recreational activities; and have a voice influence decisions that affect them” (Social Inclusion Unit, 2009) and the *Australian Public Service Social Inclusion and Policy Design and Delivery Toolkit* (2009): *“building partnerships with key stakeholders; developing tailored services; giving a high priority to early*

intervention; building joined-up services; using an evidence-based approach; using local approaches; planning for sustainability and building on individual and community strengths” (2009, page 1)

– provide a methodology which aims to influence policy design and delivery ensuring better outcomes for disadvantaged individuals and groups. The definition of social inclusion and supporting methodology is based on evidence derived from a decade of application in Europe and more recently in Australia regarding communities experiencing concentrations of disadvantage and exclusion. The key areas of disadvantage identified by the Social Inclusion Unit include: homeless people; people with disabilities; indigenous Australians; communities experiencing concentrations of disadvantage and exclusion; and jobless families with children. The definition and supporting policy were utilised to code qualitative data into meaningful themes and develop recommendations, given the high degree of relevance to the current project.

Project Report

The following section provides the key findings regarding demographics, disability prevalence, barriers to access and support needs.

Demographics, Disability Prevalence, Barriers to Access and Support Needs

About Hume Region: Aboriginal and Torres Strait Islander Demography

The Australian Bureau of Statistics (2006) census has shown an increase in ATSI population in Victoria from 27,846 people in 2001 to 30,053 people in 2006, an increase of approximately 9.2%. ATSI people comprise 0.62% of the total Victorian population.

The Hume Region

The Hume Region is composed of 12 areas covering North Eastern Victoria and the Goulburn Valley. The Regions population is approximately 256,000 persons with major concentrations in Shepparton, Wodonga, Wangaratta, Benalla and Seymour. Physically the region is defined by the Great Dividing Range in the East and the Murray River in the North with the Goulburn Valley area to the West.

At the last ABS census count in 2006, it was reported that the Hume Region had approximately 3686 ATSI people living in the region or around 1.5% of the Hume Regions general population.

The majority of ATSI people living in the Hume Region, according to 2006 census data, resided in three local government areas:

- Greater Shepparton City Council 1886
- Wodonga Rural City Council 475
- Mitchell Shire Council 356

RAC and the Hume Region Aboriginal Reference Group (2003-2006) suggest that this is an underrepresentation of the population. Underrepresentation of data regarding ATSI people has been attributed by the ABS (2003) to issues identified in

the collection of ATSI population data including variable registration of indigenous status and a lack of a national Register of critical information for example Births.

Data from the RAC Health Service (2010) and reports to the Australian Indigenous Health Infonet (2010) suggests that ATSI people represent at least 7.4% of the regions population or approximately 6,369 people.

Key Findings | Hume Region: ATSI Demography

- Accurate data about the ATSI population is not available
- Population figures range from 3,686 to 6,369 ATSI people

About Incidence and Prevalence of Disability

Population-based statistics

The Australian Institute of Health and Welfare (2006) attributed difficulties in obtaining data on disability among ATSI people to problems in definition and construction as well as qualitative and quantitative data collection methodology. Population-based data is therefore limited. However, the Australian Institute of Health and Welfare and the Australian Bureau of Statistics (2005) estimated that severe and profound disability rates were more than twice as high among ATSI Australians compared to non-indigenous Australians. It should be noted that prevalence of disability in non-indigenous Australians is 18 per cent (Australian Institute of Health and Welfare, 2003). In the only Australian study of its kind, Thompson and Snow (1994), found that the level of reported disabilities among the Aboriginal population of the Taree area was 2.5 times higher for males and 2.9 times higher for females than for males and females in the total Australian population. The levels of handicap were 1.7 times higher for males and 1.8 times higher for females, and those of severe handicap 2.4 times higher for males and 2.3 times higher for females.

It is worth exploring here the ATSI construction and understanding of disability, arguably it is the difference in this understanding that has a significant impact on disability incidence and prevalence data collection.

ATSI Construction and Understanding of Disability

What is unique and 'additional' to the experience of being an ATSI with a disability relates to the inclusive aspects of ATSI culture (O'Neil, Kirov and Thompson, 2004) and the positive way ATSI people understand and construct disability (Aboriginal

Disability Network, 2007). These factors are generally not understood by non-indigenous Australians and have resulted in a lack of reliable data regarding the incidence and prevalence of disability amongst ATSI people and a significant underrepresentation of ATSI people with disabilities accessing disability services.

ATSI people construct and understand disability differently to non-Indigenous Australians. O'Neil, Kirov and Thompson, (2004) found that ATSI people with disabilities are seen as special, that disability is viewed as a community rather than personal problem and that reliance on others as opposed to independence is a cultural norm.

"Disability can't be seen alone, they have a family and a community, it is the connections that are important" (Project Participant, 2009)

"My mother said kids with disability were the special ones, that's how we were brought up, we looked out for them" (Project Participant, 2009)

Further, Carers Australia suggested that ATSI carers do not self-identify in many instances, seeing their caring role as a natural extension of family or kinship obligations.

ATSI carers are less likely to see themselves as carers because caring for their own is what they do" (House of Representatives Standing Committee on Family, Community, Housing and Youth, 2009)

For many reasons there is no definitive data regarding the incidence and prevalence of disability in the Hume Region among ATSI people. If you simply assume however that the incidence of disability for ATSI people is at least that of the non-indigenous people, i.e. 18% there are 663 ATSI people with a disability (Population base of 3686) or 1.080 ATSI people with a disability (Population base of 6,369) of which approximately 300 people would have a profound disability (O'Connell, 2005).

Underrepresentation – Disability Services

The significant underrepresentation of ATSI people accessing services on a population basis reported by the Aboriginal Disability Network New South Wales (2007) is replicated in Victoria. According to data provided to the current project by the DHS Disability Services Hume Region, 36 ATSI people with disabilities access disability services, i.e. are registered as eligible for disability services and of 278 people in DHS funded supported accommodation 8 are of ATSI background, from a population base of between 3,686 or 6,369 ATSI people. Other regional data of note includes:

- 1075 ATSI people said that they provided unpaid assistance to a person with a disability two weeks prior to census night (ABS, 2006)
- 900 people receive disability support pensions, 100 people receive a carers allowance (Centrelink Shepparton, 2009)
- 16 of the 100 students who attend Verney Street school are ATSI (Verney Street School, 2009).

Examples of over representation

Corrections

- “The data as you would expect is not great however there are 60 ATSI offenders on community based orders in the Hume Region with about 60% reporting to the Shepparton CCS, approximately 15 have an acquired brain injury from the Shepparton cohort, 3 have an intellectual disability or 28% of the CBO population. There are currently 2 ATSI Offenders who identify Hume as their region of origin in prison” (Corrections Victoria August 2009)

Employment

- Unemployment rate for ATSI across Australia is 16% (ABS, 2006). In the Hume Region employment rates for ATSI people especially in mainstream settings is very low (O’Connell, 2005).

Key Findings | Incidence and Prevalence of Disability

- Accurate data about ATSI people with disabilities is not available
- Severe and profound disability rates are more than twice as high among ATSI people compared to non-indigenous Australians
- ATSI people with disabilities are seen as special, disability is viewed as a community rather than personal problem and reliance on others as opposed to independence is a cultural norm
- There is a significant underrepresentation of ATSI people accessing services on a population basis

About Barriers to Service Access

There is a significant body of research regarding barriers to service access. Significant barriers were also reported as part of the current project. In addition

therefore to the way ATSI people understand and construct disability discussed previously, other barriers to service access identified include:

“The experiences of many aboriginal people with a disability is that their disability is often medicalised. Interventions often simply treat the individual’s health condition without considering the broader implications of their condition, i.e. the social barriers to participation.” (Telling it Like it is, 2007)

“ Many Aboriginal people consider both health and disability related conditions to be disabilities. This is not surprising given that many health issues such as renal failure, diabetes and chronic asthma-some of those named by Aboriginal people to be disabilities-can result in restrictions in everyday activity.” (Telling it Like it is, 2007)

“Policy and structural failures. These failures include services that are poorly targeted and located as well as culturally insensitive or inappropriate. Furthermore there are very few ATSI specific services, or non-indigenous disability services with Aboriginal staff.” (Telling it Like it is, 2007)

“Access to services requires filling out forms and talking up your issues-community members are not comfortable talking about what is really going on, because of the shame, they will tell you what they think you want to hear..... mainstream workers assume people understand, but they don’t ...it is all jargon”. (Project Participant, 2009)

“The things people are asked to talk about by mainstream service providers are deep and not what they would normally share” (Project Participant, 2009)

“I really have to work hard to get them to apply, to test eligibility and talk up their story” (Mainstream Worker, 2009)

“Poverty which impacts on affordability of services, ability to get around” (DHS Southern Region, Region Koori Disability Information Kit, 2009)

“One of our mothers had a bad experience when her son was a toddler, (he is now 21) who has severe cerebral palsy, and was admitted to hospital for respite. When she came to visit him she found him alone in a bean bag with ants crawling across his mouth. She will only take him to hospital now if it is an emergency. She is worried about who will look after her son if she passes.” (Project Participant, 2009)

The factors contributing to Indigenous use or non-use of Disability Support Services are complex and they range from fear, racism, stereotyping, misinformation, shame, attitudes towards Aboriginal clients among service providers or the interpretation of what a disability is defined as within the

aboriginal community (DHS Southern Region, Region Koori Disability Information Kit, 2009)

Communities on the whole reported low levels of service usage and access attributed to a lack of information, distance and lack of transport, fear of involvement with government agencies and lack of aboriginal workers at agencies (DHS Disability Services, 2000)

Key Findings | Barriers to Service Access

- Factors contributing to service use or non-use are complex
- The majority of ATSI people seeking services would need considerable support to do so

About Multiple Disadvantage

Having a disability and being indigenous are key areas of social disadvantage recognised by the Australian Social Inclusion Unit. Arguably the experience of having a disability is further exacerbated by the experience of being ATSI and has been described by ATSI people as that of “*double disadvantage*” (National People with Disabilities Carer Council, 2009). The aim of the following section is to articulate the social exclusion of people with disabilities and ATSI people as distinct groups, and then to document the social exclusion experienced by ATSI people with disabilities. Finally this section will discuss the specific circumstances of the community.

The Experience of Social Exclusion: People with Disabilities

A recent report entitled “*Shut Out: The Experience of People with Disabilities and their Families in Australia*” (National People with Disabilities Carer Council, 2009) identified significant barriers to participation by people with disabilities in the cultural and economic life of the community. Many people with disabilities and their associates reported instances of being segregated, excluded, marginalised and sometimes abused, on a daily basis. The report which was based on 750 submissions and consultation with 2,500 people, emphasises the multiple disadvantage people with disabilities and their families face with exclusion reported

in the areas of participation; rights; justice and legislation; income support and the cost of disability; employment; accommodation education; transport; health and well being; and the built environment.

The report continues attributing the social exclusion of people with disabilities to a number of factors impacting on capability including: misconceptions and stereotypes regarding their ability to learn, explore their potential, succeed or contribute, or the denial of human rights including the right to food, shelter and protection or freedom from abuse or neglect. Or opportunity including: entrenched discriminatory practice impacting on access to services across all dimensions of government, business and the community.

“Many live desperate and lonely lives of exclusion and isolation. The institutions that once housed them may be closed but the inequity remains. Where once they were physically segregated many Australians with disability now find themselves socially, culturally and politically isolated. They are ignored, invisible and silent. They struggle to be seen, they struggle to have their voices heard” (2009, page 11).

The Experience of Social Exclusion: ATSI People

The experience of disadvantage by ATSI people has been dramatically related in the recent report, *“Closing the Gap on Indigenous Disadvantage: The Challenge for Australia”* (Australian Government, 2009). The report identifies significant gaps in the area of life expectancy: approximately 17 years lower than the non-indigenous population where life expectancy is said to be affected by many variables including social economic status, quality and accessibility of the health system, smoking, alcohol, nutrition and exercise, social and environmental factors for example overcrowded housing, poor drinking water and sanitation; child and infant mortality rates, 12.3 deaths per 1000 live births, compared with 4.2 for non-indigenous infants; early childhood development and in particular participation in preschool; numeracy and literacy, where achievement is lower for ATSI students across all year levels; Year 12 attainment 45.3 percent for ATSI, compared to 86.3 percent for non-indigenous; and employment 48% of ATSI people compared to 72 percent of other Australians. While the Australian Government Royal Commission into Aboriginal Deaths in Custody (1991) found that ATSI people were significantly over-represented in the justice system.

Racism, a belief that members of each racial group possess characteristics specific to that race, which are used to distinguish it as being either superior or inferior to another racial group, has been found at individual, institutional and systemic levels and can be overt or covert and manifested in word or action (Gallaher, Ziersch, Baum, Bently, Palmer, Edmonson and Winslow, 2009). In recent years, Paradies

(2006) draws our attention to the association of racism and mental health maladaptive behaviours in found in other countries. The impact on the health of Aboriginal and Torres Strait Islanders of racism has not been well researched (Paradies, Harris and Anderson, 2008) however the Human Rights and Equal Opportunity Commission (1991, cited in Paradies, 2006) concludes that racism *“permeates the very fabric of contemporary Australian society.”*

The evidence in support of the social exclusion of people with disabilities and ATSI people as distinct groups is overwhelming. These groups face individual and systemic discrimination across all dimensions of the social inclusion/exclusion paradigm. Hunter (1999) described ATSI disadvantage as multidimensional reflecting its complexity and cumulative nature. In the current Australian context this means the absence of resources, and exclusion from opportunities and capabilities needed to participate in education, work and play, have relationships or a political voice. In practical terms a lack of access to disability supports resulted in *“people being stuck at home 24/7”* (Project Participant, 2009), denied the opportunities and capabilities needed to participate within their own community, or within the wider community.

Key Findings: Multiple Disadvantage

- ATSI people are among the most socially excluded in Australia
- The experience of having a disability is further exacerbated by the experience of being ATSI “double disadvantage”

About Disability Support Needs

There was significant congruence between research and/or consultation outcomes presented above and the findings of the current project regarding complexity. RAC Health Services and Aged Care and Disability Services report increasing numbers of people with disabilities and their families seeking support. Consultation and analysis of active lists found significant unmet need in a number of areas including: aids and equipment; accommodation; information and advocacy; respite and carer support programs; support to manage challenging behaviours; skills and social skills development; community access and participation opportunities; day programs and employment; case management; and transport.

Possibly the most significant finding however was the apparent overrepresentation of people with multiple and complex needs. That is, a disability, (intellectual or acquired brain injury); a mental illness; and/or an alcohol or other substance misuse issue;

behaviour that would expose the individual or community to risk; and a significant health issue for example obesity or heart disease.

“There are many issues in lots of families, alcohol or drugs, violence (against self and others), mental illness, disability, they have health problems” (Project Participant, 2009)

“One of my Aboriginal clients witnessed and suffered shocking violence, his father has an acquired brain injury so there was poor parenting, he was introduced to cannabis as a 12 year old, there is nothing suitable for him, he needs mentoring from Aboriginal men and stable accommodation where he can learn life and social skills. I would like to work more closely with aboriginal workers” (DHS Disability Services Worker, 2009)

Protective Factors, Localised Approaches and Building on Community Strengths

A number of protective factors with the potential to reduce risk were identified. ATSI people with disabilities in the current project are not excluded within their own community, they are family and community members, are valued and considered ‘special’, and their problems are community problems. Moreover, project participants provided numerous examples of person and family centred responsive and flexible service delivery. Examples included: the provision of runners to a 28 year old with an acquired brain injury to enable his participation in sporting activities/events his attendance, gives his grandmother a break: support to attend a jewelry making course with other ATSI women and have access visits to her children, for a 29 year old woman with an ABI, who was being cared for by her father but is now caring for him (due to chronic illness); regular respite in a local motel for a 35 year old man who lives with his ageing carers and has been banned from mainstream services due to violence; support to a 28 year old women with an ABI, who lost her mother and therefore her carer, was being treated for depression and was suicidal, to reconnect with family living elsewhere; support to the family of a 14 year old boy with intellectual disability to resume attendance at school, where it had been reported that he was thriving.

Project participants highlighted the individual and familial benefits of for example the Galnya Maya Program, which provide skills development and engagement opportunities to 8 men and 6 women (with a range of disabilities i.e. ABI, intellectual disability and physical disabilities) who attend 2 days per week, and respite for their families.

Other RAC services also act as entry points and provide a range of “disability supports.” Mothers with disability and their babies and mothers with babies with

developmental delay attend mother and baby support/play groups; people with alcohol related brain injury attend AOD treatment programs; young people in or at risk of entry into the youth justice system are supported by a youth worker; family services are provided to families where family members have a disability; aids and equipment and other supports are organised by the health service in conjunction with Aboriginal Liaison Officers at the Goulburn Valley Health; and, elders including elders with disability are involved in regular activities.

Project participants suggested a number of ways that these 'generic' responses could be enhanced including: General Practitioner access to timely neuropsychological and other formal assessment to better inform responses and referral for disability support; play equipment/craft materials; training; support to link into disability specific programs and/or support to transition for example to school. Finally, Project participants advocated for the development and implementation of strategies to inform possible early intervention responses; areas highlighted included: babies at risk of foetal alcohol syndrome; children over the age of 5 years at risk of falling behind or leaving mainstream or special education; children and young people at risk of entry to youth justice; suicide prevention; families at risk of breakdown or homelessness and people at risk of developing alcohol related brain injury.

Meeting disability support needs

A common theme in discussions regarding responses to presenting support needs is represented in the following quotes:

"People don't need flash things, just little things can make it easier"
(Project Participant, 2009)

"We are not up ourselves, we don't want more than anybody else we just want to be a part of this community" (Project Participant, 2009)

It is clear from consultation however that support needs cannot even begin to be met until community members are registered as either carers with Centrelink, in order to receive basic commonwealth entitlements or as a person with a disability, with DHS Disability Services Hume Region and therefore eligible for disability services. Given this therefore, stakeholders agree that the most significant need identified was the need for 'case management', help to navigate the disability service system, *help to get on the books, fill out the forms* advocacy to ensure access to culturally appropriate disability services and finally advocacy to secure an appropriate outcome.

With regard to achievement of outcomes one participant said: *"We have been asked what we need, we give information, have groups, but nothing ever comes of it"*

sometimes we don't even give feedback, why would we trust it." (Project Participant, 2009)

To end on an optimistic note, it is heartening to read a recommendation that the National Disability Strategy, currently under development, should include statements acknowledging: ATSI people as the original inhabitants of Australia and custodians of the land; the destruction of ATSI communities that occupation of Australia has produced; and, the resulting dislocation and alienation as the primary contributor towards disability in ATSI Communities (The National People with Disabilities Carer Council, 2009).

Key Findings: Disability Support Needs

- Significant unmet need was identified including: aids and equipment; accommodation; information and advocacy; respite and carer support programs; support to manage challenging behaviours; skills and social skills development; community access and participation opportunities; day programs and employment; case management; and transport.
- A significant proportion of people were found to have multiple and complex needs
- RAC Aged Care and Disability Services are providing a range of services to ATSI people with disabilities
- A number of protective factors with the potential to reduce risk were identified
- The most significant need identified was the need for 'case management', help to navigate the disability service system, *help to get on the books, fill out the forms* advocacy to ensure access to culturally appropriate disability services and finally advocacy to secure an outcome.

Pathways And Partnerships and Capacity Building

The following section provides the key findings regarding pathways and partnerships and capacity building.

Pathways and Partnerships

Both RAC and the DHS Disability Services Hume Region have demonstrated a commitment to the progression of this initiative. There has been an open and honest dialogue throughout and the project team has had unlimited access to data,

personnel and other relevant information. The leadership, provided by Lena Morris (RAC) and Cecily Fletcher (DHS) has seen the respective organisations face up to the issues and take ownership of the values impacting on service access. Most importantly the partners have a mutual understanding that there are no simple solutions and that new approaches to community problem solving are needed. The hope for this project is that the partnership will continue, strengthen and grow to include other key stakeholders in recognition of the mutual benefits to the Hume Region.

Other potential project partners to consider for inclusion in problem solving activities are: RAC Health; AOD; Youth; and Family services; Community Interlink; CentreLink; the Goulburn Valley Hospital; Verney Street School; DHS Youth Justice; Mental Health and Drug Treatment Services; Aged Care and Corrections Victoria.

Finally, consideration of other regional and/or statewide initiatives of significance should be made by the project partners for example reference to the Hume Region Aboriginal Services Plan and the development of the Victorian ATSI Disability Network.

Key Findings | Pathways and Partnerships

- Both RAC and the DHS Disability Services Hume Region have demonstrated a commitment to the progression of this initiative
- The partners have a mutual understanding that there are no simple solutions and that new approaches to community problem solving are needed
- The hope for this project is that the partnership will continue, strengthen and grow to include other key stakeholders in recognition of the mutual benefits to the Hume Region.

Building Capacity: RAC workers

The primary aim of Australian governments' social inclusion approach is to build capacity. The starting point for this, at the family and/or individual level is to improve quality of life. That is to ensure that people have the capacity i.e. *"people have the resources (skills and assets, including good health, opportunities and capabilities"* (Social Inclusion Unit, 2009), to make informed decisions about issues that affect them. In practice, similar criteria could be applied to a group, community or organisation.

Lena Morris the Manager of RAC Aged Care and Disability Services was asked about building the capacity, of RAC Aged Care and Disability Services staff made the following points:

- *They (community members) trust our staff, we have worked with families for a long time, they come to us. We do not want to lose what we have gained.*
- *We are frustrated that we are not able to respond, we are asked to provide services that we are not funded for. We are not funded to provide support to community members to access mainstream services, we get requests from mainstream services, who have a package to work with a family, to provide secondary consultation and we are not funded for this. Our people should receive the same services as anyone else with a disability in the community receives*
- *Workers are part of the community: they have family members with disability, they are carers, sometimes they need care*
- *We are creative with what we have, we have to be, people work very hard to meet the criteria and targets*
- *We have recently employed a staff member with certificates in disability, our staff need training, we always strive to employ workers with the right qualifications, it would be good if there was more information about disability services.*

Training Needs

The training needs of RAC Aged Care and Disability Services staff are the same as you would expect for any worker providing services to people with a disability. With a couple of notable exceptions that is: training to manage vicarious trauma and an emphasis on working with disadvantage and multiple and complex needs i.e. “*double disadvantage*.”

The Cooperative Research Centre for Indigenous Health, (2009) argues that in developing capacity there should be no compromises in meeting standards or in work performance, as “*only by holding to the highest standards can we ever have any hope of closing the gap.*” However, it is understood that “*that there are ways of ensuring people reach these standards that take into account particular circumstances, background and responsibilities from which people emerge.*”

Key Findings: Building Capacity: RAC workers

- Worker and organisation strengths should be acknowledged and incorporated into any capacity building strategies
- Training and Information strategies should incorporate responses to vicarious trauma and “*double disadvantage*”

- Learning approaches/methodologies should be individualised, flexible and responsive.

Building Capacity: Mainstream Workers

Working in Culturally Appropriate Ways

Angela (not her real name) works in a mainstream service in Shepparton and was described by a number of people as having a good working relationship with the community and with community members. Angela was described glowingly as a mainstream worker that “*went that extra mile.*” When asked to describe what this looked like community members and RAC workers discussed: her knowledge of families and relationships and understanding of the issues/burden being faced; her knowledge (Angela understood that some of the requirements of her job breeched tradition and strove to find alternatives to meet organisational and client needs); her respect and understanding of the role of elders (Angela had earned permission to use terms such as Auntie and Uncle when addressing people); length of time in the job, she had been in her current position for well over 5 years; her ability to explain and explaining as many times as was needed and sometimes not just explaining but doing. From a systems perspective Angela consults, asks for opinions, provides information, listens and facilitates links with other mainstream organisations. She also advocates within her organisation on behalf of ATSI people and works alongside ATSI workers employed by the organisation. Clearly Angela reflects what is described in the literatures as effective cultural practice incorporating four elements:

- *Awareness and knowledge of culture*
- *An awareness of how our own culture influences our perceptions and our practice (critical reflective practice)*
- *Skill development in appropriately culturally safe responses in relation to another culture*
- *A commitment to social justice and anti racist practice.*

(Telling it Like it is, 2007)

The Cooperative Research Centre for Indigenous Health (2009) recently published a guide to support the supervisory relationships of ATSI researchers and their research supervisors. The Guide provides tips, which can be generalised to the current project including:

- *Listen and watch*
- *Work as collaboratively as possible-share information and encourage all team members to work this way and help each other out*
- *Ask the worker what would help and support him or her and follow through (if you can't follow through, explain why)*
- *Encourage the worker to ask questions and express views and opinions*
- *Be clear about roles and expectations*
- *Be honest and upfront*
- *Recognise the need for reciprocal skill development, and the time needed to work out how they work together-learning is an ongoing and two-way process*
- *Analyse and talk through issues and strategies together, recognising that you have different perspectives-don't be afraid to ask questions when you are unclear about something*
- *Acknowledge personal difficulties and dilemmas*
- *Encourage a wide circle of professional support*
- *Look out for signs of stress and offer help*
- *Pair indigenous workers with indigenous workers*

Further the guide promotes a way of working which supports cultural safety. Cultural safety, first used in the 90's in New Zealand, refers to a workplace or service which is:

"safe for people, where there is no assault, challenge or denial of their identity; of who they are and what they need. It is about shared respect, shared meaning, shared knowledge and experience, of learning together with dignity, and truly listening" (Williams, 1992: 213)

"Cultural safety is contrasted with institutional or systemic racism, where Indigenous people in Australia have experienced discrimination and disadvantage through prejudice, ignorance, thoughtlessness and racist stereotyping: much institutional racism is unofficial, unnoticed and unintended. Social institutions like schools, the judicial system and health care have their own cultures, specific ways of operating based on narrow understandings of what is normal or proper" (Hollinsworth 1998: 54).

Cultural safety in the workplace is about systemic change, not just individual actions. Institutional practices, values, resources and governance arrangements need to respect cultural, social and human values.

In addition to working in culturally appropriate ways, Muriel Bamblett CEO of the Victorian Aboriginal Child Care Agency, in a presentation to VCOSS (2008) provided the following as requirements for the engagement of ATSI Services in meaningful partnerships:

- Acknowledge and accept the ATSI communities right to self-determination and participation in all aspects of decision-making
- Show high levels of respect in all aspects of engagement
- Acknowledge that ATSI service do not enter partnerships with the same finance and resource capacity
- Undertake a community development approach (Bamblett, 2008).

Finally it should be noted that many of the possible partner organisations identified in the current project employ ATSI workers.

Key Findings | Working in Culturally Appropriate Ways

- There are mainstream workers in the region who have a positive reputation with the community because they *go the extra mile*
- Building capacity in mainstream organisations requires the implementation of effective cultural practice and the engagement of ATSI services in meaningful partnerships
- Many mainstream services in the region employ ATSI workers

Summary and Recommendations

The project aims were two-fold. In the first instance, the project undertook to develop an evidence base regarding the disability support needs of the community. Secondly, the project explored the capacity of RAC Aged Care and Disability Services and services providing disability-specific responses to meet the challenges identified. Finally, the project undertook to distil the evidence collected, enhance our understanding and facilitate the development of an action plan to progress access to disability services for ATSI people with a range of disabilities residing in the Hume Region.

Summary: The Disability Support Needs of the Community

Learnings from the literature and the current project validate the Australian Government targeting of people with disabilities and ATSI people as social inclusion priority groups. An analysis of the nature and causes of disadvantage and exclusion of ATSI people with disabilities in the current project has found multiple disadvantage and multiple barriers across all dimensions of the social inclusion/exclusion paradigm. In the current project this is reflected in the underrepresentation of ATSI people with disabilities accessing disability services in the Hume Region and associated unmet need.

A number of protective factors with the potential to reduce risk were found. ATSI people with disabilities in the current project are not excluded within their own community, they are community members, are valued and considered 'special', and their problems are community problems. RAC Aged Care and Disability Services has an extensive and impressive history of service provision to their community; they have the experience, connections and know the stories; to access existing social and health programs you need only identify as ATSI. RAC Aged care and Disability Services has demonstrated, a capacity to develop tailored services using locational approaches, with preservation of family, kinship and culture at the fore, in response to the presenting needs of community members including those community members with disability. This is not meant to suggest that the organisation does not see a need for disability specific responses. Unmet need resulting in the denial of opportunities and capabilities needed to participate within their own community, and the wider community have been identified. The organisation recognises the valuable professional development opportunities available to staff and tangible benefits to community members with disabilities arising from partnerships with 'experts' in the disability sector.

Summary: Capacity Building

Both RAC Aged Care and Disability Services and DHS Disability Services Hume Region have demonstrated a commitment to the progression of this initiative. The partners have a mutual understanding that there are no simple solutions and that new approaches to community problem solving are needed. Many opportunities to build capacity, drawing on the respective partners' individual, community and organisational strengths have been identified. This includes: professional development opportunities where expertise is shared, to increase the capabilities of RAC staff to assess eligibility, in compliance with State government disability legislation and associated policy; and DHS staff to implement effective cultural practice and the engagement of RAC Aged Care and Disability Services in a

meaningful partnership. In recognition of the obvious benefits hope was expressed that the partnership will continue, strengthen and grow and an undertaking was made to work together and construct the partnerships necessary to progress this initiative.

Recommendations

Having provided an evidence base to support the development and implementation of an action plan it is recommended that an advisory group comprising key stakeholders be established. The advisory group will undertake to progress this initiative in three ways

- The advisory group will acknowledge the importance of history, traditions, culture and spirituality to ATSI people in the provision of culturally appropriate disability services
- The advisory group will ensure that the partners will: *“Act as guardians’ of the partnership’s mission and stand up for its values; coach each other in good partnering behaviour; empower other members of the partnership to be proactive, to be innovative and to be allowed to make mistakes; create hope and optimism when the process seems to be stuck”* (Tennyson, 2003)
- The advisory group will develop actions in relation to the key findings under the headings: *building partnerships with key stakeholders; developing tailored services; giving a high priority to early intervention; building joined-up services; using an evidence-based approach; using local approaches; planning for sustainability and building on individual and community strengths* (The Australian Public Service Social Inclusion and Policy Design and Delivery Toolkit, 2009)

Finally it is recommended that funding provided by DHS Disability Services Hume Region to RAC Aged Care and Disability Services for a disability support worker continue to enable the implementation of actions identified by the advisory group.

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