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DISABILITY ISSUES [UPDATED 2011]:

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The impact of disability on the Central Australian Aboriginal community

a) *the personal, social and financial costs of disability in Australia*

The very high rate of disability, within many families on remote Central Australian Aboriginal communities, means that there are few people without personal stories of being part of providing care for a person with special needs from their family. There is an extreme lack of development of disability supported accommodation options since the early 1990s. There has always been a chronic lack of support services to people with disabilities and their carers, especially in remote Aboriginal communities.

The burden of care falls disproportionally on small groups of older women [and some older men]. These people are often the heads of the more stable and responsible households. They also carry a disproportionate burden of care for their grandchildren, sometimes great grandchildren. The care often includes a considerable financial burden to the carer. Centrelink carer payment entitlements have rarely been claimed, tested and/or accepted. Many of the carers are themselves in receipt of disability support payments or aged care pensions. The housing situation for most carers doesn't reflect the high number of people residing with the carers, and the houses rarely have any level of disability modification to assist with managing the physical burden of care. Disability aids and treatment services are hard to access or entirely unavailable. Mobility is a major problem for people with significant mobility issues. Remote communities do not have adequate roadways or pathways that enable easy wheelchair travel.

The trauma for carers in not being able to adequately care for family members with special needs, impacts on the willingness of many family members willingly being available to support family members with significant special needs. The history of not having disability services that can adequately support carers has been that there has been a significant erosion in the number of willing and suitable carers available on many communities. In particular, there has been a loss of younger, more physically capable carers. Currently what support is available for people with special needs and their carers comes, from largely from community based HACC funded aged care services, the volunteerism of local health clinic staff, some access to Aboriginal traditional healers and from a very small number of visiting allied health and specialist medical staff that may be able to get to the community on rotational basis [often only once in three months].

It should be noted that since the Commonwealth –State Disability Agreement signed in the Northern Territory in early 1990s, [and working off some very small base line figures] the funding allocation for remote Aboriginal communities currently made available demonstrates that;

- there has been very little increase in the number of allied health professionals providing services to remote Aboriginal communities,

- there has been little increase in the number of community based disability specific, supported accommodation beds, and

- there has been little additional money spent on building disability modified accommodation, providing funds to modify existing housing, additional disability aids and equipment, and/or other disability support structures.

The recent history of disability service development in regional centres like Alice Springs is also a dismal story. The last decade has seen lots of reviews but very little action. Across all disability sectors the level of under-resourcing is creating enormous distress for individuals with special needs, families and carers. The NT Government has clearly failed to implement the recommendations of its own reviews; and has clearly failed to provide the necessary funding to address known inadequacies. The financial pressure on all sections of the NT Budget make it very difficult to feel any confidence in the NT Government addressing these problems without assistance from the Commonwealth Government.

b) the accuracy of disability reporting in Central Australian Aboriginal community,

Smaller remote Aboriginal communities do not have resident allied health professionals, disability assessment and treatment services or disability support services. As a consequence there can be long delays in identifying disability care needs, particularly of the more itinerant people with a history of substance misuse. A commonly heard comment from health staff, is why would we diagnose and propose care planning, when we know that services won't become available. As a consequence disability issues are under-recorded.

When the causal event leading to the onset of disability is within a cultural 'payback' framework, or as a consequence of violence [including self harming acts], it is less likely that there is the reporting of injuries to health clinics. This leads to fewer occasions of early assessment and treatment of injuries. It leads to reduced referrals to hospital services and/or to visiting medical and allied health staff. Many incidents resulting in traumatic injury to remote community residents occur when people are away from their home community and can involve being intoxicated in Alice Springs, Tenant Creek or at a highway alcohol outlet. Often the other people around are similarly intoxicated. Many of the victims and witnesses have English as a second or subsequent language. Often they have a poor history with medical services and an even more disasterous relationship with the police and court systems. Some people are unlikely to volunteer information to the police or courts.

There are also cultural reasons that spectators don't volunteer information to health services or police. There can be serious additional consequences for people reporting an injury. Most traumatic events and/ or accidental harm within traditional Aboriginal culture needs to be attributed to an individual or enemy forces. As a consequence unless the injury results in police being called and/or a visit to the health clinic or hospital, there may be very limited reporting and minimal medical or other treatment accessed. This can result in insurance claims for treatment and rehabilitation for injuries not being pursued, or not being pursued in a timely fashion that might allow claims to succeed. Consequently people with injuries, that often result in special needs, are less likely to receive adequate or timely follow-up care and support, and ongoing care for their compensable injuries.

There can be a significant under-recording of traumatic head injuries as a result of violence or accidents. Because of poor reporting there is inadequate data on cognitive loss, and/or acquired brain injury as a result of intentional trauma. Explosive and violent behaviour by residents of remote communities with significant cognitive loss and/or ABI is very under recorded on most communities. It is often the prison system that houses this group of people with special needs.

What is also poorly assessed and reported is the level of young babies and children with special learning needs caused by foetal alcohol syndrome, and/or cognitive loss due to childhood malnutrition [failure to thrive children]. As a consequence no early intervention or treatment is provided. The often undiagnosed special needs of young children underpins much of the behavioural problems that are seen within schools. Many children are not assessed because there is a perception that there are no services available. And the stigma reduces the ability of the children to be integrated into mainstream services. It increases the likelihood of children with special needs not attending school regularly and/or of them leaving school early [often with little or no literacy or numeracy skills]. Than as teenagers and adults they become a very vulnerable group. They are also very over-represented on court lists, in juvenile detention centres and prisons.

What is also evident is that there is a high level of unassessed and undiagnosed cognitive loss due to sustained periods of substance misuse. The pattern of binge drinking, inhalant usage and poly-drug use is a major problem, particularly for visitors to town from remote Aboriginal communities. Many get trapped in cycles of homelessness, poverty and neglect. They are often the public face of epidemic alcoholism across remote and regional Australia. Many of these people develop or have pre-existing cognitive loss. In particular, they develop difficulties with forward planning, being able to adhere to decisions, and in making appropriate judgements. As with the above groups, they are over represented on court lists, in juvenile detention centres and prisons. They are very likely re-offenders without considerable post release support.

Sensory loss is rarely assessed, and as a result, is very under-recorded. Even where the special need is known, treatment options are not always available. There are inadequate services for hearing impaired children and adults. There are even less support services for visually impaired children and adults. Other sensory losses are rarely assessed and treated.

Services for children and adults with physical impairment are chronically under-resourced. Assessment and access to specialised seating equipment is very problematic with long waiting lists and inadequate staffing and financial assistance. Continence services have poor infrastructure to follow up vulnerable people. Access to adequate home based allied health, nursing and other health treatment is a major problem. As a result people take longer to recover and are likely to have preventable impairment. Similarly mobility equipment and aids are under funded with inadequate follow up maintenance and repair. Access to modified public housing, or to funds to modify existing housing involves long delays.

c) *the effectiveness of general health services in assisting Aboriginal people with special needs;*

In general the remote Aboriginal community residents access what services are available at the local health clinic. When in Alice Springs they have difficulty getting access to disability and carer support options. There has been very limited cross cultural and specialist disability training provided to the reception staff of government health and disability services, Aboriginal community controlled agencies, and non government agencies. Treatment and case management staff that provide services to the various Aboriginal communities can also have difficulties in accessing cross cultural awareness training.

Appropriate and culturally sensitive training would do much to improve the effectiveness of many reception and assessment staff working in government agencies and NGOs when these staff are responding to requests to assist Aboriginal people with significant disability and their carers. The very high turnover of professional staff in disability care and health agencies, [particularly staff in remote settings] means that agencies need to continue to develop better training that targets the recruitment of appropriate Aboriginal staff. Strategies are required to develop ways of providing better training opportunities on a regular basis to all staff seeing people with disabilities and their carers.

d) *the effectiveness, to date, of public awareness programs and their relative success in providing information, encouraging help-seeking and enhancing public discussion of disability;*

As stated above there has been very little useful cross cultural or cultural safety training. Public education campaigns encouraging public discussion of disability issues have been few and far between. Agencies have few resources to improve the awareness of staff working in government agencies and NGOs on issues associated with assisting people to access to disability support services for Aboriginal families, especially Aboriginal families from remote areas. There has been few effective attempts in recent times to engage the Aboriginal community in disability awareness discussions or workshops. It is seen as too difficult and expensive to deliver community education programs on disability issues in remote settings. Especially when there are few services that people can access in any case. It has been difficult to develop better and more culturally sensitive and appropriate disability awareness material that can be used effectively in remote Aboriginal communities where English is a second or subsequent language

e) the efficacy of disability prevention training and support for front-line health and community workers providing services to people with a significant disability and their carers;

The high turnover of staff and staff overload means that we need to continue to provide effective training opportunities for staff. In recent times there has been little disability specific training that engages in the cross cultural challenges of access to services and the cultural appropriateness of services as they currently exist.

f) the role of targeted programs and services that address the particular circumstances of high-risk groups of people with disabilities and their carer networks;

The attached discussion paper explores ways of enhancing locally based services to address some of the underlying challenges in providing good quality and effective programs for residents with significant levels of disability in remote Aboriginal communities. There would appear to be few resources currently spent to appropriately address the high risk groups of people with disability and their carers. Few preventative programs and community education campaigns exploring risks factors for disability do not appear to be funded at this time, with the exception of risk factors associated with substance misuse.

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g) the adequacy of the current program of research into disability and disability prevention, and the manner in which findings are disseminated to practitioners and incorporated into government policy;

There seems to be little planned and targeted research into disability and disability prevention happening at the moment. There is also limited commitment to strategic regional and local community planning. Little action has been taken by funding bodies on findings and recommendations of recent and/or historical reviews of needs and priorities for people with special needs and their carer networks. New funding in the disability area has often been outside of normal funding cycles, and designed to provide a solution for some individuals that are seen as politically embarrassing; or who are difficult to discharge from hospital systems without some supported accommodation being provided.

DEVELOPING ABORIGINAL FAMILY SUPPORT SERVICES TO IMPROVE OUTCOMES IN DISABILITY PREVENTION IN REMOTE ABORIGINAL AUSTRALIA. IMPROVING TH SUPPORT FOR THE FAMILY SURVIVING & HEALING AFTER A DISABILITY.

Updated from discussion paper developed within the Social And Emotional Wellbeing Branch of Central Australian Aboriginal Congress by Christine Palmer, Gerard Waterford and Sue Grant [2008].

Background: Central Australia has many quite different Aboriginal communities. For the purpose of this paper these local Aboriginal communities have been broadly placed into three groups;

- Aboriginal families that live and identify with traditional land outside of urban centres. These communities targeted under the National Emergency legislation in 2007.The families have their local Aboriginal language as first language and English as second or subsequent language. They still practice many aspects of traditional culture. Poor infrastructure investment[1] over time in the areas of housing, employment, health and education and rapid population increases have seen the reduction of opportunities for local residents to access adequate disability support services.
- Aboriginal families originally from remote communities who have made the transition into urban town camps usually over the past thirty years. They retain links to their community of origin, language and culture. Inadequate infrastructure has reduced the amenities of most town camps to the level where they operate as transient camps between town and remote areas. These were communities targeted under the National Emergency legislation in 2007.
- Aboriginal families that are traditional owners of urban centres; or have long intergenerational association with an urban centre through Government missions and/or employment policies.

This paper focuses on the first two groups. It is Aboriginal people from these two groups and families in transition between the two groups that are overwhelmingly represented in the disability data.

Whilst extensive demographic analysis of disability figures is difficult because of low population, and perceived inconsistencies in recording what is often a self reporting of disability data, the thrust of the data is that the burden of disability is very high within these two groups. Our expectation is that the high burden of disability is replicated across all communities in remote and regional Indigenous Australia[2].

Across Central and Northern Australia, there has been a growing awareness of remote area Indigenous distress. The burden of disability within some remote area Aboriginal families and the lack of services to assist carer is alarming. It contributes to the alarming rates of children taken into care, family breakdown, sexual abuse allegations, completed suicide and self harm behaviour, this awareness has grown out of media exposure about endemic poly-drug use patterns, [particularly of petrol sniffing by Aboriginal youth], and stories of increased family violence including the sexual abuse of children.

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[1] See appendix 1. ‘A snapshot of the Territory’ complied by CAAC from many sources

PROPOSED GUIDELINES FOR DEVELOPING EFFECTIVE DISABILITY SUPPORT AND CARER PROGRAMS IN CENTRAL AUSTRALIAN INDIGENOUS COMMUNITIES.

1. The cornerstone of any effective local Aboriginal disability services will be the engagement of senior Aboriginal people in the design, development, and delivery of the programs. We need to build meaningful and sustainable local Aboriginal employment pathways for Aboriginal community members as disability support workers, carer support workers, counsellors, and crisis response team members. This needs to acknowledge the current literacy and English as a second or subsequent language problems that add costs and complexity to delivering training to meet disability care skills gaps. Proper access to training and support for Aboriginal staff will support better client outcomes, data collection and the ability of services to meet the reporting requirements of successful services. It can assist with developing strategies to overcome the known difficulties and obstacles that indigenous workers face in working in these areas over time.
2. Cultural rituals associated with death, funerals and 'sorry business' are very important within Aboriginal families. It is an area where traditional cultural rules have been steadfastly maintained despite colonisation and dispossession. Mainstream service development plans needs to be very conscious of the fear that some cultural leaders have, of their culture being further replaced by non Indigenous service models and non Indigenous 'expertise'. Program development happens best where it ensures the centrality of respectfully working within an Aboriginal cultural framework. The timing and manner of any planned disability accommodation and support service models should be aware and respectful of existing obligations and responsibilities of family under currently practiced cultural processes surrounding caring for people with disabilities within the appropriate family kinship systems.
3. Any effective disability service should be comprehensively linked into existing local health clinics, schools, substance misuse, disability and other family or community service infrastructure. The service also must develop effective links to specialist visiting medical and allied health programs, counselling and residential rehabilitation services. This includes linkages to family support programs operating within prisons, correctional services, employment, child protection, family violence & legal services.
4. Staff working within disability and carer support services need the support of local family leadership structures. This includes having clear understandings with local agencies, health councils, and Nightpatrol and community policing structures. These community based leadership groups need to support community debate that creates effective understanding about limitations of disability support structures and the active protection of particularly indigenous staff from possible payback situations and/or the unreasonable level of demand from some desperate family groups.
5. There is an urgent need to customise and improve the accessibility of information packages in the disability and early intervention areas. This can perhaps be best done within an action research process that works with communities to develop and customise their own resource packages.
6. There is a need to better understand disability care and family care systems within Aboriginal communities in transition. An active community discussion that stories existing community knowledge would be an effective way of engaging the community in

finding and supporting cultural change that reduces preventable disability within particular sections of the Aboriginal community.

7. Carer groups within the Aboriginal community have a desperate need for respite care services. The failure to provide these services is a part of the distress currently experienced by many carers. It is a barrier for people continuing to support and care for high needs and at risk people over time. Mobile outreach respite care services may need to explore taking carers out of high demand situations [giving carers holidays] in addition to providing out-of- community placements for behaviourally challenged and at risk family being cared for.
8. We need to find ways of working well and harnessing the knowledge of groups of grandmothers, mothers and carers. In addition we need to engage with groups of strong men. This will ground service developments within an effective community owned and supported framework. Knowledge about contemporary relationship patterns, extended family parenting systems and separation issues. This knowledge is important to build effective preventative care pathways; and to support families and carers to develop better ways of supporting their family members with high needs to remain within their home and community.
9. We need strategies to address the high levels of abuse of vulnerable people with special needs and elder abuse by some people when they are intoxicated; and by people with challenging behaviour problems.
10. It would be very beneficial to explore developing capacity building events and wider spiritual healing ceremonies for communities that celebrate the role of existing care networks within the community.

Other Partial Solutions include:

- Preventative and early intervention options need to be explored that engage young people with their families whilst they are still at school. Children with special needs should be identified and specific strategies employed with families that allow them to maximise opportunities at school.

- Disability accommodation and carer support services need to be developed that can cater for inter-generational family groups.
- There is a need to develop residential treatment and longer-term rehabilitation programs that actively explore with the client's carers and extended family, the healthy re-engagement of these clients within their community of origin. Strategies need to be explore including crisis accommodation, counselling and support.
- There is an urgent need to tackle entrenched poverty, under-employment and the lack of primary and preventative health care infrastructure within remote Aboriginal communities.

SOME EXPLANATIONS FOR HIGH RATES OF INDIGENOUS DISABILITY TODAY:

CULTURAL TRANSITION: According to Colin Tatz's research report titled 'Aboriginal suicide is different'[3] the historical experience of Aboriginal communities in Australia since colonisation provides a framework for understanding contemporary distress within Aboriginal communities.

'Their losses have been catastrophic: a land base, their "country", cultural practices found to be "abhorrent" to white society, decision-making by the elders, discipline and control by elders, birth and mourning rituals, even the traditional employment of men and women as vegetable pickers, or men as railway gangers, fencers or shearers, and much more. These losses are not experienced only by those considered to be traditional people; they have occurred among those Aborigines living in the mainstream suburbs and towns who maintained a strong sub-culture of Aboriginality.' 'Regardless of regional, linguistic, tribal, clan, and "degrees-of-blood" differences, Aborigines were, and are, perceived as *one people*. If there is indeed a one-ness, it lies in a *commonality of history* - victims of physical killing, settler animus, missionary contempt, decimation by disease, legal wardship, and destruction of their social institutions. History, rather than race, colour or culture, has been their unifying and sustaining separateness.'

Known Factors That Need to Be Addressed in Disability Service Planning:

- Inadequate housing, employment, recreational, social and activity based programs on most communities.
- Increasing income management arrangement and associated social controls in place on remote communities.
- Decreased access to intoxicants on many remote communities. Increased availability and use of mood altering drugs [particularly marijuana and amphetimines] by young people in and around most regional centres. The trade in drugs and use of drugs is increasingly centred around towns.
- Ongoing intergenerational stress within many Aboriginal family groups leading to increased family breakdown, and single parent households.
- Increased funding of health care and rehabilitation accommodation support services in Alice Springs and similar regional centres as an alternative to confronting the challenges of developing services adapted to smaller remote Aboriginal communities . Residents with special needs in remote area communities, miss out on services. The approach further reduces access to remote residents because of non-compliance and/or episodic misbehaviour, due to being unsupported and vulnerable away from home.
- Increased relative poverty of Indigenous youth and under-employed groups

It is expected that there will be a higher number of Aboriginal teenagers and younger men and women from remote areas who will be diagnosed with a dual diagnosis and/or disorders of personality. People with an existing dual diagnosis are at high risk of developing additional physical, psychological and/or cognitive deficits because of the

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[3] *'Aboriginal disability is different' : Aboriginal youth suicide in New South Wales, the Australian Capital Territory and New Zealand : towards a model of explanation and alleviation' Colin Tatz Criminology Research Council grant ; (25/96-7) 14 July 1999*

lack of early intervention treatment. The chaotic, often violent behaviour patterns associated with their diagnosis places the individuals and the community at high risk of violence.

The current experience of the Central Australian Aboriginal Congress- Social & Emotional Wellbeing staff is that at the expense of our traditional urbanised Aboriginal families, that we provide an increasing percentage of our resources in the crisis counselling, advocacy and emergency support area for an growing number of vulnerable Aboriginal young people with special needs, originally from remote areas, These people are transient and homeless in town. They have often been denied access to specialist disability services and/or psychological support services because of a perceived ineffective engagement and/or the prognosis by services of poor client outcomes on the rare occasions that these people do successfully access these services. The clients are great challenges to Congress SEWB and other existing services. Congress is without adequate resources to provide an adequate framework for meeting this group's ongoing housing, personal care and other support needs. Language and cultural appropriateness etc can also be major barriers to providing services that people will use. The failure to address the physical, psychological and emotional distress of this client group contributes to ongoing accelerated patterns of poly drug use, suicidal ideation and chaotic violent behaviour. The group are very heavily represented in police, court, juvenile detention and prison systems. They are also taking up a lot of hospital, health, youth program and family support resources. They compete for the scarce disability accommodation and carer support funds.

Payback Systems: Many within the culture traditional Aboriginal family groups seek traditional reasons for any disability and/or traumatic injury. These explanations are a part of attributing responsibility and/or blame. People wanted a world that was understandable. So explanations used often gave spiritual powers to people, other family groups, mystical figures and even objects, that were then blamed for causing a tragedy. Senior family members tried to establish a framework for 'payback' as a way of restoring balance between different family groups. In traditional culture when people lived in small family groups and the authority of law and culture was strong, senior law men and women met after an event to give weight to one interpretation of events. This then flowed into controlled and measured 'payback' responses. By today's standards payback punishments, particularly against wives, could often be seen as extreme. But they were largely understood and accepted within the Aboriginal family groups.

Today's Aboriginal community in Central Australia is much larger and more fragmented than ever before. People come from a variety of tribal and language groups. Many are at quite different stages of transition from their homelands into a more urban existence in town. Traditional authority of senior local Aboriginal leaders has been severely eroded. But the sheer weight of population and their connectedness through intermarriage sees many families of the resident Aboriginal communities participating in 'sorry business' arrangements over most months of the year. The weight of grief and loss within the community is overwhelming. Perhaps because of this, substance misuse, violence and chaotic behaviour is a growing local concern. It is often the younger, and more chaotic members of the families who make decisions to carry out acts of substance-effected revenge under the guise of it being traditional payback punishment.

Fear of chaotic payback by groups of intoxicated young men seeking to randomly punish members of another family group can see potential victims of such payback inventing stories to avoid being blamed almost from the moment that a tragedy becomes known. These days contemporary stories or explanations can include shifting the blame to within the victim's family or on to another family group, and/or that the injury was caused by Kaditja men, spirits, white groups like the KKK and/or what some Aboriginal people see as racist elements within police, health and other government services. For people that might be the subject of payback it can get very mixed up and dangerous. These personal safety fears for themselves and/or close family can see potential victims of payback leave town to avoid punishment. Alternatively they develop defensive [even attacking] capacity to stop what they see as unfair payback processes. This can mean organising and authorising their own group of chaotic substance affected group of young men to take action against another family as a warning. Currently there can be many people deeply concerned about violence happening within the Indigenous community that is labelled 'payback'.

FEARS OF BEING BLAMED:

Working in the high needs disability care area, carries great risk of being blamed, particularly for indigenous workers. We already see this with Aboriginal Health Workers, Aboriginal Mental Health Workers and Aboriginal Family Support Workers. In the event of a person with special needs dying, the family of the deceased can blame the disability care workers for failing to prevent the death. This can be a way for family to avoid being held to be responsible themselves. But it can also be a legitimate criticism of the limitations of service provision in the family support and disability care area.

The disability care services have major funding and workforce problems. They lack of suitably trained staff and service provision resources generally. Case management without being able to access adequate [or any] supported accommodation services and/or allied health and specialist medical treatment services can be useless. At the moment residential rehabilitation services are extremely hard to access. Because of travel and the intermittent follow up care that can be provided. Remote area clients with special needs have had very limited sustained benefit from restorative and rehabilitative care services.

THE OVER-REPRESENTATION OF PARENTS & CARERS FROM REMOTE COMMUNITIES IN THEIR OWN SPECIAL NEEDS CATEGORY: Aboriginal parents and carers from remote communities describe themselves as being left behind and without hope. In addition, many remote area Aboriginal parents and carers face additional challenges because of some of the following common features:

- The carers themselves have special needs because of a history of poverty and childhood malnutrition, chaotic parenting patterns made worse by parental and extended family substance abuse patterns. The fathers and supportive men can often suffer from low self esteem and lack status within their own community.
- There is often a pattern of poor family attachment through childhood and adolescence. This can include family history of childhood abuse, transience, neglect, the involvement statutory child protection and periods of time as children spent in out-of home care services.
- Over recent decades there has grown a pattern of intergenerational substance abuse. Alcohol is a major concern. But poly-drug use patterns in young people has also grown. Intoxicants of choice tend to be psychotropic substances [petrol &

inhalants], marijuana, and barbiturates]. Because of availability issues and extreme poverty young Aboriginal teenagers often have access only to the cheapest and most dangerous intoxicants. They often with significant side-effects that include cognitive loss, psychosis and physical disability. Addicted young people are at high risk of being recruited into prostitution where access to intoxicants are traded for sexual favours. Being heavily intoxicants makes them very vulnerable to other perpetrators of abuse.

- Many young parent's of children with special needs have their own story of poor attendance at primary school and early onset behaviour problems. They exhibit behaviours often ranging from excessive isolation patterns through to mood swing cycles and violence. They have left school early and are unlikely to continue into further training or employment. They often face long periods with no income because of an inability to satisfy Centrelink income support requirements, until such time as they are supported to be accessed for disability support payments. Often it is extended family care networks that are supporting two generations of young people with special needs.
- Often parents have a history that includes an admission into a psychiatric admission centre for behaviour problems with psychotic symptoms by their late teens. The diagnosis on admission often queries schizophrenia, drug induced psychosis and disorders of personality. These young parents with special needs can struggle with providing an adequate parenting system.

- Similarly often within some families from remote communities the parents have a history that includes episodic readmission to MHU over subsequent years following a continued pattern of violent behaviour, self harm, substance abuse and erratic behaviour. It can lead to other problems including; increased isolation from family networks and friends; increased periods of transience and homelessness; a futile referral for disability case management and support services who have little capacity to accept the referral because of accommodation program wait lists; reduced engagement of mental health funded services over time, as the person's erratic behaviour sees them refused further services because of compliance, effectiveness and worker safety issues; and episodic violent behaviour that leads to police involvement, court charges and periods of imprisonment.

CHANGING PATTERNS OF FAMILY STRUCTURES & PARENTING:

A related story from the last fifty years is that today we have very altered roles played within Indigenous families by Aboriginal fathers. Fifty years ago most Aboriginal children grew up in remote Aboriginal Central Australia within in intact families. There was a mum and dad looking after their kids mostly within a well-known and easy to reach extended family and community networks. Fathers had established roles within family and culture. The men were often older than their partners and had already made their way into an adult world prior to their marriage. It was a patriarchal world, where men had a lot of authority and power.

These days it can be dramatically different. The age difference between husband and wife is usually small. Relationships and parenting frequently commence as teenagers. Mothers and grandmothers are seen as having much greater power in relation to their children.

Their male partners are often left with little power and few roles. If parents separate many children see little of their father or other caring men in their growing up years.

Aboriginal fathering roles have been made more difficult by changes in employment patterns, social security payments, child protection practices and the relocation of many Aboriginal families from a remote and more traditional lifestyle into a more urban and culturally changing lifestyle. Commonly Aboriginal fathers have become forgotten and almost invisible in social planning and thinking. Perhaps as a consequence of difficulties experienced by Aboriginal fathers and government social planning we are witnessing huge increases in separated parents with many more children brought up in women headed households. Fathers after separation are not perceived as having equal status in the care and parental decision making. In a related issue many men and women have more than one relationship. Kids live in blended families with step-brothers and sisters. There are more single fathers, step-fathers, fathers that only see their kids for short visits, and fathers that don’t see their kids at all. This can be painful for fathers and rarely works out well for kids.

The lack of successful married relationships, little access to their children, and dislocation from country and extended cultural connectedness sees many Aboriginal men from remote communities living on the edges of overcrowded and alcohol saturated town camps with few if any socially valued roles. These are the men that commit disability often whilst heavily intoxicated and after many attempts. It is often well known within the community that these men are at very high risk.

The lack of strong two parent families has a major impact on the ability of a family to support and care for family members with special needs. Personal care can involve a lot of heavy physical work. Without men to assist it is often beyond the physical capacity of an often ageing female care network to provide the lifting and physical support needed to ensure good quality care at home.

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Scoping Exercise- Aug 2007
Santa Teresa [Ltyentye Apurte] Disability Service Proposal

Overview:
At a meeting at Ltyentye Apurte health clinic attended by family carers on the community, representatives of the community health clinic, Territory Health and Community Services, on the 7th of August, I was asked to prepare a scoping document for a proposed young person's disability accommodation, respite care and outreach disability support service for the community.

The disability accommodation needed to be able to provide full time care for one developmentally delayed young man and provide a base for outreach support and respite care for a group of young men with some developmental and learning delays. It is envisaged that Lionel may require residential care in the future because of ageing parents. The service would also develop case management support, day time service options including social and employment activity support for people with disabilities and their carers on the community.

Not covered in this plan, but that need to be considered are
- Other people with disabilities in family care who might benefit from community based respite care support.
- Younger children with special needs being cared for by their families.
- People with disabilities originally from Santa Teresa, or with family resident here, who would benefit from being able to return home for visits or to live, with access to supported accommodation on Santa Teresa
- Families caring for people with support needs because of chronic disease;
- Families caring for people with support needs who are recovering from medical treatment.
- Frail aged people requiring more care than can be adequately provided at home at this time and where respite and day activity support would be useful.
- People linked to the palliative care team requiring support to die at home.

Resource Issues.
Venue: A three bedroom house [previously built by ATSIC but currently managed by the council and occupied by a single person] was seen as the preferred venue until a purpose built facility could be developed. Plan was to approach the council about renting the above house for the service. One staff accommodation house exists.

Proposed Staffing Structure: It is suggested that the house will require 24 hr staff with passive sleepover shift. This will require **Mon- Fri** 7am- 3pm house worker [who might support outreach program once the house resident/s is in day programs. 2nd worker on a 1pm – 9pm shift again with the worker doing some outreach work when resident/s is in day program. The 3rd shift doing 7pm -10pm active shift 10pm-7am passive shift 7am-9am active shift.

Weekends might involve 7am – 8pm pm shift with additional recreation program worker support hours The 2nd worker 6pm until 9am shift active passive shift. 3rd worker 8am – 9pm shift again with additional recreation program worker support hours. 4th shift from 7pm until 9 am Monday.

Staff: Monday-Friday 1st worker 5x8hr morning shift. 2nd worker evening shift. 3rd worker 5X5 active hours then doing sleep-over shifts. The roster could rotate workers or it might be better to employ people on regular hours that may better suit other commitments. [90 hrs + 5 sleep-overs]

Saturday-Sunday 4th worker doing 2 X 13 hr daytime shift [with some casual day activity support workers] 5th worker doing 2 X 15 hrs night-time shifts. [38 hrs + 2 sleep-overs]

Relief staff person [to cover for staff on holiday, training and/or sick leave] It might be important to establish conditions that include 12 weeks paid annual leave that take into account the demands of remote area employment/travel time etc. If this was the case you would require an additional relief staff position [Relief staff 70 hrs/wk average]

Outreach Disability worker [possibly also filling the position of service and staffing co-ordinator/ IPP assessor/ case planning & co-ordination/ training roles] Hours could be Monday to Friday 9am -5pm [with some 2nd on-call responsibilities. 1st on-call may involve health clinic on call worker]. The 2 disability workers with daytime Monday-Friday shifts would support the outreach worker where residents were in day time programs. [37.5 hrs]

Casuals providing individual program support worker roles. [22.5 hrs/wk?]

Administration/financial support role would be through Health Clinic and/o Community Council [at say 20% of salaries]

Note: It would be useful to provide traineeships for potential local Aboriginal workers interested in a career in disability and aged care work. Training could be linked to a Registered Training Organisation in Alice Springs and possibility a residential care provider in town.

Estimated total staff: Co-ordinator SACS 5?
3 residential care workers Mon – Fri [SACS 2-4?]
2 residential care worker W/ends [SACS 2-4?] possibility travelling to- from Alice Springs each weekend.
2 residential care workers relief [SACS 2-4?]

Estimated Total staff hours per week: 258 hrs

ESTIMATED COSTS

Salaries: Estimated Total staff hours per week: 258 hrs [X $25[4]/hr X 52 wks/yr]
Estimated Total Staff costs [$335 400]

Operational Costs[5]:

Vehicle:	4wd vehicle. Leased under replacement package	$10 000
	Fuel & maintenance [@500km /wk x $1/kmx 52 wks]	$26 000
Rent	Disability house	$10 400
	Staff accommodation house	$10 400
Houses repair and maintenance	[hard to estimate]	$04 000
Food	[Could look at client contribution and staff contribution]	$10 400
Training support costs		
Other respite care costs associated with family support and access to services.		
Total Operational Costs		**$61 200**
Estimated Total Costs		**$400 000**

SOURCE OF FUNDS:

In the discussion with Michael Woodhouse NT Health & Community Service will consider funding requests for an extended disability accommodation service.

There is an existing funding arrangement with NT Health & Community Services for the current Disability Outreach Service[6].

JUSTIFICATION FOR FUNDING

The need for additional disability services in Santa Teresa is being more actively discussed again as a consequence of the recent murder of a disability services carer in Santa Teresa. The person killed was a ‘family way’ carer trying very hard to continue in the role of carer because the lack of any alternative care options. It is alleged that he was killed by the young seventeen year old man in his care. The community has been devastated by the death of this very caring and committed man.

The alleged young perpetrator of the murder was in the Guardianship of the Minister having been under a NT FACS care and protection order for a very long time. Whilst in the care of the Minister he has been assessed and treated through the NT FACS Positive Behaviour Support Unit. He suffers from congenital developmental delay complicated by organic brain damage caused by uncontrolled epileptic fitting. His illness is associated with extreme violence and behavioural disturbances. It was known that his needs were

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[4] Check against SACS award & Mutitjulu Disability and/or Yuendumu Aged care staff costs
[5] All costs are estimates and need to be checked.
[6] Find out details of funding agreement

much higher than could be provided within available at Santa Teresa service options. There had been earlier concerns raised by Santa Teresa and Alice Springs based medical and disability staff for the physical safety of the carer. There were grave concerns about the adequacy of the support program being provided to the young man. These concerns had been documented to NT FACS followed earlier explosive and potentially murderous rages by the young man against his carer and other disability staff. We can only speculate what the provision of adequate accommodation and treatment services might have achieved over his young life. He is now in secure care awaiting court.

Supported Disability Accommodation linked to an integrated family support/early childhood centre as Cost Effective Secondary Prevention initiative.

Long term disability accommodation costs very large amounts of recurrent funding to support a small number of high needs clients in residential care. Some of these costs can be avoided where other day time activity programs, reduce the need for rostered accommodation workers. These day time activities can be incorporated within an integrated family support/ early childhood program.

The disability day programs can target teenagers and young adults in addition to special needs children to achieve rehabilitative and educational outcomes that can also enhance the person’s longer term daily living skills. They can optimise personal functioning, teaching both physical and social skills. They can reduce the level of individual dependency. Integrating these programs with school and community based programs can assist family carers in their support of a home placement for much longer, delaying the time when ‘out of home’ residential care is necessary. Where a young person with special needs has received good quality early intervention and day activity programs they can often be sustained throughout their lives with higher levels of functioning If the person still requires supported accommodation during their life, the recurrent cost of residential care is lower; and the quality of life of the person is much higher as a consequence of better functioning.

Multi-purpose Centres: Building Links Between Primary, Secondary and Tertiary Prevention Programs across Small Communities.

Small communities don’t usually have the population basis to justify running separately and independently managed prevention programs. A more cost-effective model for providing a range of services at reduced costs is to combine organisational and management location and roles by establishing a multi-purpose family support, day activity and early intervention centre. An integrated centre can also have the effect of improving access to a variety of different levels of service delivery that can be tailored to individual need.

The community also gets the benefit that comes from combining community transport resources, , improving reception functions and improving staff capacity to provide treatment options in periods where workers are difficult to recruit; or are on leave. The client and carers get better assessment processes that can link into available treatment plans. It can also assist where there are big fluctuations in demand for specific services at particular times of the year.

In Santa Teresa there are a number of health and community service programs that already financially managed through the Community Council. There are a number of these services that are co-located within the health centre. The Ltyentye Apurte Council's health committee has something of a mandate to co-ordinate the planning and operation of all health and community services under a single organisational plan.

Current Health, Community Services and Family Support Programs.
Disability Outreach Service: The disability program was initially auspiced through the Women's Centre, and since July 2006 by the Health Service of the Community Government Council. It has been supported through the Positive Behaviour Support Unit since its inception. There are two outreach disability support positions doing work with families at Santa Teresa. There is a staff house provided as part of this program. Behaviour assessment, carer respite and specialist medical assessment and treatment can be accessed on a needs basis from Alice Springs –NT H&CS.

Mental Health Program: About $90 000 recurrent funding has been provided by NT H&CS Mental Health Program to the community clinic to support individual and family spiritual healing and to build social wellbeing on the community. Initially the funds were to support the work being undertaken through the Spirituality Centre. The program has been poorly utilised in the recent past with the key participant in setting up the Spirituality Centre passing away recently after a long illness.

Spirituality Centre: The Spirituality Centre was the culmination of a lot of energy and ideas of Santa Teresa women with strong religious faith about how to grow up culturally strong ways of healing people within their local community. Set up in the old girl's dormitory of the original Santa Teresa Mission, the Spirituality Centre runs great art therapy styled programs. It links into local traditional Aboriginal healers.

Santa Teresa- Amoonguna Mental Health project. Funded through the Division of Primary Health Care, this pilot project [2yrs possibly extending to 3 yrs] provides a 0.6 of a position based within Congress to provide a visiting counselling and community development service to these two communities. It also can assist to some funds to support men, women and family healing groups, events and trips.

Home And Community Care [HACC] program. Supported through the Women's Centre the program includes meals on wheels for frail aged and disabled people being cared for in their homes. Limited personal care, laundry and other supports are provided to clients and carers.

Ltyentye Apurte School: [to be detailed later]

Strong Kids Program: This began as a project along the lines of the program at Kinotre, in 2001. It provided an infant feeding and maternal nutrition education program, but was suspended for the duration of the clinic renovations. There has been discussion about moving the program to the Womens Centre.

Sport & Recreation Programs: [to be detailed later]

Barriers to developing an Integrated Disability Accommodation Support and family support/early intervention centre services: But there have been a number of challenges in improving links and outcomes across various health programs. I have listed some these barriers below:

1. There have been few meetings of the Community Council and even less of its health committee.

2. There is a lack of co-ordinated strategic planning at a regional level that has appeared to be influential at government funding decision making forums.

3. There has been a lack of adequate growth funds in the preventative health and community programs that encourage the development of strategic plans.

4. There has been an erosion of longer term planned funding processes in favour of National and regional competitive tendering arrangements that have had a negative impact on community based planning and development initiatives. Ltyentye Apurte doesn't have the management and policy staffing resources to produce competitive proposals within the time frames required under competitive tendering processes

5. The lack of growth monies for housing and community services infrastructure has seen increased overcrowding across the community. Staff housing options have been adversely effected by competition for all housing stock.

STEPS FROM HERE

1. **Engage community and council about this proposal immediately after the council election in August. On getting their support for the initiative, make decisions about the short-term and longer term management of the service and access to the required accommodation. Possibly look at recruiting a project co-ordinator.**

2. **Formalise discussions with relevant funding body [NT H&CS] and other stakeholders.**

3. **Finalise an audit of potential users of the service.**

4. **Develop detailed plan for the proposed service including costings, recruitment strategies, purchasing schedules etc.**

Gerard Waterford 17/8/07
Congress SEWB