Yolŋu Information sharing and clarity of understanding

1.   Introduction

This project *Yolŋu Information sharing and clarity of understanding* is stage 1 of a programme proposed by Motivation Australia consisting of 5 stages called *Inclusive Community Development in East Arnhem Land*. Five community visits to carry out Discovery Education sessions were carried out in Ramingining, Milingimbi, Galiwin'ku, Gapuwiyak[1] and Darwin, and a workshop was held in Darwin in the first half of 2013. This project was carried out with the Aboriginal Resource and Development Services Inc. (ARDS) and funded by the FaHCSIA Practical Design Fund.

Content

This is the final project report with appendices detailing all of the content discussed during the five community visits to carry out Discovery Education sessions. The content is as follows:

Yolŋu have a rich and sophisticated culture with deep knowledge of all aspects of life; it would be disrespectful to attempt, within the limited scope of this report, to give a full account of Yolŋu culture, language and worldview; only to try to understand and communicate how these relate to disability.

Background

In 2003 ARDS Inc. conducted some preliminary research into disability and impairment. The findings from this research are documented in the report "Breaking Down the Barriers - Dhumbal'yunnawuy rom bakmaram dhu – Learning How to Talk About Disabilities in Yolngu Matha". The vocabulary list from this paper was used extensively during field visits conducted by the research team.

This project follows directly a situational analysis carried out for Motivation Australia in East Arnhem Land in July 2012 by Dr Lloyd Walker and Rodney Angelo. The study team travelled to Nhulunbuy, Yirrkala, and Gapuwiyak in East Arnhem Land and Darwin. The objectives of the situational analysis were to investigate the feasibility of and gauge the level of support for a pilot Inclusive Community

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[1] The decision was made not to visit Yirrkala during this project, as Motivation Australia had previously consulted with people with disabilities there during the Community Consultations project in 2011. It didn't fit with Motivation Australia's philosophy to do more consultation without the ability to 'give something back' to the community.

Development (ICD) project in East Arnhem Land by meeting with local and regional stakeholders. In addition the team sought to understand how working with an ICD approach could help to achieve the goals of the proposed National Disability Insurance Scheme (now DisabilityCare Australia) in rural, and particularly, remote Australia. If successful the approach could serve as a model for other communities.

In June 2011, the First People's Disability Network (Australia) submitted a policy paper on the implementation of CBR in Australia to the Productivity Commission. The paper *"Inclusive Community Development; Community Based Rehabilitation and its potential application in Aboriginal and Torres Strait Islander communities"* was written by Kylie Mines and Ray Mines of Motivation Australia. This approach, drawing on the principles of Community Based Rehabilitation (CBR) and adapting them for the Australian context, would be a person-centred, community-orientated, rights-based approach to providing basic services in rural and remote communities. The approach would enable local workers to support vulnerable people in their community in a flexible and culturally appropriate way with support from specialist medical and allied health personnel as required. The approach would support Indigenous people with disability to participate in and contribute to social and economic life to the extent of their abilities.

Acknowledgements

Richard Trudgen's 2000 book "Why Warriors Lie Down and Die"[2] was the initial orientation to the Yolŋu world for the Motivation Australia team, and continued to inform and guide us throughout the project.

Howard Amery's 2003 paper[3] was invaluable because it provided a large vocabulary of Yolŋu Matha words related to various aspects of the disability discussion. In particular Appendix 3 of the paper served as a starting point for many discussions with Yolŋu. The five discovery and education sessions further validated and refined these translations, improving our understanding, as well as generating new terms not previously listed.

The best collaborations are boiling pots of inspiration and information: the whole is often greater than the sum of its parts. Neither Motivation Australia or ARDS could have successfully delivered this project in such a short timeframe without the skills and experience that the other brought to bear on the subject.

We'd like to acknowledge the Aboriginal Resource and Development Services (ARDS) team of: Joy Bulkanhawuy, Miriam Yirriṉiṉba, Yasunori Hayashi, Dr Jamie Mapleson & Jane Chalmers who coordinated, facilitated and translated during the five community visits to carry out Discovery Education sessions with the Motivation Australia team. With decades of organisational experience working with Yolŋu (focusing since the 1990s in the area of adult education on health issues) and their philosophy about Yolŋu knowledge, ARDS have a great deal to contribute to future projects to add more detailed knowledge about disability to the Yolŋu cultural knowledge base.

Thank you to the Motivation Australia team: Dr Lloyd Walker, Lauren Houpapa (OT) & Ray Mines, for bringing their professionalism and experience with disability and assistive technology (AT) in less resourced settings, to this fascinating project.

Finally, none of this work would be possible without the patient participation of the thirty six Yolŋu men and women, boys and girls; people with disability, their families, carers and elders, living in Ramingining, Milingimbi, Galiwin'ku, Gapuwiyak and Darwin who discussed Yolŋu language & worldview with us during the Discovery Education sessions. It was a privilege to spend time speaking with you and we acknowledge your ownership of the aspects of Yolŋu culture and law which you have

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[2] Trudgen, R. (2000) Why Warriors Lie Down and Die. Aboriginal Resource and Development Services (ARDS), Darwin.
[3] Amery, H. (2003) Breaking Down The Barriers Dhumbal'yunnawuy rom bakmaram dhu: Learning How to Talk about Disabilities in Yolŋu Matha. Aboriginal Resource and Development Services (ARDS), Darwin.

shared with us. Those that consented to have their names included in the report are listed in Appendix A.

2.   Executive summary

The geographical context in which this project took place is especially relevant; Yolŋu communities are located in East Arnhem Land far from capital city based services, with very few service providers in the region. The social context is one of inequality and barriers to inclusion[4]. Yolŋu people with disability face many barriers to their inclusion in community life. Assistive technology where it's available is often not durable, not having been designed to withstand the tough physical environment. Most methods of transport, many homes and often public buildings are inaccessible. Where service providers do come in contact with Yolŋu a high turn-over of staff, communication difficulties and misunderstandings, a lack of cultural competency, and lack of information translated into language all reduce the possibility of long term relationship building, further reducing the effectiveness of services for Yolŋu. Australian society has a track record of failing to provide appropriate care and support for Yolŋu people with disability. More than a lack of resources, Balanda (non-Aboriginal) have simply not taken the time to listen and understand.

Perhaps the largest barrier that Yolŋu people with disability face is access to culturally and linguistically appropriate information leading to understanding about their disability, impairment or health condition. There are many reasons for this, not least that the details of many of the body's internal functions and health-related cause/effect relationships are not currently part of the Yolŋu *cultural knowledge base*[2] particularly for disabilities only seen in recent times (e.g. caused by complex brain damage). Another prominent reason is a lack of effective communication with Balanda[5], which Trudgen explores extensively[2], proposing that "this communication gap is the main reason underlying the people's continual loss of control over their lives". These coupled with the web of jurisdictions and departments which make up the Balanda 'system', and the complexity and number of forms to be completed, leave many Yolŋu completely confused. Balanda culture is as confusing to Yolŋu, as Yolŋu culture is to Balanda.

Relationships are very important to Yolŋu. Yolŋu understand their place and the place of everyone they meet in a complex social network of kinship relationships, intrinsically linked to family history and heritage, arising from the land of each clan. Upon meeting someone for the first time, Yolŋu will ascertain the position of the person within the kinship structure, in order that no one is insulted or offended, and for mutual respect and understanding to be established[6]. Kinship relationships can dictate behaviour between Yolŋu, and between Yolŋu and Balanda. Kinship relationships can affect who can be a carer, who has the right to teach someone new information and who should be involved in decision making. As Balanda service providers, becoming aware and respecting basic elements of Yolŋu culture will dramatically improve the quality of interactions and in turn the outcomes for Yolŋu people with disability.

While the concept of *disability* is well understood by Balanda, particularly professionals in the healthcare and social service sectors, there is no single word for it in Yolŋu Matha. Yolŋu language and worldview focuses on impairments (weak arm, numb leg, etc) and activity limitations (unable to talk, unable to walk, etc), objectively describing what is observed about the person without association to stigma or negative connotations. This represents an almost ideal acceptance of human diversity in the Yolŋu community (with certain limits discussed in section 9). It is imperative that through our haste to intervene we don't simply impose a Balanda concept of disability over the top of Yolŋu culture.

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[4] Mines R, (2011) *Community Consultations: Mobility For Aboriginal And Torres Strait Islander People With Disabilities Who Require Wheelchairs, Living In Remote Communities.* Motivation Australia

[5] Balanda is used by Yolŋu to refer to non-Yolŋu, non-Aboriginal or ethnically European people. Today Balanda is synonymous with English speaking Australians (See Glossary, pii, *Why Warriors Lie Down and Die*).

[6] Manikay.com (2003). *The 'family' concept and Yolŋu/Balanda relations by Peter Lister*. [online] Retrieved from: http://www.manikay.com/library/yolngu_family_concept.shtml [Accessed: 18 Apr 2013].

"It was interesting that it wasn't until the end of the second day that people remembered a 'very smart' woman who was now working in a customer service role in the community who has never been able to speak (so uses sign language) and has impaired hearing though this was debated because her skills in lip-reading meant many didn't think she had a hearing problem at all."[7]

Yolŋu appear to benchmark a person's function against whether they can do activities/work/effort independently or not, and whether they can walk or not. These are both facets of directly observable, physical ability. Therefore if a Yolŋu person with a disability is compensating for their impairment in some way but is still able to do activities and walk (even if that involves a 'support' of some kind) the Yolŋu don't appear to distinguish that person as different to themselves. It was observed that people with acute and sometimes chronic conditions are referred to as 'sick', however people with physical disabilities were generally 'not sick'. The positive consequence of this is that no evidence of people with disability being stigmatised was observed or reported. The possible negative consequence is that if a Yolŋu person with a disability is able to 'get by' in community by compensating in some way, that person may not be identified as needing further support.

In general, physical impairments or activity limitations were better understood than intellectual disability[8] or mental illness[9]. Yolŋu related more easily to impairments which were observable on the outside of the body. Yolŋu cultural knowledge base contains less information about intellectual disability or mental illness[2]. It was observed that often Yolŋu did not differentiate between people with intellectual disability and people with a mental illness, and did not group these together with people with physical disabilities. Significantly less language was generated that related to intellectual disability or mental illness.

For all of these reasons it's necessary to develop a shared understanding of what the concept of *disability* is, and communicate it in ways which are meaningful to Balanda and to Yolŋu.

Even through total immersion in Yolŋu society, learning and speaking Yolŋu Matha everyday for decades, Balanda can only hope to gain an appreciation of the sophistication of the Yolŋu world. However it isn't practical to expect every service provider, practitioner or Allied Health professional to immerse themselves in years of learning before working with Yolŋu people with disability. It is appropriate to expect service providers to prepare their personnel for working with a respectful attitude and in a culturally competent way in any Aboriginal or Torres Strait Islander community. This project has identified three key processes from the experience of the five community visits to carry out Discovery Education sessions which will assist DisabilityCare Australia and service providers to improve outcomes for Yolŋu people with disability, and deliver more effective and efficient programmes.

The principle of governments ensuring informed decision making for people with disability to maximise their autonomy and independence[10]; through providing assistance and support to ensure people with disability have access to information[11]; and by raising the awareness of rights, dignity, autonomy and the needs of people with disability[12], is explicit in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The National Disability Insurance Scheme Act 2013 states that "People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity."[13]; and the National Disability Insurance Agency "must use

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[7] Lloyd Walker's notes from a Discovery Education session.

[8] The National Council on Intellectual Disability state that: intellectual disability is characterised by significant limitations in intellectual functioning; and adaptive behaviour expressed in conceptual, social and practical skills; which originates before age 18. (ncid.org.au)

[9] The Mental Illness Fellowship Victoria state that: mental illness refers to a group of disorders that affect the way a person thinks, feels and acts. Mental illnesses include depression, bipolar disorder, schizophrenia, anxiety and personality disorders. (mifellowship.org)

[10] United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org. Preamble, p2.

[11] United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org. Article 9, Accessibility, p9.

[12] United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org. Article 25, Health, p18.

[13] Commonwealth Government of Australia (2013) *National Disability Insurance Scheme Act 2013*, Commonwealth Government of Australia, Canberra. Chapter 1, Section 4.

its best endeavours to provide timely and accurate information to people with disability and other people in order to assist them in making informed decisions about matters relevant to the National Disability Insurance Scheme".[14]

Going forwards it will be impossible for *DisabilityCare Australia* to implement its aspirations for 'all Australians' in East Arnhem Land without addressing the fundamental issue of culturally and linguistically appropriate information for Yolŋu. A remote area pilot site for the NDIS in East Arnhem Land would form the space for foundational stories to be created, Balanda to learn what level of cultural competency is acceptable and necessary to work safely in communities, innovative approaches to service provision to be trialled, the requirements for durable assistive technology to be understood and for mutual understanding and trust to be nurtured.

Main achievements towards project objectives and outputs

Objectives
To explore Yolngu understanding of impairment and thus their worldview of disability (to be educated and informed about Yolngu concepts of social (community) acceptance and care of people with 'impairment/disability' and how they differ from those of Balanda society). To enhance community engagement in disability related issues in East Arnhem Land.

Proposed outputs
- Shared resources of culturally and linguistically appropriate information about disability.
    - Various formats are likely, and could include written resources, illustrations, audio and audio-visual programmes.
    - These will be made available to the Yolngu people to increase their ability to communicate and make informed decisions on disability issues.
    - The resources will be made available to educate and guide practitioners, agencies and departments in their approach to disability in the Yolngu community.
- A tested framework and approach to exploring disability/impairment language and concepts in Indigenous communities.

- The project received ethics approval from Human Research Ethics Committee (HREC) of the Northern Territory Department of Health and Menzies School of Health Research (reference HREC-2013-1932).
- Five community visits to carry out Discovery Education sessions were facilitated by the Aboriginal Resource and Development Services Inc. (ARDS) in Ramingining, Milingimbi, Galiwin'ku, Gapuwiyak and Darwin, and a workshop was held in Darwin in the first half of 2013.
- Thirty six Yolŋu men and women, boys and girls, people with disability, their families, carers and elders participated in Discovery Education sessions and the final workshop; plus three Yolŋu employees of ARDS.
    - In line with Motivation Australia's gender equity policy, women were well represented; of the thirty six Yolŋu participants; twenty three were female and thirteen were male. Both female and male investigators contributed to the project team.
    - Twelve people with disability and twelve carers participated. The remaining twelve people were a mixture of relatives, elders and Yolŋu language consultants.
- The Discovery Education sessions and final workshop validated the original project premise that there was no direct translation of the word or concept of *disability* into Yolŋu Matha.
- The project has validated and refined the available disability related Yolŋu Matha vocabulary from Amery's 2003 paper, as well as uncovering new words and phrases not previously documented by ARDS (section 8).
- The project partially explored Yolŋu worldview in regard to disability issues and made a series of observations (section 9).

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[14] Commonwealth Government of Australia (2013) *National Disability Insurance Scheme Act 2013*, Commonwealth Government of Australia, Canberra. Section 15.

- The project has utilised *the process to understand language & worldview* describing the approach and methodology used by ARDS on this project (and many others) to understand Yolŋu language & worldview about a particular subject (section 10).
- The project has described *the process which is needed to tell the foundational stories of different disabilities.* In order to be able to make informed decisions[14] about their care and supports, Yolŋu require accurate information, in a language and format that they can understand.
- The project has sought out and proposed a *process when working with Yolŋu people with disability and their families*. This is practical guidance for interacting with Yolŋu people with disability and their families, describing how to improve the quality of communication between Balanda and Yolŋu.
- Learning from the project will be documented and disseminated in the following ways:
  - This detailed project report,
  - Practical Design Fund summary report (See attached: 'Final_Performance_Report_PDF50_Ray Mines.docx'),
  - Two proposed academic papers (to be confirmed after the NDIS Conference),
  - Two educational resources: one prepared for Yolŋu and one for Balanda personnel. See attached files:
    - 'MA PDF50 Disability tree RM DRAFT NOT FOR PUBLICATION.pdf' & 'MA_PDF_50 letter Ray Mines.pdf'
    - The booklet: 'True story: Telling Foundational Stories About Disability In Yolŋu Language': 'MA PDF50 Booklet RM FINAL-print.pdf' and 'MA PDF50 Booklet RM FINAL-web.pdf' (Low resolution web version)
  - Potential radio programme by ARDS on Yolŋu Radio (to be confirmed by ARDS),

3.   Conclusions

- Yolŋu people with disability face many barriers to their inclusion in community life:
  - Assistive technology where it's available is often not durable, not having been designed to withstand the tough physical environment.
  - Most methods of transport, many homes and numerous public buildings are inaccessible.
  - Where service providers do come in contact with Yolŋu a high turn-over of staff, communication difficulties & misunderstandings and a lack of cultural competency reduce the effectiveness of services for Yolŋu.
- There is a lack of understanding amongst Yolŋu about disability issues and no direct translation of the word disability into Yolngu Matha.
- Yolŋu do not commonly categorise groups of things in the same way as Balanda. In this context, Yolŋu do not identify all people with disability as being part of one identifiable group.
- Yolŋu appear to have a worldview which is very accepting of human diversity, up to certain limits (see section 9).
- Perhaps the largest barrier that Yolŋu people with disability face is access to culturally and linguistically appropriate information.
- Kinship relationships are very important to Yolŋu and can dictate behaviour between Yolŋu, and between Yolŋu and Balanda.
- Yolŋu language and worldview focuses on impairments and activity limitations, objectively describing what is observed about the person without association to stigma or negative connotations.
- Yolŋu appear to benchmark a person's function against whether they can do activities/work/effort independently or not, and whether they can walk or not.

- In general physical impairments or activity limitations were better understood than intellectual disability or mental illness.
- Analogies, stories and illustrations have been used successfully to assist in communicating Balanda concepts to Yolŋu.
- Rehabilitation currently happens outside of the community; in Nhulunbuy, Darwin, Adelaide, etc. These stages of a person's experience are largely a mystery to people who do not see the person with a disability during that time.
- During the five community visits to carry out Discovery Education sessions the most commonly requested support for people with disability and their families was residential respite facilities in local communities.
- There are not enough Yolŋu being trained and recruited to work in the disability sector.
- It will be impossible to realise the aspirations of the NDIS for Yolŋu people with disability and their families without working in a 'whole of community' way to address key issues such as accessibility, communication with Balanda and a Yolŋu disability workforce.
- There are very few organisations providing disability sector services to East Arnhem Land, and there are even fewer who are working in a culturally appropriate way using local language and building local capacity (eg: MJD Foundation).

4. Recommendations

4.1. DisabilityCare Australia acknowledge that *informed decision making* means that the Yolŋu person and their family have access to appropriate explanations in language, which result in their full understanding of their impairments, health conditions and disabilities, and this becomes the foundation for the pathway through the system.

4.2. DisabilityCare Australia support and coordinate stakeholders working with Yolŋu to develop culturally and linguistically-appropriate resources, which tell the foundational story of the disabilities most commonly affecting Yolŋu. *Process 2* is a proposed framework for undertaking this and is described in section 11 of this report and the booklet 'True story: Telling Foundational Stories About Disability In Yolŋu Language'.

4.3. Disability specific organisations are supported to assist in this effort by collaborating/partnering with organisations such as Aboriginal Resource and Development Services (ARDS) to develop resources for Yolŋu for their related area of interest.

4.4. DisabilityCare Australia collaborate with First People's Disability Network to collect, store and disseminate these resources free of charge to Yolŋu and disability organisations.

4.5. Accessing a comprehensive cultural competency training course is recommended for all personnel working in remote Indigenous communities[15].

4.6. Engage with local communities to explore how residential respite facilities could become part of the strategy of disability sector development in East Arnhem land.

4.7. Increase the number of Yolŋu trained and recruited into the disability sector as part of a broader NDIA sector development strategy.

4.8. Ensure the cooperation of other local, state and federal government departments and other relevant stakeholders (such as NT Housing, East Arnhem Shire Council, etc.) in order for the local NDIS representatives to be empowered to solve practical, everyday problems experienced by Yolŋu people with disability and their families.

4.9. FaHCSIA fund a sector development project to investigate NDIS implementation strategies for remote Aboriginal & Torres Strait Islander communities. This is necessary to address key implementation issues such as workforce development, use of traditional language based resources, cultural competency for external personnel, lack of advocacy, innovative

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[15] For example the course offered by The Remote Area Health Corps (www.rahc.com.au). Remote Area Health Corps (2009). *Remote Area Health Corps Cultural orientation handbook*. [PDF].

approaches to service provision, the requirements for durable assistive technology and for mutual understanding and trust to be nurtured.

4.10. FaHCSIA create a remote area pilot in East Arnhem land. A remote area pilot site would create the space for the remote area implementation strategies to be trialled.

5. Report

The following report aims to capture the detailed learning of the project, gained through the five community visits to carry out Discovery Education sessions and final workshop that will be disseminated through various media. Yolŋu have a rich and sophisticated culture with deep knowledge of all aspects of life; it would be disrespectful to attempt, within the limited scope of this report, to give a full account of Yolŋu culture, language and worldview. However these three are so closely intertwined that it's virtually impossible to discuss Yolŋu worldview of disability, without first understanding some key aspects of Yolŋu culture and language.

6. An introduction to Yolŋu culture; as it relates to disability issues

Yolŋu *rom* means 'law' and 'culture'. Rom has been there for many thousands of years, it has several dimensions and relates to many aspects of Yolŋu life and the natural world. Gurrutu (kinship) is one aspect of rom. Yolŋu use over seventy specific names to describe family members in kinship terms (more than twice as many as Balanda). Everything in the Yolŋu world belongs to one of two moieties (including people), either Dhuwa or Yirritja. Mälk is a category system of sixteen names for Yolŋu.

Gurrutu, mälk, and the two moieties; Dhuwa and Yirritja all interact to create a complex web of Yolŋu relationships between each other and the land, art, history, stories, animals, etc. The more that Yolŋu can help Balanda to understand and appreciate these relationships, the more effective their interactions will be. When beginning to work with Yolŋu, even if you don't understand kinship relationships, it's important to appreciate that these complex kinships relationships exist, to respect them as important and to not make assumptions based on Balanda society.

Carers within the family

Generally in Balanda families when an adult requires a carer (and a family member is preferred to an outside paid carer) it is often the partner of that person who fulfils this role. When this is not possible responsibility usually falls to one of the children. These societal norms inevitably shape the perspective with which Balanda personnel approach their work in Aboriginal communities.

It was observed that in Yolŋu families, partners will often become carers for each other too. When this is not possible or not working for some reason, the family will meet and decide who will care for the person. For older Yolŋu the carer (djägamirr) will often be a gender appropriate grandchild, particularly when personal care is required. Some grandparents and grandchildren are *märi-gutharra*, which is a special, culturally significant relationship. Yet the *märi-gutharra* relationship only takes place between a grandmother and her daughters' children, and grandfather and his sister's daughter's children, which means not every grandparent / grandchild relationship is *märi-gutharra.* Conversely in some cases when a grandchild requires care, *märi-gutharra* relationship is applied, which means the grandchild's mother's mother become a carer. However, it was reported that some people misuse grandparents and grandchildren relationships to justify certain care arrangements when it isn't strictly applicable. Other family members will likely help with general things such as cooking, cleaning and laundry.

If the situation isn't working for whatever reason, the family will meet and appoint a different grandchild to the role. Importantly the children of the older person are *responsible* for their care but delegate the actual day-to-day care role to a grandchild. One woman described her role as that of 'witness' to ensure that the grandchild was doing a good job of being a carer. There are Yolŋu Matha terms for this

caretaker role which have meaning to Yolŋu (which have been published elsewhere), but because they relate to ceremonial culture we were asked not to use them.

The gurruṯu system also designates the kin who should be treated with great respect, and often complete avoidance[19]. Some avoidance relationships are public knowledge and some are private. The most commonly known (but there are others) Yolŋu avoidance relationship is between brother and sister. Out of respect a man must not use his sister's name and it is very important to Yolŋu that nothing personal about his sister is referred to in his presence (including pregnancy, childbirth, bodily functions or sexuality). The same is true in reverse (talk about a man's personal issues with his sister). Consequently a brother and sister must not provide personal care for the other. This includes any classificatory brother not just a biological brother. There are even stricter avoidance requirements for some extended family links.

Yolŋu, like Balanda, care very deeply about their relatives and want the best for people with disability. The main learning here is for Balanda to appreciate that there are many overlapping and sometimes complex factors which influence who a family choose as the primary carer. A little bit of knowledge can sometimes be dangerous: attention is drawn to the aspects of Yolŋu culture described above, in order for Balanda personnel to appreciate how little they understand about Yolŋu. Care must be taken so that unworkable arrangements are not imposed on Yolŋu families based on incomplete perceptions of Yolŋu culture.

Further discussion is needed with Yolŋu to understand whether the matrix of kinship relationships (gurruṯu) contains other rules which influence the family's choice of carer.

Making decisions

For the reasons explained above, it is important that certain family members are involved in decision making related to people with disability in their family. The obligations and responsibilities of the Yolŋu kinship system can influence decisions made about the care and support of a family member with a disability. However it was reported that the wishes of the individual are always respected and that they are not forced by the family to do things that they don't want to.

The main learning here for Balanda is to be prepared to make the space and time for the family to make decisions in private. In many cases where information about the person's disability is not part of the cultural knowledge base, this will mean providing all of the information that needs to be understood in advance to a translator with medical knowledge (see section 11) and allowing time for the translation and subsequent understanding by the family. The family member with caretaker responsibilities may be away from community, and decisions that they have a right to be involved in may need to wait until they return. It's important to recognise that there are many factors at play, and to be patient.

Proper introductions

Yolŋu understand their place and the place of everyone they meet in a complex social network of kinship relationships, intrinsically linked to family history and heritage, arising from the land of each clan. Upon meeting someone for the first time, Yolŋu will ascertain the position of the person within the kinship structure, in order that no one is insulted or offended, and for mutual respect and understanding to be established[16]. From then on Yolŋu will have at least three different ways of addressing the person. When you may know someone's name, mälk and the Yolŋu word for their specific kinship relationship to you, the idea of speaking about someone as a *wheelchair user* or a *person with a disability* seems ridiculous to Yolŋu.

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[16] Manikay.com (2003). *The 'family' concept and Yolŋu/Balanda relations by Peter Lister*. [online] Retrieved from: http://www.manikay.com/library/yolngu_family_concept.shtml [Accessed: 18 Apr 2013].

The learning for Balanda here is to take the time to allow proper introductions to be made. In practice this means being patient while the translator and the person you've come to speak to introduce themselves. Once the kinship relationship is established and if it's deemed acceptable to proceed, then the Balanda person needs to explain who they are, what their role is (which generally includes profession) and the reason for the visit.

Imparting information

For Yolŋu, it's important that information comes from a credible source and to understand that the person giving them information has the right to impart it as its rightful owner. In traditional Yolŋu society information and knowledge is 'owned' by particular groups of people, and the owners must authorise and organise the learning of that knowledge by others[2]. Knowledge ownership is also subject to gender division; with women 'owning' information about female sexuality, reproduction & birth for example. It was observed that for medical information Yolŋu recognise that Balanda doctors are credible sources of knowledge.

The learning for Balanda here is in establishing credibility with Yolŋu, particularly older people, when imparting information. This will likely be more difficult if the Balanda person is a younger woman visiting an older Yolŋu man. When it is necessary to discuss information of a personal nature relating to women, there is a preference that women have the conversation in private. In general this would be true in reverse (except for wives and mothers).

Personal spaces in the home

The gender sensitivity around information of a personal nature relating to women extends to the private spaces such as sleeping areas and bathrooms. Male service provider personnel should not enter these areas without explicitly seeking permission from the female client. Similarly, female service provider personnel should not enter the sleeping area or bathroom used by a Yolŋu man without explicitly seeking permission. An acceptable compromise is for a Yolŋu person who is authorised to be in that space to chaperone the service provider. In general, male personnel visiting male clients, and female personnel visiting female clients reduces the chances of offending anyone, and means that the Yolŋu client is free to speak about things of a personal nature if they choose to.

Traditional beliefs

The foundational story (dhu<u>d</u>i-dhäwu) of many impairments, disabilities or health conditions is not already part of the Yolŋu cultural knowledge base. It is important for Yolŋu to understand cause and effect for many reasons. If no clear cause can be observed or identified, it leaves space for suspicion of other, more sinister influences. Yolŋu relate much more easily to physical disabilities which are observable and the cause is often much more easily explained and understood, in comparison to intellectual disabilities and mental illness which relate to the workings of the brain. It was observed that some older people who tend to understand the Yolŋu culture and Balanda medical language better can get frustrated with younger (less educated about the 'old ways') Yolŋu for the improper attribution of events to interference by sinister influences. This has caused division and even violence in some communities. This is a difficult subject for Balanda personnel to handle, as it's very difficult to discuss these sinister influences with Yolŋu.

Connection to traditional land or country

> "All aspects of the Yolngu cosmos are inseparable. Each clan…is associated with a tract of land, the clan estate of which all clan members belong. Identity of an individual (and the group to which they belong) is expressed through language and the arts such as dance, song and designs that relate to this same tract of land[6]."

The identity of Yolŋu (and similarly many traditional Aboriginal people) is intrinsically linked to a tract of land with which they have a deep spiritual connection. Being separated from this land is like being

separated from their identity. Travelling from town back to homelands for holiday often has a marked restorative effect on some elderly Yolŋu – hinting at the depth of the connection between the wellbeing of the land and the wellbeing of the person.

> "Institutionalising the aged rather than facilitating their care in the community is contributing to the loss of traditional knowledge and culture in communities by removing their elders. For the aged person this disconnection with Country can mean a loss of dignity, pride, feelings of isolation, depression, hopelessness and despair[4]."

During the five community visits the most commonly requested support for people with disability and their families was residential respite facilities in local communities: because the person was still close to their family and didn't have to leave their country. Engagement with local communities to explore how residential respite facilities could become part of DisabilityCare Australia's strategy of sector development in East Arnhem land. For example the East Arnhem Shire Council already runs and Aged & Disability Care service in many communities and potentially could manage additional residential respite facilities added to their existing buildings. It's important that the issues around the management of resources in relation to different clan groups is discussed with the Yolŋu community.

7. Issues for people with disability in this context

Yolŋu communities are located in East Arnhem land far from capital city based services, with very few service providers in the region. The social context is one of inequality and barriers to inclusion[4]. Yolŋu people with disability face many barriers to their inclusion in community life. Assistive technology where it's available is often not durable, not having been designed to withstand the tough physical environment. Most methods of transport, many homes and numerous public buildings are inaccessible. Where service providers do come in contact with Yolŋu a high turn-over of staff, communication difficulties & misunderstandings, a lack of cultural competency and lack of information translated into language all reduce the possibility of long term relationship building, further reducing the effectiveness of services for Yolŋu.

According to a recent Australian National University study "Indigenous disability: Recent evidence":[17]
- Indigenous Australians are at greater risk of disability due to health trajectory.
- Indigenous Australians are at increased risk of acquiring disability through accidents and violence, mental health problems and substance abuse.
- These factors tend to be more prevalent in communities where there are higher rates of unemployment, lower levels of income, poorer diet and living conditions, and poorer access to adequate health care, early intervention and rehabilitation services.

According to the same study the implications of remoteness are:
- A low population density which can provide a number of challenges to service delivery, making it more expensive than in cities and larger towns;
- Difficulties in attracting and retaining a professionally skilled workforce;
- Distance from key infrastructure such as hospitals;
- Often a lack of physical infrastructure or poor quality infrastructure (for example roads, suitable buildings and so on);
- Particular lack of disability-friendly housing and transport in remote areas
- Harsh climatic conditions and inaccessibility due to weather events for extended periods of time.

> "Studies have identified poor communication between sectors, lack of understanding of the level of care, insufficient support for carers, insufficient support for self or family management and inadequate staff skills in working across

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[17] Biddle, N. (2013). "Indigenous disability: Recent evidence", paper presented at *CAEPR Seminar*, April 17th. Canberra: Australian National University.

the sector as driving systems failure. This has resulted in frequent readmissions, people 'walking out', duplication of interventions, significant additional costs and greater risk to the individual's health and wellbeing[18]."

The issues for people with disability specifically raised during the Discovery Education sessions were:

- During the five community visits to carry out Discovery Education sessions the most commonly requested support for people with disability and their families was residential respite facilities in local communities. This was seen by all participants to be the most appropriate form of respite support that the government could offer: because the person was still close to their family and didn't have to leave their country.
- "Many carers are family members; any new scheme needs to be able to work with that."
- "It's difficult to expect Yolŋu to express *individual* aspirations about the future."
- "It's very difficult to ask for support when you don't know what's possible or what's available."
- "Why do Balanda systems and forms have to be so complicated?"
- If the goal is equalisation of access to supports and services, it's important that all people with disability in the community are identified.

"A mental shift is needed to place the person at the centre of the network of support services and recognise that services exist to support the person with a disability and enable them to participate as equal citizens in society. The complexities of the systems needed to deliver those services in a remote community are irrelevant to the person needing to access them. It is the quality of the person's experience of the product or service, their interaction with it and the outcomes leading from that interaction that are important to them[4]."

8.   Yolŋu language about disability

Brief introduction to Yolŋu Matha

There are many languages spoken by Yolŋu. Balanda group these languages together as dialects of Yolŋu Matha, but Yolŋu know them as distinct languages associated with different cultural groups[19];

"According to linguistic classifications of Yolŋu Matha there are 8 major language groupings namely Dhuwal, Dhuwala, Dhaŋu, Djaŋu, Dhay'yi, Nhaŋu, Djiniŋ and Djinaŋ which all the clan languages can be classified by."[20]

Yolŋu commonly speak three or four local languages as well as English. Of the different Yolŋu languages, Djambarrpuyŋu (of the Dhuwal group) is mostly intelligible to all other clans. Wherever possible the project tried to focus on Djambarrpuyŋu and Gurraŋay Matha words.

Gurraŋay Matha is the academic language of the Yolŋu Matha clan groups of central and north east Arnhem Land:

"Gurraŋay Matha is an extremely important educational resource that has been used by Yolŋu for thousands of years to record and store academic knowledge and intangible concepts covering the areas of health, anatomy, economics, commerce, law, theology, biology, zoology, the social sciences, ecology/ conservation and astronomy. While Gurraŋay Matha has been regarded by some anthropologists and linguists as "the old ceremonial" language; it is our understanding from many discussions held with senior clan leaders that Gurraŋay Matha constitutes a whole language in its own right and indeed encompasses the cognitive affective or academic language that is necessary to explain complex terms and concepts across a wide range of subject areas still relevant to Yolŋu today…Of great concern to those who are clan leaders is the fact that young people are no longer learning Gurraŋay Matha language terms. However, this endangered language provides the key to ensuring that Yolŋu have access to knowledge and information in their own language that will facilitate the

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[18] Dept. of Health and Community Services (n.d) *Aboriginal Health and Families: A Five Year Framework for Action*. Dept. of Health and Community Services, NT government.

[19] Christie, M. (2004) *Yolŋu languages and culture: Gupapuyŋu*. School of Australian Indigenous Knowledge Systems, Faculty of Law, Business and Arts, Charles Darwin University, Darwin.

[20] Ards.com.au (n.d.) *Gurrangay Project.* [online] Available at: http://www.ards.com.au/www.ards.com.au/lang_gurrangay.htm [Accessed: 11 Apr 2013]

understanding of contemporary information and concepts into the future…Losing Gurraŋay Matha, the academic language will significantly impact on Yolŋu people's ability to participate in meaningful dialogue with both government and the wider Australian community in all facets of their daily lives."[20]

Yolŋu Matha vocabulary

In order to assist service providers in communicating more effectively with Yolŋu, this project endeavoured to generate an explanation in Yolŋu Math to describe what Balanda mean when they talk about *disability*. From the Discovery Education sessions it was clear that the main elements which needed communicating to Yolŋu were that the Balanda concept of *disability* involved; a permanent loss of function/ability anywhere on the body; inside or outside. The following Yolŋu Matha sentence was discussed in the Darwin workshop and was intended to cover the overarching idea of *disability:*

Wäŋayam	*ŋayi*	*ŋuli*	*ga*	*yolŋuwal*
make home	it (disability)	habitually	is	peoples'

rumbalŋur	*ga*	*yolŋuw*	*ganydjarr*	*ŋuli*	*dhawar'maram*
in body	and	peoples'	strength	habitually	finished

ŋuruŋiyi.
by it (disability).

The literal translation is "It makes our body as its home and finishes our strength."

Following the workshop, ARDS educators decided that it was necessary to validate the phrase through the use of an Uninitiated Native Speakers check (UNS). The subsequent face-to-face and phone UNS checks revealed that Yolŋu that hadn't been present at the workshop couldn't make sense of 'wäŋayam' in this context, and weren't sure what 'ŋayi' referred to in this sentence.

It was clear that two things needed to be reconsidered. Firstly the lack of context needed to be addressed. The concept of *disability* is literally covered in the sentence by the words listed above; but the sentence does not bridge the knowledge gap between Yolŋu and Balanda regarding the concept. The sentence does not clarify what 'it' refers to sufficiently: anyone who used the sentence would have to add examples of 'it' such as blind, deaf, being paralysed, etc. As in process 2, it is fundamental for educational dialogue to commence from what Yolŋu already know to what they do not know. The concept of 'disability' is unknown to Yolŋu and only some examples of different disabilities are known such as blind, deaf, being paralysed, etc. In this regard, the existing knowledge was not being reflected in the proposed sentence.

Secondly the term 'wäŋayam' was used as a metaphor to describe the *permanency* of the disability (the disability had made the body its home). The term was generated at the very end of the Darwin workshops through which Yolŋu participants had learnt well about the concept of 'disability'. This meant that they as initiated users understood the sentence well having spent several hours discussing it.

ARDS Yolŋu and Balanda community educators then reworked the sentence and ended up proposing the following sentence:

'*Disability*'	*ŋayi*	*ŋayamarrŋu*	*dhäruk.*	*Ŋunhi*	*dhäruk*	*mayali'*	*nhakuna*
Disability	it	whole	word.	That	word	meaning	such as

mel bambay,	*rumbalpuy*	*waka'*	*ga*	*burrumunuŋdhirri,*
blind	belonging body	part(s)	is(are)	paralysing

buthuru dhumuk	*wo*	*rumbalpuy*	*waka'*	*bäyŋu.*	*Ga*	*ŋuruŋiyi*
deaf	or	about body	part(s)	missing	And	by that

'disability'dhu	*rumbalpuy*	*waka'*	*bäyŋu*	*ŋuli*	*djäma*
by disability	belonging body	part(s)	not	habitually	function

manymakkuŋ	*gupa-ḏälnha.*
make good	permanently.

The English translation is:

"The word 'disability' is a big word. That word means things such as blindness, parts of body are paralysed, deaf or parts of body are missing. And by having that disability it means parts of our body permanently do not function well."

Yolŋu appear to benchmark a person's function against whether they can do activities/work/effort (djäma) independently or not, and whether they can walk or not (marrtji). Therefore the following phrase, which literally translates as *doesn't do activities well*, was commonly used in explanations but doesn't describe any particular condition:

> Bäyŋu gi djäma manymakkuŋ

Similarly the phrase *doesn't walk well* describes an activity limitation but not a particular condition:

> Bäyŋu gi marrtji manymakkuŋ

In Amery's 2003 paper[21] the following phrase is proposed for disability:

> Rumbalpuy waka' bäyŋu gi djäma manymakkuŋ.

The literal English translation of this being "A part of the body that does not function properly/normally". The five community visits to carry out Discovery Education sessions and the workshop reinforced that Yolŋu relate more easily to impairments which are observable on the outside of the body. Generally physical impairments or activity limitations were better understood than intellectual or mental health conditions. Detailed information about intellectual disability and mental health conditions are not currently part of what Trudgen refers to as the *cultural knowledge base*[22] of Yolŋu. More discussion and education is needed around the distinctions between physical, intellectual and mental health conditions before they are clearly understood. The rationale for seeking a more encompassing explanation about the Balanda concept of *disability*, is to ensure that it communicates a conceptual model to Yolŋu that includes people with intellectual and mental health conditions as well as physical impairments.

The literal English translations and certain commonly used words are included in the tables below; however it is not the intention to provide a full dictionary of Yolŋu Matha vocabulary, but to provide a limited vocabulary which will assist Balanda service providers in communicating with Yolŋu about disability related issues. For example the word *bambay* (blind) and anatomical word *mel* (eyes) can be used together to discuss the person's impairment: mel bambay (blind eyes).

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[21] Amery, H. (2003) Breaking Down The Barriers Dhumbal'yunnawuy rom bakmaram dhu: Learning How to Talk about Disabilities in Yolŋu Matha. Aboriginal Resource and Development Services (ARDS), Darwin.
[22] Trudgen, R. (2000) Why Warriors Lie Down and Die. Aboriginal Resource and Development Services (ARDS), Darwin.

Commonly used general words or phrases

English	Yolŋu Matha	Literal English translation
Detailed explanation	Dhu<u>d</u>i-dhäwu	Deep/base story
Good/well	Manymak	Good/well
Not good/not well	Yaka manymak	Not good/not well
New/young/recently	Yu<u>t</u>a	New/young/recently

Common anatomical body parts

English	Yolŋu Matha
Body	Rumbal
Brain	Bamburuŋburuŋ
Head	Mu<u>lk</u>urr or <u>l</u>iya
Face	Buku
Eyes	Mel
Ears	Buthuru
Shoulder	<u>L</u>ambarr
Arm	Wa<u>n</u>a
Elbow	<u>L</u>ikan
Hand	Goŋ
Hip	Dharwa
Upper leg	Yu<u>t</u>uŋgurr
Knee	Bunkumu
Lower leg	Yaŋara
Foot	<u>L</u>uku
Blood	Gulaŋ or maŋgu

The disability related terms which were most commonly generated by the Yolŋu participants in the five discovery and education sessions

Current disability terminology	Yolŋu Matha	Literal English translation
Paralysis	Bundhurr	Paralysis
Numbness	Burrumunuŋ	Numb/stiff/slow moving person
Hearing impaired	Buthuru dhumuk	Ears closed/blocked
	Buthuru mukthun	Ears covered to stop/quieten the noise
	Dhoŋulu	Hearing problem
To limp	Djuka<u>t</u>thun	Limp (verb)
Speech impaired	Matha yalŋgi	Language weakness
Blind	Bambay	Blind

Weak	Yalŋgi	Weak
Dead	Rakuny	Literally means 'dead' and can be used to refer to 'no feeling' in sentence like ŋarra waṉa rakuny (my arm has no feeling)
Pain	Dhuṉ'thuṉdhun	Pain (verb)
Sickness/disease	rerri	Sickness/disease (observed it was also used to indicate pain)
Sick person	Rerrimirr	With sickness (possessing sickness)
Healthy	Rerrimiriw	Not with sickness
Old people	Rirrkminy	Yolŋu men must avoid calling their sisters by their names and use words like bambay, miḏiku and yalŋgi. The word 'rirrkminy' is used to refer to old men and women in a respectful way. It doesn't necessarily mean they are frail (clarified).

Disability related terms from Amery's paper which were <u>*discussed*</u>*, some of those which were* <u>*clarified*</u> *and words which were* <u>*recorded*</u> *during the Discovery Education sessions but which had not been previously listed in Amery's paper (although these were new to the investigating team, they were previously known to ARDS)*

Current disability terminology	Yolŋu Matha	Literal English translation or explanation
Crutch or stick user	Dharpamirr	(Person) with crutches/walking stick (discussed)
Wheelchair user	Wiltjiyamirr	(Person) with wheelchair (recorded)
Shower chair	Waḏapthunawuy nhinanhamirr	Something to sit down for shower (discussed)
Below knee prosthesis	Toy-one yaŋara	*Toy-one yaŋara* is a new colloquial term, compared to the alternate *yuṯa yaŋara* (new leg). The literal translation of the sentence is: "Toy-one lower leg"
Hearing aid	Buthurupuy girri	The thing that relates to hearing (recorded)
Head injury	Liya-wutthunawuy	Head injury resulting from physical impact or injury (discussed). The meanings of liya, mulkurr (head) and bamburuŋburuŋ (brain) overlap and are interchangeable.
He/she perpetually/permanently isn't thinking in a good way (clarified)	Bäyŋu ŋayi ŋuli gi guyaŋa manymakkuŋ	Also the phrase *bitjan bili*, which means 'always' (adverb) can be used instead of 'ŋuli'. Further work is needed to understand whether this phrase can be translated as Balanda phrase such as 'mental health'.
Being paralysed	Burrumunuŋdhirr	Being paralysed/numb (recorded)
Accident/injury	Wutthunawuy	Accident/injury (discussed)
A person who is slow in learning and moving	Bundhuwulu	Further work is needed to understand whether this phrase can be translated as Balanda phrase such as 'intellectual disability'.
About the body	Rumbalpuy	'Physical disability' is a concept that doesn't translate into Yolŋu Matha (discussed)
About the head or brain	Liyapuy or muḻkurrpuy	'Psychiatric / mental illness' is a concept that doesn't translate into Yolŋu Matha (discussed)

What makes you sick?	Nhäliy nhe rerrikthun?	There is no word equivalent to 'cause or causation' (discussed)
At the time when you were born	Ŋuli nhe ŋuli dhawal-guyaŋa	There is no direct equivalent of 'congenital' (discussed)
Through the line of blood	Ŋunhiyi bili maŋgukurr yarraṯakurr	There is no direct equivalent of 'genetic' (discussed)
The baby sitting inside of his or her mother	Ŋäṉdimirriŋuwal yothu guluŋŋur	There is no direct equivalent of 'pre-natal environment' (discussed)
Premature baby	Walumiriw yothu	Baby without days (recorded)
Can't walk at all	Bundhurr	Unable to sit up, walk, go to toilet or any activities, also means paralysis (discussed)
He/she is walking with support	Ŋayi yolŋu ŋuli ga marrtji ḏälkunhamirr	He/she is walking with support.(recorded)
Can walk independently	Marrtjinyamirr	A walking thing.(recorded)
Can't do activities	Bundhurr	Unable to sit up, walk, go to toilet or any activities, also means paralysis (discussed)
With aid/support	Ḏälkunhamirr	Something strengthening someone.
Can do activities independently	Waḻanyawaḻanya	The person being highly motivated to do lots of activities (discussed)

More investigation needed

The table below shows other disability related terms which have been discussed, but for which the process of discovering a meaningful translation is not complete. The lack of knowledge over the exact translations of the terms below means leaving them out of the educational resources at this time. Most of the concepts below which still require clarification relate to the brain and thinking. There are many Yolŋu Matha terms which overlap, and more time working with Yolŋu is required to differentiate between the various types of head and brain injury, damage or malfunction. It's also currently difficult for Yolŋu communicating with Balanda to differentiate between intellectual disability and mental illness. These difficulties point to the need to discover more about the Yolŋu understanding of the brain and its functions. The telling of foundational stories about individual conditions by knowledgeable practitioners will generate better shared understanding.

English	More discussion of these Yolŋu Matha terms required	Literal English translation
Acquired?	Märranhawuy	'Märranhawuy' literally means *concerned with receiving*. In this context 'märranhawuy' could also mean diseases which a baby acquires from her mother, which we would normally associate with *congenital* rather than *acquired*. More investigation is needed.
To sense	Gatjarr'yun	Verb: taste, hear, feel, smell, listen
Lifestyle factors?	No term currently known	Explanation: our lifestyle can affect us becoming disabled eg: drugs & alcohol, malnutrition, etc
Neurological?	No term currently known	
?	Muḻkurr-ŋäriŋumirr	Brain is sometimes functional (engaged) and sometimes malfunctioned (disengaged)

Literally *head sickness?*	Muḻkurr-rerrimirr	This covers several conditions/disorders of the head or brain. This phrase hasn't been discussed sufficiently yet to be certain of it's exact meaning for Yolŋu, distinct from the other terms
Literally *brain injury?*	Bamburuŋburuŋ wutthunawuy	This phrase hasn't been discussed sufficiently yet to be certain of it's exact meaning for Yolŋu, distinct from the other terms.
Stroke?	Guḻaŋbuy gurrkurr gungam bamburuŋburuŋŋur	The literal translation: "the blood in the vessels covers the brain" describes the scientific fact of a haemorrhage, but does not necessarily mean stroke (clarified)
	ḏalalakthun	this word covers both stroke and heart attack. Literally means the body shakes and vibrates due to serious damage on body
	Burrumunuŋdhirr	this word means *you go numb*
Alzheimer's disease?	Guyaŋanhawuy rerri worruŋuw	the condition which affects your thinking when you get old (clarified)
	Dhawuthuwa	some old people naturally forget things easily...doesn't necessarily mean that they have a mental illness
Dementia?	Guyaŋanhawuy rerri	"the sickness concerned with thinking" this is a new word based on Balanda view point. It is better used in a sentence:
	Muḻkurrpuy rerri ŋunhi bäyŋu ŋayi ŋuli gi guyaŋa manymakkuŋ	this sentence literally means "the sickness in your head or brain by which you habitually don't think clearly"
Autism?	Muŋmuŋ ga dhärukmiriw	a *muŋmuŋ* person listens to people but doesn't interact with them actively, often sit quietly not speaking. If a dog jumps over a baby when he/she is little, the baby will become *muŋ'muŋ ga dhärukmiriw*.
He/she is living with support	No term currently known	The term 'living' needs to be broken down and better understood in order to translate this concept.

Amery was clear that the findings of his work were predominantly linguistic in nature, and emphasised that understanding language is an on-going process;

> "It is recognised that the terms generated from this project need wide circulation within East Arnhem communities, especially with clan leaders and Yolŋu health personnel, so that more informed discussion can occur and feedback obtained. Some testing and further development of concepts and linguistic constructions derived in the Disability workshops has continued to occur in on-going conversations with individuals in several East Arnhem Land communities, as well as with some Yolŋu persons living in Darwin, however there is still need for much more to occur."

The above statement is as true today at the completion of our project as it was in 2003; the process is on-going and going forwards much work is needed in order that Yolŋu people with disability and their families gain a clear understanding of their disability and underlying medical conditions. Whilst the Discovery Education sessions conducted during the project have further contributed to the understanding of Yolŋu Matha relating to disability; this project focused more on worldview and drawing out practical learning for service providers.

9. Yolŋu worldview of disability

Yolŋu objectively describe what is observed about the person with a disability without categorising them or any stigma or negative connotations. This represents an almost ideal acceptance of human diversity in the Yolŋu community (within certain limits discussed below). It is imperative that through our haste to intervene we don't simply impose a Balanda concept of disability over the top of Yolŋu culture.

Every cultural group has its own perspective on the world. Human's have mental models/concepts of what represents a complete person to them: a human body, with all its observable, physical attributes that are familiar to them; behaviour which fits with their social and cultural norms; development and learning which happens at a rate that they can recognise, etc. These mental models define the boundaries of what we consider normal human development and behaviour.

Yolŋu appear to benchmark a person's function against whether they can do activities/work/effort independently or not, and whether they can walk or not. These are both facets of directly observable, physical ability. Therefore if a Yolŋu person with a disability is compensating for their impairment in some way but is still able to do activities and walk (even if that involves a 'support' of some kind) the Yolŋu don't appear to distinguish that person as being different to themselves.

The positive consequence of this is that no evidence of people with physical or sensory disabilities being stigmatised was observed or reported. This is supported by Elliot (1994)[23] and Senior (2000)[24] cited in the Productivity Commission's report on Disability care and support[25].

The possible negative consequence is that if a Yolŋu person with a disability is able to 'get by' in community by compensating in some way, that person may not be identified as needing further support. In the first instance the person may not identify as being disabled:

> "…most Aboriginal people that have a disability don't generally identify as being a person with disability so the language in the disability area is often a barrier for a lot of Aboriginal people."
> Damian Griffis, CEO, First Peoples Disability Network (Australia)

It is anticipated if service providers prepare well with a Yolŋu cultural and linguistic liaison officer who is conversant with both Yolŋu and Balanda bio-medical worldview and languages, the Yolŋu Matha explanation of the concept of 'disability' discussed and proposed by this project (see section 8) will aid in the identification of Yolŋu with disabilities; helping people in community to think about all the Yolŋu they know who fit the definition.

In general physical impairments or activity limitations were better understood than intellectual disability[26] or mental illness[27]. Yolŋu related more easily to impairments which were observable on the outside of the body and less information about intellectual disability or mental illness is part of the Yolŋu cultural knowledge base[2]. It was observed that Yolŋu did not differentiate between people with intellectual disability and people with a mental illness, and did not group these together with people with physical disabilities. There remains unease among many Yolŋu around mental illness, particularly since it often manifests in teenage and later years. While intellectual disability is often emergent almost from birth, the development of aberrant behaviour and thinking associated with mental illness is often attributed to bad spirits. In one case the team heard of a 'cursed hat' that a teenager had picked up

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[23] Elliot, D. (1994) *Aboriginal Perceptions of Disability and the Formulation of an Appropriate Method of Providing Rehabilitation Services to Clients on Remote Communities*, Pilot Project Number 1, Commonwealth Rehabilitation Service, Darwin.
[24] Senior, K. (2000) *Testing the ICIDH-2 with indigenous Australians: Results of field work in two Aboriginal communities in the Northern Territory*. Australian Institute of Health and Welfare, ICIDH Collaborating Centre and the Department of Health and Family Services.
[25] Productivity Commission (2011) Disability care and support: draft report [vol 1 & 2]. Canberra: Productivity Commission (section 9)
[26] The National Council on Intellectual Disability state that: intellectual disability is characterised by significant limitations in intellectual functioning; and adaptive behaviour expressed in conceptual, social and practical skills; which originates before age 18. (ncid.org.au)
[27] The Mental Illness Fellowship Victoria state that: mental illness refers to a group of disorders that affect the way a person thinks, feels and acts. Mental illnesses include depression, bipolar disorder, schizophrenia, anxiety and personality disorders. (mifellowship.org)

accidentally and since that time had suffered mental health problems. As noted earlier, Yolŋu are very perceptive and often seek an explanation for sudden changes in behaviour.

The two areas of disability which were the cause of shame for Yolŋu are incontinence and outbursts of challenging behaviour and loud noises in public. Reportedly the fear of an episode happening in public made some carers reluctant to assist the person with disability to go out into the community. In Yolŋu culture, the taboos associated with personal hygiene (especially toileting) are very strong, and public incontinence brings shame to not only the person and their carer, but also the family. Consequently this area of support (and space/facility to deal with it in privacy) is almost the top priority for most families.

10. Process 1: The process to understand language & worldview

Background and principles of ARDS educational methodology

After many years working in the field with Yolŋu people, Aboriginal Resource and Development Services (ARDS) have developed a successful educational methodology that allows for the sharing of knowledge covering a wide range of often complex subject areas. These include health, legal and economic topics. This educational methodology incorporates principles of adult education, community development and applied linguistics. A crucial aspect of the ARDS approach is the use of the people's own language in the educational setting. All programmes are delivered in language, using two-way dialogue between Yolŋu and the educator. The ARDS education approach aims to incorporate and respect the people's own experiences, knowledge, worldview and intellect. It is delivered in a way that is culturally-appropriate, respectful and comfortable. ARDS staff attempt to provide people with the 'full story' that many Yolŋu people request, as opposed to a short message which conveys little or no intellectual understanding. The use of people's language, world view and existing knowledge allows for the use of what ARDS calls 'Discovery Education'.

Central to the ARDS educational methodology, Discovery Education aims to deliver concept-based education around 'problems' that people are wanting answers to. The subject or issue is identified by the people themselves, usually being something that is affecting them or causing confusion. The educator begins by building up background to the general subject and working out what knowledge people hold on this topic. The educator thoroughly researches the topic and the nature of the people's questions and starts collecting a list of key Yolŋu Matha words on the subject to spark discussion. After this has been done education on the topic can begin with the educator and people using two-way dialogue in the people's own language. The educator builds on the existing knowledge and through dialogue clarifies misunderstandings and fills in knowledge gaps. During this process the educator is also learning from the people and adapts the content and approach as appropriate. Using the Discovery Education method allows the people to drive the educational content. They 'discover' information of relevance and significance to them, as opposed to having it fed to them indiscriminately. It is an approach that engages and empowers people, making them active participants in constructing and owning the information.

Preparing the team

A critical part of the work was to build a team that had language and cultural experts, and those with expertise in disability. For cost and operational reasons, the team that visited community was kept to a maximum of four people (one or two from Motivation Australia, and two or three from ARDS). This size proved quite manageable and worked well on community. Gender balance within the team was also considered.

The team worked to understand each others' strengths, and to build and explore examples from their experience to achieve a shared understanding of important concepts (e.g. what is the difference between impairment and disability; types of assistive technology that people may need; how it all relates to medical care/rehabilitation, etc.)

Preparing the community

Yolŋu Radio, newsletters and word of mouth was used to tell those in the target communities in general terms about the purpose of the project, and in particular that a team would be coming to do *djäma* (work) on community. A key part of this introduction was to explain who the team were.

ARDS is well known throughout East Arnhem Land, for many decades of economic, health and legal educational sharing with Yolŋu and more recently through their radio station (Yolŋu Radio). Motivation Australia has traditionally worked in less resourced settings internationally, and while it had done some work in East Arnhem it was an 'unknown' to the East Arnhem Land people. Consequently an important part of the introductions (both prior to and when arriving on country) was to explain who Motivation Australia are, what they do, and why they had come to do this *djäma* in East Arnhem.

Establishing the protocol for djäma

The Project Team planned the work on community as a collaborative *djäma*. Sessions were anticipated to be interactive, and built heavily on narrative (the telling/sharing of stories). While the Motivation team members present would provide disability-related expertise, the expertise in Yolŋu language, worldview, culture and law (*rom*) would come from those in the community and from the ARDS educators. The project was one of exploration and development (as opposed to *question and answer*) in keeping with Indigenous approaches to learning and sharing valued information – the basis for Discovery Education.

Ethical clearance

The project was required to have human research ethics clearance (HREC) by the funding body. The Ethics Proposal required careful negotiation with the Ethics Committee to ensure that the contribution of individual Yolŋu could be recognised.

Timing

Planning for any work in northern Australia requires consideration of weather due to the tropical environment. The team aimed to meet participants in their communities (on country). There is generally less mobility between communities (and homelands), and fewer ceremonies planned during the wet season period thus increasing people's availability for consultations in community. This can also be a good time to visit people on established homeland communities who are more likely to remain in more permanent shelter. The wet season does pose risks associated with flights and extreme weather events and the team did have to postpone one trip due to bad weather.

Team dynamics

Team members who had not previously worked using the ARDS methods were provided with background reading including:
-   Friere's 'Stages towards critical consciousness in dominated cultures'
-   Harris 'Have your Manners'[28]
-   Savage & Godwin 'Controlling your language: Making English clear'[29]

In addition it was accepted that the ARDS Community Educators would undertake the requests for participation and the introductions. With rare exceptions, the Community Educators facilitated all conversations in Yolŋu Matha, translating and clarifying as necessary for the English speaking team members. The Community Educators also ensured the team did not breach cultural or law protocols,

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[28] Harris, S 1987, 'Have your Manners' in Ruth Liscombe (ed.) *Living and Learning in an Aboriginal Community*. NT Dept of Education, Darwin.
[29] Savage F & Godwin P (1994) *Controlling your language: Making English clear'* Contact No 136 (Apr 1994) p1-6.

providing guidance and later explanation to Balanda members particularly on topics that carried shame or taboo. In some communities, one or more senior people would also interact directly with the Balanda members of team in English, sometimes translating conversation with others nearby. As a consequence, at times there would be multiple conversations underway, but inevitably when points of worth had been agreed, these would be shared with and written down by a Balanda team member.

It was also agreed that there would be time in the schedule for discussions just within the team. This proved invaluable to:
- enable Balanda members to explore some of the feelings and issues that may have been too sensitive to be translated in the public forum;
- permit the team to reflect on and adjust the process (and plans for future meetings) to ensure it avoided causing any distress to participants, or tension within subgroups or the community;
- provide time for the Community Educators to explore and clarify their understanding of disability terms and concepts with the Motivation content experts.

Logistics

Flights, vehicle hire and accommodation were arranged to facilitate the team to travel & work together. The vehicle hire also proved valuable in assisting community members to attend group sessions.

All members sought and gained a Northern Land Council access permit to cover their time in East Arnhem. Although not strictly necessary for the target population, all team members also had appropriate child safety clearances.

One of the members of the team took responsibility for managing the payment of the cash honorarium to active participants. This included completing the necessary tax and administrative documentation with those participants.

It was critical (and a requirement of the Ethics Clearance) that the team had access to relevant referral pathways when participants raised issues where they wanted advice or support beyond the scope of the project (e.g. with Centrelink).

Undertaking a consultation

Upon arrival in a community, the Community Educator(s) would visit key contacts known to have interest in or work in disability. In several cases, local facilities permitted the use of their community space for the discussion groups. Typically it would take up to half a day to make introductions, and then work with local community members to schedule meetings or discussion groups. The early phases often involved being directed to individual's homes where the Educator would follow cultural protocols (usually with the Balanda members waiting in the vehicle or at a distance) to introduce themselves and the work, and then determine if it was convenient to do *djäma*. Families were very accommodating, with some immediately welcoming the team in, while others scheduled an appropriate time or went with the team to a neutral space.

Where possible, key community contacts such as the aged care service and Shire staff were made aware of the Team's presence and the work it was doing.

Focus or discussion groups tended to form as a result of word of mouth around the community, with community members encouraging key stakeholders to attend. Such group sessions were usually one to one and a half hours in length, started with a reminder that the process was voluntary and they could leave if they wished and in some cases was opened with prayer by one of the community members. The team ensured it provided biscuits or other items for morning or afternoon tea, and meetings adjourned if necessary for a one to two hour lunch break.

The team sought to offer flexibility and be available whenever local people expressed interest in having a conversation. Thus some sessions occurred early, while others started in the late afternoon.

The notes taken by the team reflected a 'consensus of thinking' from the sessions, except where it was clear there were differing points of view, when the diversity of views was noted. Team members and participants also used large paper with markers to draw and sketch out information in a collaborative and sometimes iterative way.

Following some initial discussions with participants in Darwin, diagrams were prepared to illustrate a number of types of assistive technology (e.g. wheelchair, walking frame, patient hoist, crutch etc.) Team members also utilised a word list related to disability that had been prepared in a previous ARDS project (Amery, 2003). Discussions and the language used was compared with and, if appropriate, added to this list. At times these descriptions proved helpful at stimulating discussion on a particular topic.

Discovery Education in action

The team based its interactions on the Discovery Education approach that is a hallmark of ARDS. Only minor adjustments were required to adapt the approach to enable the project team to seek education from Yolŋu. There were instances when the Team was able to respond, in true Discovery Education style, to the 'problems' raised within a community. In one case the team prepared a meaningful explanation (in language) for cerebral palsy to help a mother understand the particular disability. In general though it was the Team that was trying to understand traditional and current ways Yolŋu communities understood and met the needs of their members with disability.

The Team focused on building broad concepts and vocabulary to facilitate the dialogue, which included aspects of medical, social and environmental knowledge and information. A common start to a discussion would be 'what usually happens when someone in the community has (an impairment)?' The Team focused on hearing the descriptions, the words used and even observing who was contributing to the discussion. Ideas or words related to the topic that had been gathered from earlier work were checked to see if they were relevant (or appropriate). This iterative process resulted in clarity about when certain terms applied and the nuances that flowed from the Yolŋu worldview. It also helped 'map out' the cultural practices that related to including and meeting the needs of family members with disability.

Having gathered a wealth of stories and expressions, the Project Team convened a two day workshop in Darwin, to include additional elders and experienced Yolŋu translators and educators. This group sought to sift and clarify the concepts and words that the Balanda Team members were forming to describe Yolŋu approaches to disability. This process was often protracted as Yolŋu struggled to help their Balanda colleagues understand the complex nuances at play, while Balanda disability experts sought to explain the emerging understanding of causes of disability and possible supports (from a western biomedical/scientific perspective). Numerous breakout discussions (often in Yolŋu Matha) linked with diagrams and metaphors helped forge consensus that could then be shared and explained.

At the conclusion of the workshop, the Team had a number of concepts and terms from which to create both an explanation of Yolŋu cultural expectations in dealing with disability and relevant Yolŋu Matha descriptions of Balanda concepts around disability and impairment. The ARDS Team members then continued to test these materials with their Yolŋu Educators and several Yolŋu groups to see if the materials 'made sense' and most importantly were accurate in Yolŋu Matha. This process will be on-going for some time because a number of the disability concepts are new knowledge for Yolŋu and more Discovery Education is required to ensure the information is correct. In particular the areas of intellectual impairment and mental health disability are complex and difficult to explain and understand for many Balanda as well as Indigenous peoples. Many disabilities in these areas have only been seen relatively recently in Indigenous communities following substance abuse and health impacts of the

economic and social challenges in the last century. Detailed Indigenous explanations and ways of dealing with those impacted by such neurological disability are still in their earliest phases.

Keeping Records

To maintain confidentiality there was no electronic recording of any sessions. Motivation Australia team members recorded written notes of discussions, highlighting key points, without attributing specific statements to any individual (although names were recorded with consent).

In addition to maintaining the administrative records (e.g. tax forms, receipts etc.) the team filed the completed consent forms, and all materials completed during the work including flip chart pages and hand drafted notes.

Usually the Motivation team members would prepare a report to capture the findings at the end of each community visit. These formed the basis for subsequent sessions and the final workshop, and informed other members of the extended team of the outcomes.

11. Process 2: The process which is needed to tell the foundational stories of different disabilities

Why is it necessary?

In order to be able to make informed decisions[14] about their care and supports, Yolŋu require accurate information, in a language and format that they can understand. For many Yolŋu with disabilities and their families, the dhudi-dhäwu (deep, true or foundational story) of their particular impairment or health condition will not be commonly known; it will not already be part of their *cultural knowledge base[2]*, and people will generally not understand *how*, *why* or *what* is happening to their bodies.

The principle of governments ensuring informed decision making for people with disability to maximise their autonomy and independence[30]; through providing assistance and support to ensure people with disability have access to information[31]; and by raising the awareness of rights, dignity, autonomy and the needs of people with disability[32], is explicit in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).

The National Disability Insurance Scheme Act 2013 states that "People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity."[33]; and the National Disability Insurance Agency "must use its best endeavours to provide timely and accurate information to people with disability and other people in order to assist them in making informed decisions about matters relevant to the National Disability Insurance Scheme".[34]

It is therefore understood as a fundamental principle that people with disability and their primary caregivers, have the same right as non-disabled people, to understand their own disabilities, impairments and health conditions, in order to make informed decisions about all aspects of their lives.

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[30] United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org. Preamble, p2.
[31] United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org. Article 9, Accessibility, p9.
[32] United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org. Article 25, Health, p18.
[33] Commonwealth Government of Australia (2013) *National Disability Insurance Scheme Act 2013*, Commonwealth Government of Australia, Canberra. Chapter 1, Section 4.
[34] Commonwealth Government of Australia (2013) *National Disability Insurance Scheme Act 2013*, Commonwealth Government of Australia, Canberra. Section 15.

An example of an "introductory conversation" about the story of cerebral palsy between Joy Bulkanhawuy (ARDS) and Lauren Houpapa (Motivation Australia)

During a field trip in one of the Yolngu communities we arranged to meet with two young men with cerebral palsy and their families to undertake discovery and education sessions. This was a new story for Bulkanhawuy, who asked Lauren to explain to her the foundation story for cerebral palsy so that she could better understand this disability and better translate this story when working with those families.

It is best practice when undertaking Discovery Education to follow the process proposed in the next page for *'Telling the foundational stories of different disabilities'* and *'Guidance for working with Yolŋu people with disability and their families'* on p27. However, in this instance the team decided to comply with the request for information and proceed with the education sessions with limited pre-requisites to see what would happen and to also learn from the overall experience.

The process as it unfolded was something like this:

- We had just arranged to work later that day with one client with cerebral palsy and were hoping to also do some work with another client with cerebral palsy later in the field trip. Cerebral palsy was a new topic for Bulkanhawuy. She asked Lauren to explain 'cerebral palsy' in order for her to understand and be able to better translate the concepts into Yolŋu Matha for the child's mother,
- The male ARDS educator / health professional was aware that this conversation would require discussing pregnancy and birth which was likely to be uncomfortable for Bulkanhawuy in the presence of men. He advised that he and the other male member of the team should leave the room and allow the discussion to continue between Lauren and Bulkanhawuy. This occurred very early in the conversation before any in-depth detail had been entered into.
- Knowing that she herself did not speak Yolngu Matha, Lauren decided that she first needed to describe to Bulkanhawuy the core concepts about cerebral palsy using plain English. She also realised that it would not be possible to describe the impact of cerebral palsy on the brain without first explaining what the brain does and the different ways it can be damaged.
    - o Lauren set out to explain the following concepts in plain English, accompanied by drawings, to illustrate the following key points: the difference between a disability that was congenital versus acquired,
    - o The 'capacity' of a person to do something, and 'potential' of a person to learn and complete a new activity,
    - o The functions of the brain, and how they relate to: movement, thinking, body functions etc,
    - o The process of "growing a baby" and how the "ingredients" (genetic material) that make up a person can mean that they develop a condition/disability,
    - o "Ingredients" came from the mother and the father, and 'grew' a baby,
    - o Some of those conditions were things like intellectual disability, which affected the capacity of the young baby to learn new information and skills. That their capacity was 'fixed': they could learn new things, but their capacity to learn at a 'normal' rate would be reduced,
    - o That sometimes once the baby was already formed, and had grown, and injury to their young brain can cause problems with movement, thinking, talking and eating,
    - o That cerebral palsy was probably caused by lack of oxygen to the brain of a pre-natal, newly born or very young baby,
    - o Because the amount of damage was related to how much oxygen was restricted, and what area of the brain was more impacted, that the presentation of cerebral palsy was different in different people,
    - o Many people with cerebral palsy are able to think and learn in the same way as we do, but may not be able to express it (i.e. talking, writing),

- That cerebral palsy was a 'fixed' disability: it could change as their body grows, as they might grow a different way (i.e. contractures, bone growth), but it would not "get better". Therefore it was permanent,

- All of this was "new information" for Bulkanhawuy hearing it for the first time and in the 'foreign language' of English, rather than in her first language of Djambarrpuyngu (a dialect of Yolngu Matha). Bulkanhawuy then asked a number of questions to try and clarify in her own mind the meaning of the English words and concepts. English concept words used such as *capacity*, *potential*, *ingredients*, *fixed* and *normal* were particularly hard to understand in a short, introductory session. She was able to understand some, but not all of this deeper story from this single session. What she understood, she shared with the families and clients. Due to the lack of time and without an ARDS educator present to record the Yolngu Matha: no new Yolngu words were documented alongside the English words and diagrams (including a term for *cerebral palsy* itself).

- The team later went to visit the mother of one of the clients with cerebral palsy. They commenced a discovery and education session allowing her to share her story. It became apparent during this conversation that she had little understanding of the foundational story of cerebral palsy. Bulkanhawuy and Lauren offered to help her understand more of this story which she was keen to hear. At this point they again asked the male team members to leave.

- Sitting outside under a tree, Bulkanhawuy then asked Lauren to repeat the explanation (since she was the rightful knowledge holder) which Bulkanhawuy helped to translate in Yolngu Matha with some additional English words.

From this introductory conversation we can observe the following:
- that an explanation of "what is cerebral palsy?" relies on an awareness of other information (such as how the brain works and how it is formed) which may or may not already be part of the cultural knowledge base.
- There was no understanding of the differences between intellectual disability and complex physical disability.
- The concept of permanency was 'new' information. (It was a surprise to Bulkanhawuy that there was no procedure or medicine to treat cerebral palsy).
- Time is needed to document and to 'test' new Yolngu Matha terms.
- Time and language are needed to work through complex new concepts.

Telling the foundational stories of different disabilities

The proposed process for creating and telling foundational stories:

1. Identify the disability that you want to tell the foundational story of,
2. Understand the detailed clinical features of the specific disability, causation, symptoms, etc,
3. Research / discover what is already understood by the cultural group about that specific disability (without making assumptions)[35],
4. Research / discover knowledge gaps, questions and misunderstandings of the cultural group about that specific disability (without making assumptions),
5. Map out the story and create a mental picture 'in the mind's eye' for a trusted group of Aboriginal people from the cultural group you want to communicate with,
6. Answer their questions clarifying the meaning of words or concepts,
7. Together generate language around the topic, discuss analogies and pictures that would help communicate the ideas,

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[35] A common mistake is to assume that aspects of a story, often the 'basic' physiology or function of part of our body, form part of the existing knowledge base. These are ultimately vital to the understanding of the full story. Examples include: role and function of the brain; circulation of blood through our body, germ theory of disease.

8. Create a clear storyline of the disability using plain English (with as little jargon as possible)[36], and verify that the details are clinically correct,

9. Develop the story in language

10. Give the person who's going to translate for you the time to learn the story in advance and ask questions about the meaning of words or concepts,

11. Medical and allied health professionals tell the story through the translator using whatever visual resources they have created, to Aboriginal people from the cultural group.

Continue to use the story in the field, developing and refining it over a long period of time (months or years) as necessary to address questions and knowledge gaps. It's important to recognise that the story and the language is not static or fixed, but an on-going, living process. Only after a long period of testing should you consider developing a resource, which again needs to follow the processes above and go through much field testing before being 'finalised'.

Yolŋu must be involved in developing the content. It must work from their worldview perspective, build on their cultural knowledge base and be delivered in their language. Trudgen[2] describes the following criteria for the process of telling the foundational story of a subject to Yolŋu:

- The information must come from a credible source – the owners of the knowledge,
- The information must be delivered in the 'culturally-correct' way,
- The information must build on culturally accepted knowledge and truths,
- The information must be able to survive intellectual debate,
- The information must receive peer group affirmation,

12. Process 3: The process when working with Yolŋu people with disability and their families

The project has partially documented the process used by ARDS *when working with Yolŋu people with disability and their families*. This is practical guidance for interacting with Yolŋu people with disability and their families, describing how to improve the quality of communication between Balanda and Yolŋu.

Accessing a comprehensive cultural competency training course is recommended for all personnel working in remote Indigenous communities[37]. The processes described in this section are not intended to replace the need for good quality cultural competency training. The intention of this section is to provide extra guidance for working with Yolŋu people with disability and their families in a remote community.

It's important to acknowledge that there is much to learn about cross-cultural working practices. It takes ARDS educators at least two years to become experienced, competent and independent in working with Yolŋu. This can be likened to training that professionals undertake before they become independent, such as that of a doctor or lawyer; and is an on-going, life-long learning experience.

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[36] Using plain English doesn't mean simplifying the content, it involves not using medical or technical jargon to explain the concepts. It's important that detailed information is given and the story is not 'dumbed down'.

[37] Such as offered by The Remote Area Health Corps (www.rahc.com.au). Remote Area Health Corps (2009). *Remote Area Health Corps Cultural orientation handbook*. [PDF].

Guidance for working with Yolŋu people with disability and their families

Prepare well	Prepare your personnel by attending comprehensive cultural competency training.
	Identify a professional translator who has the skills to translate bio-medical information. Familiarise them with the language and concepts you want to talk about in advance.
	Prepare the foundational story for the person's disability (see Process 2).
	Identify someone from the local community to act as an intermediary who knows the Yolŋu you want to visit; and let everyone know you're coming in advance and why. Allow time and opportunity for them to educate you, correct wrong understandings and provide guidance on cultural and linguistic protocols.
	Think about what your objectives for the visit are.
Make proper introductions	Upon arrival meet up with your local intermediary, and work out where you're going to talk with the person with a disability and their family.
	Don't immediately approach too close to their house (even without a fence the space around people's houses should be respected). Often meeting outside under a tree, on a veranda or at the Aged Care centre is a good idea.
	Hang back and let your intermediary and translator introduce themselves.
	Introduce yourself; describe your profession, who you work for and the purpose of the visit. It's important that you establish credibility that you have the right to talk about and pass on the information.
	Ensure that the relevant people are present. Be aware that there are different roles within the family i.e. who is empowered to make decisions about a particular subject.
Work in a respectful way	Be sensitive about the client's gender, particularly if the discussion might cover personnel care subjects.
	Do not enter the private areas (particularly bathrooms) without first seeking permission, particularly in cross gender situations.
	Think about your attitude and body language - especially with older people.
	If this is the first time you've met the person, you have to build the relationship, including giving them the opportunity to tell you their story about their disability or other things they feel are relevant.
	Appreciate that there are competing priorities in people's lives on community.
Communicate well	Slow down: communication happens at a slower pace, be comfortable with silence. Wait patiently while someone is speaking and let them finish.
	Explain clearly in plain English what you want to say and give time for translation and thoughtful response. Give everyone time to get comfortable with you before asking direct questions, and where possible enable people to describe or draw their 'story'.
	Use the third person when speaking[38].
Tell the story	Use the language, foundational stories and illustrated resources you have

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[38] Use the third person singular (he/she) or plural (they). In the context of Yolŋu discourse, the third plural, 'walal' would be preferable rather than singular 'ŋayi'. By doing so, people being asked questioned or interviewed feel more comfortable and free to answer by referring to third person/people.

	prepared (see Process 2).
	It's difficult for people to ask for something if they don't know what's possible. Balance the desire to introduce solutions with caution about creating a situation that may fail, particularly regarding technology.
	Leave them with the information in language and allow adequate time for the family to consider it, in private after your visit.

13. Works cited

Trudgen, R. (2000) Why Warriors Lie Down and Die. Aboriginal Resource and Development Services (ARDS), Darwin.

Amery, H. (2003) Breaking Down The Barriers Dhumbal'yunnawuy rom bakmaram dhu: Learning How to Talk about Disabilities in Yolŋu Matha. Aboriginal Resource and Development Services (ARDS), Darwin.

Mines R, (2011) *Community Consultations: Mobility For Aboriginal And Torres Strait Islander People with disability Who Require Wheelchairs, Living In Remote Communities.* Motivation Australia

Manikay.com (2003). *The 'family' concept and Yolŋu/Balanda relations by Peter Lister*. [online] Retrieved from: http://www.manikay.com/library/yolngu_family_concept.shtml [Accessed: 18 Apr 2013].

United Nations (2006) *Convention on the Rights of Persons with Disabilities (UNCRPD)*. www.un.org.

Commonwealth Government of Australia (2013) *National Disability Insurance Scheme Act 2013*, Commonwealth Government of Australia, Canberra.

The Remote Area Health Corps (www.rahc.com.au). Remote Area Health Corps (2009). *Remote Area Health Corps Cultural orientation handbook*. [PDF]

Biddle, N. (2013). "Indigenous disability: Recent evidence", paper presented at *CAEPR Seminar*, April 17th. Canberra: Australian National University.

Dept. of Health and Community Services (n.d) *Aboriginal Health and Families: A Five Year Framework for Action*. Dept. of Health and Community Services, NT government.

Christie, M. (2004) *Yolŋu languages and culture: Gupapuyŋu*. School of Australian Indigenous Knowledge Systems, Faculty of Law, Business and Arts, Charles Darwin University, Darwin.

Ards.com.au (n.d.) *Gurrangay Project*. [online] Available at: http://www.ards.com.au/www.ards.com.au/lang_gurrangay.htm [Accessed: 11 Apr 2013]

Elliot, D. (1994) *Aboriginal Perceptions of Disability and the Formulation of an Appropriate Method of Providing Rehabilitation Services to Clients on Remote Communities*, Pilot Project Number 1, Commonwealth Rehabilitation Service, Darwin.

Senior, K. (2000) *Testing the ICIDH-2 with indigenous Australians: Results of field work in two Aboriginal communities in the Northern Territory*. Australian Institute of Health and Welfare, ICIDH Collaborating Centre and the Department of Health and Family Services.

Productivity Commission (2011) Disability care and support: draft report [vol 1 & 2]. Canberra.

14. Appendices

Appendix A: List of Yolŋu participants (who consented for the their name to be included)

Participants name	Location of consultation
Andrew Galitju	Darwin
Margaret Watuŋgurr	
Gapany Gaykamaŋu (Elaine)	
Waḻunydjunalil (Leena) Garrawurra	Millingimbi
Tanya Mayawalpalmiwuy	
Janita Yäkutjawuy	
Lorreanne Manamana	
Edith Mamiŋgiyawuy	
Judy Lirririnyin	
Keith Djiniyini	Galiwin'ku
Yalkarriwuy Gurruwiwi	
Helen Nyomba	
Jane Garrutju	
Tommy Biyadakara	Gapuwiyak
Dorothy Guwatjiŋurawuy	
Julie Yunupiŋgu	

Appendix B: Aboriginal language map of the Northern Territory highlighting Yolŋu area of East Arnhem Land.