ORIGINAL RESEARCH

Exploring Conceptualisations of Disability: A *Talanoa* Approach to Understanding Cultural Frameworks of Disability in Samoa

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ABSTRACT

Purpose: *The concepts of disability were explored from a Samoan cultural frame. The impact of disability conceptualisations on identity development and cultural inclusion were assessed through the Samoan language. The study also evaluated the extent of endorsement of global policy initiatives at a local level.*

Methods: *Through facilitating a Talanoa approach, which is a rich cultural tradition of sharing knowledge, space emerged for dialogue around the lived experiences of members of the disability community in Samoa.*

Results: *Incongruous conceptualisations of disability were identified as a contributing factor in the persistence of stigmatising attitudes and beliefs. Borrowing concepts and terms from moral, medical, and social disability models, this disparity of conceptualisation is reflected in Samoan disability terminology. It was also found that while global policy initiatives are generally politically embraced, they engage more effectively with the community when they are underpinned by Samoan cultural ontologies.*

Conclusion: *The findings suggest that multiple ideologies regarding rights, capabilities and experiences, challenge the development of identity, self-worth, and inclusion. There is significant value in merging cultural concepts with a social disability model framework. It is important to future development that people with disability can express a sense of cultural identity without risking the right to inclusion and equality.*

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INTRODUCTION

The human rights framework of disability identifies the removal of societal barriers as the impetus in relocating concepts of equality. However, equality concepts are subject to cultural differences, as is the conceptualisation of disability itself (Coleridge, 2000; Grech, 2009; Carney, 2011). The reality of disability, in its interaction with cultural concepts, economic circumstances and political frameworks, culminates in a deeply unique and individual experience.

Global disability policies, initiated from human rights agendas, interact effectively with established cultural, social, and economic platforms in many developed countries. In particular, the Convention on the Rights of Persons with Disability (CRPD) is ratified by 159 countries. Its application within the cultural context of Pacific Island countries has not yet been widely considered. In weighing the value of a regional disability tribunal in the Asia Pacific Region to support human rights, Carney (2011) suggests that there is inherent value in establishing a regional focal point, but it should by no means be the priority. Rather, Carney proposes regional capacity building and the implementation of culturally appropriate attitudinal changes. While global policy initiatives provide robust objectives in reshaping disability within political and social domains, there are few avenues for the incorporation of cultural values.

Samoa became a signatory of the CRPD in 2009, with ratification occurring in 2015. The introduction of Samoa's National Policy on Disability (SNPD) in 2009, introduced a social model framework to Samoan society, promoting human rights agendas. Despite political success in the ratification of the CRPD and the ultimate adoption of a social disability model framework, stigmatising attitudes towards people with disability persist (Ministry of Women, Community and Social Development, 2009; Tufue-Dolgoy, 2010, 2012; Lameta, 2013; McDonald and Tufue-Dolgoy, 2013). The introduction of the SNPD was a monumental step towards the reduction of societal barriers and the inclusion of people with disability. It was intended to challenge societal conceptualisations of disability. Through the policy, deficit conceptualisations could be targeted, eradicated and replaced by a progressive social disability framework.

General research into disability prevalence and service provision in Samoa had identified the disability conceptualisations as originating from moral and medical perspectives. It was suggested that these conceptualisations were the source of stigmatising attitudes, although no research specifically targeted this conclusion. The impact of cultural beliefs on disability conceptualisation was also not explored in any depth.

Research conducted by Tufue-Dolgoy (2010) on the effectiveness of the Inclusive Education Policy in Samoa, concluded that cultural epistemologies are still predominant features of pedagogy in Samoan classrooms, presenting a barrier for the effective implementation of inclusive education practise. Tufue-Dolgoy's recommendations included further investigation into disability conceptualisations in Samoa. In investigating conceptualisations of disability from a Samoan cultural frame it is foreseeable that the concepts of both a social disability framework and Samoan epistemologies can merge.

OBJECTIVES

This research aimed to examine cultural perceptions of disability and inclusion, analyse discourse and terminology of disability, and assess the interaction between Samoan and global disability conceptualisations.

METHOD

Study Design

A culturally responsive research method, *Talanoa*, was employed for this phenomenological study. *Talanoa*, literally meaning "to talk", is a qualitative method designed specifically as a research tool for Pacific Island populations. In seeking to construct meaning from lived experiences through sharing history, culture and language, *Talanoa* is a natural, organic style of conversation, rather than formal question and answer sessions. This gives participants the opportunity to reveal experiences through acknowledgement of oral and cultural traditions.

Study Area

The Independent State of Samoa forms part of the Polynesian triangle in the wider Oceania region. Located in the South Pacific ocean, it is equidistant to New Zealand and Hawaii, hosting a population of nearly 190,000. The two

main islands, Upolu (where the capital Apia is located), and Savaii are the most populous. Samoans retain their indigenous dialect as the official language, with English also widely spoken. The Samoan diaspora constitutes approximately 300,000 people worldwide.

The concepts of the Samoan way of life are interwoven to imbue a deep-rooted sense of culture, connectedness and identity, making up the cultural script of the *fa'aSāmoa*, literally "the Samoan way". The *fa'aSāmoa* unites individuals in ensuring strength, prosperity and collective respect for ancestors and future generations alike. Acknowledging a system of honorifics is an important aspect of collective identity for Samoans. As a set of cultural guidelines, the *fa'aSāmoa* ensures the continuity of culture in what is now a changing Samoan society.

Constructing a group self-image for Samoans is important to securing cultural identity (Kolone-Collins, 2010). For people with disability, securing cultural identity within the *fa'aSāmoa* has unique implications. Changes in Samoa regarding disability policy encourage dialogue around the development of disability in cultural, political and social capacitites.

Study Setting

This anthropological study was undertaken in villages in and around the Apia urban area. Villages were selected based upon proximity to most densely populated areas throughout Samoa's 8 islands, and where the majority of service providers are located.

Ethical clearance was granted by the Human Research Ethics Committee of Central Queensland University.

Sampling

Purposive sampling tehniques were used to recruit participants. The initial criterion was to select a sample to elicit the most accurate Samoan depiction of disability. A subsequent sample was recruited through snowball sampling method and was successful due to the rich and diverse familial networks Samoans can offer.

Informed Consent

Informed consent was granted through culturally responsive methods, underpinned by established consent procedures. In collaboration with the village

Matai (Chief), there was a discussion with participants to explain the nature of the study, the recruitment and selection criteria, the method of data collection, and the ongoing role in data analysis and theme development. This provided an opportunity to obtain oral consent prior to obtaining formal written consent.

Data Collection and Analysis

This study used individual and group interview techniques adhering to Pacific cultural protocol within the *Talanoa* method. Prior to collection of data, significant amounts of time was allocated to establishing relationships of respect, collaboration, and reciprocity. Open-ended research questions were determined while planning the research, but the fluid nature of *Talanoa* requires that the questions be used only as a guide, rather than conducting a rigid and structured interview. Interviews were transcribed and initial data sorting was achieved through open coding.

The data generated multiple realities reflecting the viewpoints and experiences of the participants. Through this process of data analysis, participant validation techniques ensured theory development was in accordance with the intended meaning of the participants. Participants provided feedback on cultural understanding, the depiction of ideas and beliefs, and the space between emerging ideas and theory. Cultural advisors provided research support to ensure the research objectives were culturally embedded. The substantive phase of analysis transformed the broad topics into themes. Participants were invited to provide feedback during the substantive phase, enabling necessary recoding and further refinement of themes.

RESULTS

Background Information

The study sample consisted of 4 groups selected according to criteria. The first group, 'carer, family member', were mothers or daughters, ranging in age from 27 to 65+ years. The 'person with disability' group, ranging in age from 21 to 65+ years, had an equal number of male and female participants. The 'family member' group (brothers, sisters, aunts, uncles, and cousins) also had an equal number of male and female participants, from 24 to 65+ years of age. The 'disability sector stakeholder' group had both male and female participants, from 21 to 65+ years of age,who either worked or studied within the disability sector (Table 1).

Table 1. Participant sample distribution

Carer, family member	Person with disability	Family member	Disability sector stakeholders
		Female	
		Female	
		Male	
		Female	
	Female		
	Female		
	Female		
		Male	
Female			
		Male	
Female			
		Male	
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Female			
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			Female
			Male
			Female
			Female
			Female
			Male
			Female
			Male
			Male
			Female
		Female	
4	5	9	12

Conceptualisations of Disability in Samoan Society

This research found that the lack of societal congruity in the Samoan perception of disability is a significant barrier to inclusion and acceptance. It was identified that disability conceptualisations in Samoa incorporate at least 3 established disability frameworks: moral, medical, and social disability models. A moral disability model, from a Samoan perspective, incorporates a spiritual philosophy of blessings and curses. Medical perspectives have been largely influential not only in conceptualising disability as an illness, but also in the development of disability terminology. The social disability model has been facilitated as a tool of policy development, although it has been challenged by entrenched societal beliefs stemming from moral and medical models. Data from this research indicates that Samoan society is still very much in an ideological transition phase regarding conceptualising disability.

> *"In the Samoan context they say she is a curse, she was born so disfigured, she was born with so many abnormalities."*

> *"That's why we call her sick because she can't do anything to meet all of her requirements."*

> *"I wouldn't say my mother is sick; she's got a disability. She can't walk. My dad is sick. He has cancer. That's the difference between disability and sick."*

Cultural Conceptualisations of Inclusion

The development of identity within the framework of the *fa'aSāmoa* incorporates concepts of belonging, contribution to family, and honour. The ability to contribute to the collective prosperity is a highly regarded trait, reinforcing concepts of identity and belonging, and building solidarity, capacity, and status. This research found that in light of prevailing Samoan disability conceptualisations, where disability is morally or medically conceptualised, people with disability are largely excluded from obligatory contribution to the extended family and their contribution is actively discouraged to avoid collective shame. This has a significant impact on the ability to secure cultural identity, status, equality, and inclusion.

> *"People can be isolated by their disability. The contributions that they make can be seen as having less worth than others, but it depends on the contribution and the community."*

"Everyone is seeing her at the Chinese shop, like a night watchman, like the security of the shop. They see she's disabled. I went past many times and saw her there. I asked my brother, 'What is she doing there?' My brother said, 'She wants to go there and talk to friends and Chinese people.' I said, 'Everyone knows our family, they ask why we're not looking after her'."

Terminology and Discourse

Disability terminology in Samoa is predominantly derived from moral and medical conceptualisations. Progressive political agendas now identify this language as derogatory. Yet, terminology developed from a social model framework is still in a developmental phase. This research found that the lack of uniformity in both conceptualisation and terminology have contributed to stigmatisation and isolation for people with disability. Descriptive terms that have evolved from either moral or medical models have resulted in disability being conceptualised as an undesirable condition. Despite recent innovations in terminology development based on social model frameworks, Samoa is yet to establish a powerful sense of shared understanding.

"Ma'i is a bad word to explain sick. If you said it in a mean way it's a bad word."

"Ma'i is a phrase to recognise that someone has a disability, but it is not necessarily negative."

"There is a need to remodel language and reshape culture to understand disability."

Perceptions of Western Influences

Samoa has largely embraced global initiatives in the area of disability policy development. The core components of the CRPD are reflected throughout the SNPD, with non-government organisations playing a fundamental role in administering action-based initiatives. The ideologies that underpin the CRPD, the SNPD and ultimately the social disability model, are driven by human rights frameworks promoting accessibility and equality. However, despite a positive reception for the social disability model, this research found that embedding of traditional Samoan cultural ideals in policy and practice is highly valued. There were concerns about the risk of societal rejection of policy that is based solely on a social disability model framework, due to a lack of cultural responsiveness.

"We can't just put laws straight in. It's the same aim but we have to look at how we can fit it into our culture. We can't go straight from international policy to schools and villages without the process of applying culture."

"Families will just struggle to look after their child without realising there could be better ways. We are not aware of all the ways of doing things, education, awareness, understanding. It's about contextualising, there are new ideas but we need to blend them with our culture."

DISCUSSION

This study found that the multitude of disability conceptualisations present in Samoan society are influenced by moral, medical, and social models, synthesised within the framework of the *fa'aSāmoa*. The concepts of the *fa'aSāmoa* play a pivotal role in the development of identity, inclusion, and belonging. Important to the maintenance of the *fa'aSāmoa* is contributing to the status and prosperity of the collective identity. Where moral conceptualisations are endorsed, disability is viewed within a spiritual paradigm and is believed to result from either blessings or curses from a higher spiritual power. The research determined that curse conceptualisations arise from a belief that disability is a spiritual punishment for misdemeanours and wrongdoing.

Ostensibly, the 'curse' of disability is placed upon a family to instigate shame, thus initiating a reduction of community status. This belief is perpetuated through restricting people with disability from accessing society, in order to avoid advertising the manifestation of family wrongdoing to the wider community.

Where disability is perceived as a 'blessing', opportunity is presented for demonstrating love, compassion, and honour, thus deepening relationships with a higher spiritual entity. This demonstration of unity between family members promotes strength and prosperity across the collective.

However, in both instances, disability is generally regarded as a flaw of the individual, thus presenting a barrier to effective identity development, equity, and inclusion.

Samoan conceptualisation from within a medical framework defines disability as a sickness, identifying people with disability as dependent on others for care, protection and security. Through their cultural systems of obligation and contribution, Samoan families view it as an honour to take on the responsibility

of caring for family members who are sick or elderly (Tufue-Dolgoy, 2010). Providing care for people with disability is also seen as honourable but not entirely altruistic. This research found that within a medical model paradigm, caring for a person with disability demonstrates a meeting of obligation, further reinforcing cultural concepts of contribution to collective prosperity.

Restricting the actions and contributions of people with disability has been referred to as the "protective approach" (Ministry of Women, Community and Social Development, 2009). It presents barriers not only within a human rights capacity, but also to cultural identity development. The research found that shame, in this capacity, arises from the assumption that placing an expectation of contribution upon people with disability is tantamount to neglect. It elicits a social judgement that the family members are failing in their obligation to provide adequate care, protection, and security for a person who ostensibly has an illness. It impacts upon the status and honour of the collective.

The intention of the Samoan government is to re-conceptualise disability within a social disability model framework. This newly emergent landscape of disability in Samoa has not yet fully permeated society. However, Tufue-Dolgoy (2010) recognised a disparity between the ethos of the social model and of the *fa'aSāmoa*, recommending further research to determine the relationship between the two. The current research indicated that the concepts of the *fa'aSāmoa* still heavily influence people's attitudes, beliefs, and practices in relation to concepts of disability. However, attitudes, beliefs, and practices that come from cultural, moral, and medical conceptualisations are largely incompatible with the social model of disability.

An important aspect of identity development for Samoans is the sense of belonging derived from being part of the family collective. A shared system of understanding and belief strengthens and unites the collective. In the absence of a shared understanding on disability, people with disability have their sense of identity and belonging placed at risk. Overcoming the beliefs and attitudes of an entire village presents a significant challenge that may risk cultural identity and belonging. Exercising the ethos of a social disability model, in conflict with established collective belief, is potentially viewed as risking the honour of the family and challenging the collective for personal gain.

This research also found that the language and terminology of disability has been a factor in perpetuating stigmatising attitudes. The term *ma'i* (translated

to 'sickness') is strongly associated with describing disability, but contributes to ambiguous understandings of disability.

Clark and Marsh (2002) report that "the language people use, reflects what they think". Language itself is a tool for communities to express thoughts and feelings. Moreover, language has a social function in creating speech communities (Finegan et al, 1992). Speech communities share not only a dialect but a code of structure, organisation, expression and, frequently, the attitudes and opinions of the collective that result in shared understanding (Finegan et al, 1992; Morgan, 2004). In this way, language has the capacity to be stigmatising (Finegan et al, 1992). This is evident in the historical discourse of disability in Samoa. Terms that contribute to a sense of shared understanding within the speech community about disability have reflected a deficit in understanding it. Terminology in Samoa has, until recently, been developed around a shared understanding of disability stemming from moral and medical models (Tufue-Dolgoy, 2010; Lameta, 2013). Language evolution may occur spontaneously to reflect societal shifts (Finegan et al, 1992), but for a social disability framework to be embraced throughout Samoan society it may be necessary to implement a more calculated approach to reshaping disability terminology.

This research overwhelmingly found that underpinning policy with Samoan cultural epistemologies greatly increases community engagement. It was found that Samoan society will generally embrace introduced policy where it advances development outcomes.

The suitability of a social model of disability is not only a question of how reflective or cohesive it is with Samoan culture. An assessment of the construction of people with disability through a social model is warranted. The basic ethos of a social disability model has generally been well received, but it has been argued that a rights-based discourse has not affected change in the actual experience of people with disability (Clapton and Fitzgerald, 1997). It has also been suggested that the preoccupation of the social disability model in identifying and removing barriers has failed to acknowledge the reality of impairment (Crow, 1996; Shakespeare and Watson, 2001; Terzi, 2005). Furthermore, the heavy promotion of a social paradigm of disability can in fact result in further marginalisation, as people with disability play down impairment to avoid challenging the ideology of the social paradigm (Crow, 1996; Shakespeare and Watson, 2001).

There has been time to reflect on the social disability model in Samoa since the publication of the SNPD in 2009. The intent of the policy was the reduction of social barriers, but the current research found that people with disability still experience barriers such as access to services, employment, transport, education, as well as in basic needs such as hygiene and sanitation. The social disability model fails to adequately consider many of the barriers that people with disability experience as a result of social and economic factors unique to developing and recently developed countries such as Samoa.

It has been reported that a high level of resistance persists towards inclusive education policy in its lack of responsiveness to Pacific Island culture (Tufue-Dolgoy, 2010; McKinstry et al, 2012; Lameta, 2013). The current research found that while Samoans respect international political and practical assistance, the importance of the *fa'aSāmoa* remains a pervasive factor in attitudes and behaviours. Policy that is not based upon Samoan cultural values has the capacity to erode the fundamental concepts of the *fa'aSāmoa*. This is already being reported through the impact of changing family structures due to increased economic engagement (Thornton et al, 2010; Thornton et al, 2013). This changing space has implications for people with disability. It is essential to ensure that people with disability are not further marginalised due to emerging policy that does not incorporate cultural identity. It is of equal importance that people with disability can exercise human rights and not be restricted by cultural limitations of policy. People with disability should not have to choose between culture and policy; they should have the choice to effectively engage with dual identities.

CONCLUSION and RECOMMENDATIONS

The study findings suggest that the lack of congruity in disability conceptualisation throughout Samoan society has contributed to the experience of stigmatisation. For people with disability, navigating multiple ideologies regarding rights, capabilities and experiences, challenges the development of identity, self-worth and inclusion.

Stigmatising attitudes and behaviours have been reinforced through terminology that perpetuates moral and medical conceptualisations of disability. The research found that it is of vital importance to ongoing awareness and social reform that terminology be evaluated in terms of its purpose, function, and suitability to the Samoan context. Addressing the stigmatisation perpetuated through language and terminology in Samoa is an important step in securing cultural

identity for people with disability. It has been widely acknowledged that there is a fundamental link between culture, language, and concepts of belonging and self-worth (Taufe'ulugaki, 2001; Va'a, 2006; Merriam, 2007; Thaman, 2008, 2009; Kolone-Collins, 2010). Being a part of the language of the cultural group provides opportunities for membership and inclusion (Sanga, 2004; Amituanai-Toloa, 2010). In the absence of a shared understanding, both in conceptualisation and terminology, marginalisation for people with disability persists. While some non-government organisations are developing Samoan-specific terms in attempting to establish a disability register, it is imperative that this language be used in a uniform capacity across agencies and throughout society. However, developing a disability register is a challenging task. The purpose of the terminology must be examined. Is it to develop global uniformity for data collection? Is it to direct effective service provision? Is it to reduce stigmatisation and remove social barriers? Is it to create a shared understanding of disability? Is it to enhance feelings of belonging and self-worth? Or does it represent a combination of these purposes? In evaluating the logistics of terminology reform, the ongoing dilemma of whether labelling is necessary requires consideration. It has been reported that labelling, whether it be for disability or for other minority groups, is inherently negative (Eayrs et al, 1993; Shakespeare and Watson, 2001; Lang, 2007). A label can overgeneralise disability, reducing a person to a set of descriptors, which can be a source of deficit identity development (Madden and Hogan, 1997; Barton, 2009). Conversely, labelling is an effective tool in shared understanding in the provision of service, and in the measurement of global disability prevalence (Madden and Hogan, 1997; World Health Organisation, 2011). The purpose of terminology development in Samoa needs to be further investigated to ensure that it meets multiple agendas.

Through this research, several potential approaches to terminology reform are proposed. Firstly, that English terms be translated verbatim into Samoan language. Secondly, that English words be transliterated (creating words such as *Autesima* to describe Autism). Thirdly, that an entirely new Samoan discourse continues to be developed for use in policy and within the community. None of these proposals simultaneously achieve global obligations to shared understanding and data reporting, or effectively respond to Samoan culture. Therefore, it is recommended that further research be conducted into the most appropriate strategy for implementing new terms across all disability agencies in Samoa. A community dialogue should occur in consultation with stakeholders to determine the best way to proceed.

During this transitional phase of disability conceptualisation, the research found inherent value in merging concepts of culture with human rights frameworks by assessing and evaluating factors that impact upon well-being, quality of life, standard of living, and economic, social and political factors. The next phase of disability policy reform in Samoa can ensure that people with disability have the freedom to express a cultural identity, without risking the right to equality and inclusion in a broader social capacity. This transitional phase is an opportunity to reflect on the value of culture and the significance of progress to reshape the political landscape of disability in the unique Samoan context. A commitment to constructive and relevant development in the area of disability needs to reflect cultural identities as well as notions of equality.Continued research into the development of disability conceptualisation and policy in Samoa will ensure that people with disability are fairly represented in society.

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