

Navigating the Cultural Landscape towards Self-Determination: Results of an Exploratory Study in American Samoa

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Abstract: The American Samoa University Center for Excellence in Developmental Disabilities, Education, Research, and Service (AS-UCEDD) with the University of Hawaii Center on Disability Studies, conducted an exploratory study to better understand how state agencies deliver services, and how disability is perceived by agency staff and consumers in American Samoa. While it initially was envisioned as a needs-sensing study that used surveys and targeted database reviews to systematically capture client needs, the study transformed to a largely qualitative preliminary investigation that was dependent on personal interviews. Findings revealed how contextual, linguistic, and cultural factors play a hugely important role when researching western-based ideals and concepts within indigenous communities.

Key Words: culture, self-determination, perceptions, research flexibility

Introduction

American Samoa in the South Pacific is five hours south of Hawaii by air and includes several outer islands necessitating airline travel from community to community within its boundaries. The largest numbers of people live on the island of Tutuila, with smaller populations on the Manu'a Islands (Ofu', Olosega and Ta'u), Aunu'u Island and Swains Island, with the smaller islands having limited services. This geographic location poses unique challenges for health and human service delivery systems particularly related to serving community members with disabilities.

Coupled with geographic complexities, the cultural context of American Samoa as it relates to disability offers another intricate layer. How the Samoan community responds to disability in the wake of traditional beliefs and practices is seldom studied. Enhanced understanding of cultural effects on service delivery for individuals with disabilities is critical since the territory receives federal funding, yet remains insufficiently documented. The American Samoa University Center for Excellence in Developmental Disabilities, Education, Research and Service (AS-UCEDD) partnered with the University of Hawaii Centers on Disability Studies to conduct an exploratory study. Its purpose was twofold: to better understand how state agencies deliver services and to know how disability is perceived by agency staff and consumers. While it initially was envisioned as a needs-sensing study that used surveys and targeted database reviews to systematically capture client needs, the study transformed to a largely qualitative preliminary investigation that was dependent on personal interviews.

Objectives

The purpose of this paper is to share the findings of an exploratory study designed to gather more information on services provided for people with disabilities residing in American Samoa. One of the objectives of the UCEDD is to conduct research to improve the quality of life and self-determination of persons with disabilities to live inclusive lives in their communities (Pacific Basin UCEDD Application, CFDA 93.632, 2006). While there are multiple agencies that provide services for people with disabilities, it was unclear how these respective agencies collect complete, accurate, and unduplicated data as well as serve consumers. The majority of these agencies receive federal funding and those that do are therefore subject to the same rules and regulations of other state agencies across the United States.

For this study, of particular interest was the extent to which these agencies support the independence of people with disabilities and how self-determination is interpreted. For example, what types of services are provided? Who are the clientele of state funded services? Do clients receive specific skills training or does the service provider do everything for the client from finding a job to transporting clients? An underlying philosophy about persons with disabilities may affect what specific services exist and how such services are delivered via the individual professional and/or the agency. This underlying philosophy is often shaped by the cultural context and may clash with the intent of the larger organization as well as the funding source. Through surveys and semi-structured interviews with agency staff members and consumers during early July 2009, preliminary information about disability and its relationship to culture sets the stage for further investigation.

We began our inquiry with an overarching research question, “How are existing services perceived and provided for by organizations serving persons with disabilities in American Samoa?” However, over the course of conducting and analyzing interviews and surveys, we felt the need to modify the intended research design and allow the information to derive theory. Thus, the results may not directly apply to the original research question but describes the context by which services are delivered.

Theoretical Framework

Socio-Cultural Context

American Samoa is a territory of the United States. Surrounded by island territories that are either French or British along with a rising number of independent island nations, American Samoa is part of a group of nine inhabited volcanic islands known as Samoa. In 1900, Samoa was divided into two separate political entities. The eastern part was named Eastern Samoa and later became American Samoa. The larger and western part was initially called German Samoa, then British Samoa, Western Samoa, and currently the Independent State of Samoa (Ripine, 2008).

According to the 2000 Census, the populace of the US territory American Samoa includes 57,291 individuals of which 92% are Polynesian, 2.9% Asian, 1.2% Caucasian, 2.8% mixed and .02% other. The primary languages are Samoan and English. The age distribution is 0-14 years 35.7%, 15-64 years 61.3%, and 65 years and older 3%. Sixty-two percent of households that fall below the poverty line include children under 18 years old. The average

household income is \$9,349. Based on tri-agency data from the Monitoring and Technical Assistance Review System Report, it is estimated that 16% of the 49,322 persons assessed are considered part of the disability population. Of those with disabilities, 1,014 are between the ages of 5 – 20 years (Administration on Developmental Disabilities, 2008).

Samoan life is structured around the 'aiga (family), a hierarchical system made up of the nuclear and extended families. Rank or chiefly status as well as age and gender determine the formation. As noted in Mokuau and Tauili'ili (1997), a matai (village chief) is responsible for the welfare of all related families in the village and each household may have its own chief. The females are subordinate to the males and young always defer to the elders. The family works toward the goal of well-being for the entire family which may be as large as an entire village. The values intrinsic in this system include reciprocity, cooperation, and interdependence.

The social and cultural contexts of village life obligate individuals to participate in, and contribute to, a variety of events. Funerals, weddings, religious holidays, and village celebrations can last days or even weeks, and members of the village are expected to provide support. Island politics shape the bureaucracies that control local education, economics, and social welfare. Elections affect all aspects of life, including shifts in jobs and power. In these settings, it is very important to work within the political structures of the community, understanding how familial ties and history play an important role in everyday life. Knowledge of language and behavioral protocols, including how to address both elected officials and traditional leaders, is critical as both a sign of respect and honoring customary practices.

The church is a highly valued institution in Samoan culture that directly intersects with the family. The church affirms the organization and responsibilities of the family and in turn, is supported by family contributions. Religion is one of the most critical features of Samoan culture following various Protestant denominations as well as the Catholic Church. Ministers are ranked higher than chiefs and political leaders.

The cash economy in Samoa has made a significant impact on the lifestyle and language of many Samoans. Such an economy stands in sharp contrast with the traditional land-based system that was at one time the foundation of Pacific society. Although island leaders facilitate the preservation of traditional ways, these practices often contradict other social trends. For example, economic development leads to such non-traditional enterprises as chain restaurants, large-scale fishing and fish packing, tourism, and heavy industry. As a result of commercialization and external influences, structural changes in the society and culture impact the language. The traditional vernacular may no longer be needed or appropriate. The language used at home may not correspond with the language needed in the larger community (Brown, Hammond, and Onikama, 1997). Samoan and English are widely spoken throughout Samoa though a majority of elders speak Samoan language as their first language. Children entering kindergarten are most likely to speak the languages of their village. The vernacular used to describe a person with a disability may not be acceptable by western standards. This representation of disability may impede how one requests or provides services.

Fitzgerald and Anderson (1992) documented several challenges when providing vocational rehabilitation services in Pacific Island communities. Although dated, this record

describes the experiences of key informants highlighting issues including transportation, isolation, limited employment opportunities, and cultural and familial considerations. Representatives from the Republic of Palau, American Samoa, Commonwealth of the Northern Mariana Islands, Guam, and four Hawaiian islands (Hawaii, Kauai, Molokai, and Oahu) convened in Molokai, one of the most rural communities in the State of Hawaii. Case studies featured the impact of modernization on sociocentric societies along with exposure to other cultures resulting in rapid change on island life. These changes often conflicted with traditional values and ways of addressing the diversity of the human condition. The issues discussed continue to be relevant within American Samoa.

Perceptions of Disability in the Pacific Islands

Depending upon where one is from within the Pacific Islands, varying attitudes and beliefs about disability exist. It would be unfair and inaccurate to assume that how one island culture perceives and treats their members with disabilities is the same across all islands. In fact, there exist differences across sociological features such as education level and gender; and depending on whether one resides on a main island or outer island, northern or southern village. We offer a broad view of how disability is perceived based on the literature describing the general context within the Pacific Islands of which we based our inquiry.

According to Locust (n.d.), interactions and influences of other cultures have shaped how Native populations of the Pacific Islands view disability. One of the overarching cultural views is that disability is a punishment for parental sins. It is also associated with the sins of the individual with a disability in a previous incarnation. In her work with rehabilitation of Pacific Islanders, Ratliffe (2005) cites numerous perceptions regarding the causes of disability. For instance, curses or spells laid on the family, ghosts or spirits living in the house or the beach, or parental behaviors such as excessive drinking, spousal abuse, or sexual promiscuity are seen as causes for disability within a family. Likewise, the behaviors of a mother during pregnancy are also taken into consideration, as exemplified in the belief that eating while cooking for elders will cause cleft lip.

While each family responds differently to a child with a disability, it is not uncommon for families to keep a child at home, isolated from community activities. In many traditional Pacific Island communities, families who have children with disabilities are shunned and often blamed for their own situation (Ratliffe, 2005). However, as people become more aware and educated about disabilities, rehabilitation efforts, and medicine, such views are changing and communities are becoming more accepting of children who are different. Yet there is still much work needed in implementing the mandates of ADA. Currently, within many Pacific Island communities an inaccessible environment contributes to the lack of exposure to people with disabilities among the general public.

Ratliffe also cites that, within some families, children with disabilities are thought of as the “most loved ones” or a “gift from God” (2005, p. 45). Thus, family life centers on the child with the disability. Not surprising though, due to shame and social rejection, these families often avoid bringing their child to social gatherings. By the same token, children with disabilities may also be seen as a result of a poor relationship with God and that God must be displeased with the

family (Mokuau & Tauili'ili, 1997). Clearly, perceptions of disability are culture-bound as is the concept of self-determination.

Disability as a word in American Samoa does not exist. Rather, the terms *ma'i* meaning sick or ill; *o le atoatoa o le mafaufau ma le tino* meaning not fully developed; or *gasegase* meaning having a health condition are some of the common vocabulary used to describe a person with a disability. Inquiring about the use and meaning of these terms provided a foundation to better understand how self-determination is defined and valued within this setting. Understanding that disability may be perceived as a topic of taboo, we thoughtfully tried to describe and comprehend self-determination within the Samoan context. Following this contextual framework of disability, the relationship between self-determination and culture was our focus of interest as we gently approached the subject with the study participants.

Self-Determination and Cultural Congruence

Self-determination is a concept that incorporates cultural beliefs— its definition or value is influenced by one's culture (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004; Turnbull & Turnbull, 2006; Zhang, 2005). Negotiating the boundaries of traditional culture while adhering to western laws and mandates to promote self-determination often results in dissonance for both the consumer and service provider. Self-determination is a western construct promoting the “individualistic” values of mainstream American culture at the expense of “collectivistic” values characteristic of indigenous cultures (Leake & Black, 2005; Leake, Black, & Roberts, 2004).

Individualism is rooted in the view that people are discrete entities who, as they transition to adulthood, should move from dependence to independence and self-reliance. Collectivism is embedded in the contrasting view that people are connected in some shape or form to others (e.g., family, neighborhood, tribe). As they transition to adulthood they should move from dependence to interdependence (Ewalt & Mokuau, 1995). Individualistic cultures tend to stress individual rights, pursuing personal interests, setting and achieving personal goals, and being true to one's own values and beliefs. On the other hand, collectivistic cultures tend to stress obligations that go along with one's group roles, being an interdependent member of a group, working with others to achieve group success, and adhering to the group's traditional values (Yamauchi, 1998).

Self-determination as related to independence and individuality has been defined, described, and summarized similarly across social science disciplines. For example, as cited by Ewalt and Mokuau (1995), social work construes self-determination in terms of freedom of an individual to apply choice and self direction. Originally defined in the special education field by Wehmeyer (1997) and updated in 2006, self-determination refers to: “...volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life” (p. 117). Turnbull and Turnbull (2006) focused on self-determination funding which emphasized that individuals with disabilities should have more control over the money allocated to serve them than they have had in the past. For the purposes of this study, we focused on the term as a broad construct integrating the basic tenets of the definitions above, but most importantly, founded on western values and ideals.

The research on self-determination spans numerous disciplines and continents as well as culturally diverse populations (Field, Sarver, & Shaw, 2003; Hardre & Reeve, 2003; Serna, Forness, & Nielsen, 1998; Wehmeyer, 1997; Zhang & Benz, 2006; Zhang, Wehmeyer, & Chen, 2005; Zhang & Law, 2005). Stanhope (2002) compared psychosocial rehabilitation in India and the United States, exploring how cultural beliefs and practices influenced the recovery of people with psychiatric disabilities. The Indian emphases on interdependence, externalized locus of control, and family involvement were found to be significant factors in the care of people with psychiatric disabilities. Rehabilitation goals in the United States, by contrast, concentrate on independence and individual productivity.

Frankland, Turnbull, Wehmeyer, and Blackmountain (2004) described how the Dine (Navajo) enacts key elements of self-determination according to their cultural perspective. While the Dine people value self-regulation and autonomy, the importance of interdependence and group unity take precedence over independence and autonomy. This study of self-determination within the Dine culture and traditions illustrated the application of particular aspects of self-determination and pointed out the need for services that reflect cultural, racial, and familial values of clients.

Ewalt and Mokuau (1995) discussed self-determination from a Pacific perspective and offered implications for social workers working with migrant Pacific Islanders. However, studies within a Pacific Island community rooted in traditional beliefs and mandated western practices related to self-determination are sorely wanting. More specifically, research conducted by indigenous investigators who possess the insider's knowledge of cultural nuances is considerably deficient (Mohatt, Hazel, Allen, Stachelrodt, Hensel & Fath, 2004; Norton & Manson, 1996).

Methods

This exploratory study was loosely based on the methods described by Tuhiwai Smith (1999). The techniques for gathering evidence became the means and procedures through which the core issues of the research were addressed. In other words, during the data collection activities, the pre-determined interview questions became secondary to the rich stories and testimonies that emerged. Thus, responses to the interview questions were analyzed in accordance with the overarching paradigm that materialized.

Recruitment

The second author played a crucial role in facilitating study recruitment as her insider knowledge, information about cultural etiquette, and local connections were invaluable particularly when setting up and conducting the interviews. Informants were recruited from member agencies within the Interagency Council on Disabilities and consumers of these services. Participation was voluntary. Individuals were provided a survey along with an information letter outlining the scope of the project and their rights as participants. The letter served as an invitation and consent to participate. The University of Hawaii's Institutional Review Board approved the study. Participants did not receive monetary compensation for their participation.

Sample

Purposive sampling allowed us to target a particular group of service providers relevant to this study which included directors and professional staff (n = 17). Twelve of the 17 service providers completed follow-up interviews. We were scheduled and confirmed to interview staff at the Department of Education-Special Education and Early Childhood Education Departments. However, upon arrival at these agencies, staff was not available to meet or complete the surveys. As a result their viewpoints are not represented in this sample.

Consumer interviews and surveys were limited based on a convenience sample of respondents who were willing to participate because of their acquaintance with one of the researchers. Scheduled meetings with a parent organization were cancelled since staff was unable to obtain approval from their director. One parent consumer was not able to attend a scheduled meeting; this absence reduced the sample to three participants. By far, results based on this sample of consumers cannot be generalized to the wider population. However, we were grateful for the conversation and insights that these three people shared as we inquired about services, self-determination, and culture. We believe their stories offer an intimate profile of what it is like to have a disability while living in American Samoa.

Procedure

Two separate standardized surveys were administered to agency representatives and consumers, respectively. The questions were co-developed by both researchers, one of whom is a member of the Interagency Council on Disabilities and also the Director of the AS-UCEDD. The surveys were written in English and completed on site by agency staff at the following:

1. Hope House Hospice
2. Department of Vocational Rehabilitation
3. Office of Protection and Advocacy for the Disabled
4. Early Intervention (Part C) – Helping Hands, and
5. Department of Health-Children with Special Health Care Needs/Maternal and Child Health

In addition, we conducted interviews using slightly different protocols for the service provider or consumer. The interview served as a follow up to the survey. Both authors conducted the service provider interviews at the individual agencies. We completed two consumer interviews at the AS-UCEDD office (American Samoa Community College campus) and one at the consumer's residence per his request. All of the participants were fluent in English. However, for those who preferred to converse in Samoan, the second author conducted or led the interview.

To capture responses to the interview questions, we relied on handwritten notes. The interviews were not audio-taped for several reasons: (1) we were concerned about the comfort level of participants speaking candidly, (2) we wanted to gauge the tone and pace of the interviews for cultural sensitivity and the possibility of recording future interviews, and (3) these initial interviews were exploratory, designed to gain a global conception of services, disability

and self-determination. Exploratory interviews encourage respondents to converse freely and emotionally with candor and authenticity as opposed to collecting facts and numbers. Audio-taping could have inhibited the richness of responses.

During the interviews, participants were asked to respond to questions about general service requests, limitations of services, and perception of self-determination. The interview protocol consisted of semi-structured open-ended questions. However, the interviews themselves were conversational, flexible, exploratory, and informal. As noted in Merriam (1998), one of the goals of the unstructured interview is to learn enough about a phenomenon to devise questions for future exploration. Participants were encouraged to talk about the Samoan culture and how it influenced the provision or perception of services. The interview protocol was used as a guide to facilitate conversation. Depending on the flow of the discussion, questions were determined relevant or not.

The interviews provided a forum to “represent” voice and expression as noted by Tuhiwai Smith (1999). While we utilized the pre-developed interview protocol, we also strayed from asking some questions depending on the respondent and flow of the conversation. These diversions proved fruitful. We were enlightened with personal narratives experienced in this cultural context which served as a canvas to better describe how agency services intersect with culture. These stories served as a catalyst for more questions regarding the availability and quality of services for persons with disabilities residing in American Samoa. The interviews led to a much-needed contextual description of how the culture influences action. Interviews also contributed to a much-needed comprehensive picture of community services, systems of care, and perceptions of these systems. A follow up study is planned that will build upon this exploration.

Analysis

To analyze interview data, we employed the method of grounded theory. Grounded theory is a specific methodology in which the researcher attempts to develop a theory by using several stages of data collection and refinement, making the inter-relationship of information categories explicit (Strauss & Corbin, 1990). Two primary features of this design are the continual comparison of emerging categories and the theoretical sampling of different groups to enhance the similarities and differences of information (Creswell, 1994). In other words, through the process of collecting, coding, and analyzing data, we generated theory. For the purpose of answering the research question, we used the first feature of conducting simultaneous data collection and analysis to generate categories and build thematic strands as recommended by Merriam (1998) and Creswell (1994). Similar to other forms of qualitative research, the investigators served as the major instrument of data collection and analysis, assuming an inductive posture and aiming to gather meaning from the data. The end result of this type of research was a theory that emerged from, or was grounded in the data.

As data were coded, the information was compared within and between categories. Also termed as constant comparative analysis (Glaser & Strauss, 1967), this technique occurred as data were compared, and categories and their properties emerged or were integrated (Anfara, Brown, & Mangione, 2002). This process included initially identifying the surface content topics

followed by classifying emergent themes and defining final categories. No codes were assigned a priori, but rather “induced” from the data. The researchers consistently read through the interview notes and debriefed after the interviews in an effort to reframe the discussions. Reframing refers to defining the problem or issue and determining how best to address that problem (Tuhiwai Smith, 1999). We wanted to make sure that we understood the information within the wider socio-cultural context. Because the interviews were a combination of unstructured and semi-structured, the first cut included coding only the responses to questions from the original protocol. The interview questions provided the organizational foundation to initially code responses. Open codes were then grouped into themes. Through inductive reasoning, the categories and their properties were classified (axial coding). Core categories were identified and formed the crux of the narrative.

Findings

For the purposes of this paper, only the results relevant to this study will be discussed. Data collected from the survey included basic demographics and are presented in Table 1.

Table 1. Description of Participants.

	Service Providers (n=17)	Consumers (n=3)	
Mean Age	45.23 (SD = 9.80)	29.67 (SD=8.65)	
% Female	88	33	
% Race/Ethnicity			
	Samoan/Pacific Islander	82	100
	Other	18	0
% Highest Degree Obtained			
	High School	24	67
	Graduate/GED		
	Associate Degree	29	33
	Bachelor’s Degree	12	0
	Master’s Degree	24	0
	Doctorate’s Degree	6	0
	Other	6	0
% Number of Years at Current Employment			
	0-5 Years	35	N/A
	6-10 Years	12	N/A
	11-15 Years	18	N/A
	>16 Years	35	N/A
Mean # Years Working in Disability	11.25 (SD = 8.46)	N/A	

Agency staff survey respondents were asked to rate the degree to which they coordinate with other disability service provider agencies on a scale of 1 to 4 (1 = Never, 2 = Seldom, 3 = Sometimes, 4 = Often). Staff responded with a mean rating of 3.11 (range = 3). Another item asked staff to rate the extent to which requests for services were made directly from potential clients. The mean rating was 2.94 (range = 3). To understand the process towards self-determination using the same scale, staff rated the extent to which clients independently complete applications for service. Mean rating for this item was 2.18 (range = 3) implying that clients rarely fill out the application on their own for services.

While only three consumers completed the survey, responses regarding services requested and not provided had a mean rating of 2.66 (range = 1). A mean of 2.66 (range = 3) was noted for requests for services made through other parties (not by the consumers themselves). In response to working with other agencies to support their individual needs, consumers had a mean rating of 3.66 (range = 1) implying that they are aware and have accessed other avenues towards receiving services.

Of special interest to the researchers were consumers' perceptions about disability and disability in general. The staff survey, using the same rating scale described above, asked respondents, "How do clients refer to themselves in terms of being 'disabled' as noted by their self descriptions (ma'i meaning sick or ill, o le atoatoa o le mafaufau ma le tino meaning not fully developed, or gasegase meaning having a health condition)?" Their mean rating of 3.29 (range = 3) is similar to that of consumers when asked, "How do you refer to yourself in terms of your disability (ma'i meaning sick or ill, e le atoatoa le mafaufau ma le tino meaning not fully developed, or gasegase meaning having a disease)? The mean rating was 3.00 (range = 3). These select survey results coupled with the interviews elicit additional questions to further understand disability and culture within an indigenous Pacific setting.

Service Providers

Service Delivery

Based on interview responses, two major themes emerged for each identified category. Table 2 illustrates Category 1: Service Delivery which includes the themes of Resources and Coordination with other agencies. As perceived by the service providers, service delivery seems to be an area of great challenge in terms of resources. Transportation problems ranging from availability to accessibility was echoed throughout almost every interview. Many families do not have cars and rely either on relatives or modified buses that are not accessible for people with physical disabilities. For those who reside in remote parts of the island getting around is an even bigger challenge since most wage labor opportunities are located in the "urban" or central areas.

Equipment such as voting machines for government elections is not available. Votes are done via paper and pencil and are hand counted. Therefore, people with visual disabilities often need a family member to cast their votes for them. This calls into question the issue of privacy as well as validity of the voting process. At other agencies, equipment such as shower chairs is needed to provide clients basic care. Like many small island communities, a limited economic base makes it difficult to find employment opportunities that provide training or job coaching. At

the same time, an insufficient number of qualified people are available to provide comprehensive services to a population of people most in need. Similarly, we heard that appropriate and relevant training of staff pertaining to proper assessment, diagnosis, and treatment was a dire need. For instance, a service provider shared that inaccurate or unqualified diagnosis of specific disabilities often leads to inappropriate medical treatment or services.

Coordination was another theme that came out in the interviews. In speaking with the various service providers about working with other agencies, there appeared to be a disconnect with the public school system, particularly the special education department. Informants shared a desire for better follow through as clients moved through the various agencies and were linked to special education. They also mentioned a need for more communication in situations when agencies have the same clientele.

Table 2. Category 1: Service delivery – Service providers

THEME	FACTORS
Resources	Limited transportation Limited equipment Limited employment Limited number of qualified people
Coordination with other agencies	Inconsistencies within the special education department Undefined priorities about training needs

Self-Determination

Through our inquiries with staff about self-determination and agency clientele, it became apparent that many staff respondents did not have a solid understanding of the concept until we further clarified it and related it to independence. This in itself was fascinating. To facilitate germane responses pertaining to clients, service delivery, and personal beliefs, we provided examples. For instance we exemplified independence by clients' behaviors such as completing an application on their own, requesting for services without parents or other family members speaking for them, or working to support themselves. All of the staff interviewed agreed with the idea or concept but in the course of discussion we heard much about how traditional and religious beliefs and practices underlie services. For example, many families seek alternative methods such as herbal medicines or lomilomi (massage) from traditional healers to address a disability. In some situations, independence is not seen as a possibility by some parents because of the cultural aspects of dependency and inter-dependency within the matai structure. Often, parents are over-protective of their child with a disability.

In other cases, language can be a barrier where formalities are important to acknowledge the status of those communicating with each other. Furthermore, if agency providers do not thoroughly check for understanding of specific instructions or care provision directions, families' perceived unresponsive or non-compliant behavior may be misinterpreted as not caring. One of the directors we interviewed emphasized the importance of knowing how to communicate as a critical part of the services they deliver. By the same token, parents of children with disabilities

often do not ask questions pertaining to rights or services, frequently leaving program staff to assume that the information was understood or comprehended. In many instances, parents place their trust with the service provider to provide what is “best.” These types of communication mismatches can lead to barriers in providing effective services.

Disability may carry a stigma in which parents may not be receptive to home visits. Having a service provider arrive in a government car is often cause for concern, particularly if neighbors see the car. In these circumstances, self-determination takes a backseat or no seat to saving face. For young adults, family dynamics in situations such as voting may interfere with enacting self-determined choices. Because the election system relies on paper and pencil, for the sight impaired, ballots must be read to the voter and the actual voting cast done by designee. This practice defeats the effort to vote independently and confidentially. For situations where political party lines are drawn in the household, and proxy voting may be questionable, service provider staff will depend on legal, religious and familial reasoning to encourage parents to respect their children’s choices.

Table 3. Category 2: Self-Determination – Service Providers

THEME	FACTORS
Self-determination concept	Limited understanding of the concept Agreement with the concept
Cultural (in)congruence	Traditional beliefs and practices Religious beliefs and practices Linguistic aspects Perception of disability Communication patterns Family dynamics

Consumers

As noted previously, we were able to interview only three consumers during the data collection timeframe (July 6-10, 2009). Tables describing specific categories as presented above will not occur in this section because of the limited number of respondents. In order to thoroughly conceal their identities, we will provide a broad summary of their responses.

Service Delivery

All consumers had experience requesting services through a state agency. All consumers shared that their requests for services in general were met by a lengthy response period specifically regarding one particular agency. However, some requests were fulfilled within a matter of months but the service itself (transportation) was limited to certain hours. Requests ranged from transportation to and from work or school to assistive technology and equipment. One consumer shared that a request for accessible daily living equipment made three years ago continues to be open. Per his understanding, although the equipment is at the agency, there is no one available to install it. Another consumer mentioned a request for specific equipment made

about five to six months prior. He did not appear aggravated and believed it was his responsibility to follow up with the agency regarding his request.

Self-Determination

When talking about self-determination, consumers understood the term in relation to independence and being able to do things for oneself. All three consumers commented positively about engaging in activities on their own such as traveling or attending college. One consumer stated that attending school provided a sense of being “normal” and that “I can do things normal people do.” In addition, service requests that were implemented allowed opportunity to become more independent and fully participate in activities.

The conversation about self-determination naturally flowed into questions pertaining to family and culture. Two of the consumers reside at home with their parents and families. One consumer resides at home on weekends, but during the week days lives at Hope House Hospice, where 21 residents (elderly and individuals with severe physical disabilities) are sheltered. The two who reside at home expressed that they receive much family support for being independent while at the same time the instinct to protect often eclipses autonomy. In regards to culture, another consumer shared that being independent came at the cost of politely disrespecting elders. While traveling alone at the airport going back to American Samoa, several Samoan elders recognized this consumer and sincerely wanted to help. However, in his determination to be independent, he respectfully declined their offers of assistance careful not to offend the elders since culturally one must listen to direction of those older in age.

In terms of how the concept of disability and culture intertwine, one of the consumers supported the perception about the cause of disability being a result of a cultural belief. Although he did not provide more detail, he translated the term disability to mean, “...for those not strong enough,” or tino vaivai referring to those weak in spirit, body, or mind. The other two consumers related personal stories about having a disability in their community. For instance, with friends and peer groups, a consumer shared how she is encouraged to take risks and go beyond her comfort zone. In so doing, she feels that she is the same as her friends when they are together. Yet on a particular afternoon when arriving at a park to eat lunch with friends, she was unable to leave the car and enjoy the park because it was inaccessible. She and her friends ate their lunch in the car. Although her friends did not mind being in the car with her, she said that incident made her feel different and that she really is not independent.

Implications

The findings in this preliminary study set the groundwork for future inquiry pertaining to service delivery, self-determination and culture within American Samoa. The interview results appear to be consistent with those of previous investigations where issues of transportation, limited resources and cultural complexities inhibit the provision of comprehensive services (Fitzgerald & Anderson, 1992). The coordination of services among various provider agencies is an area that needs further examination. Although survey respondents believed that coordination sometimes occurred, it is unclear which agencies coordinate and in what ways they work together. It would be useful to understand the quality of these collaborations.

As perceived by service providers, clients' requests for services and application completion are other areas that warrant scrutiny. Just about every professional we interviewed agreed with the concept of self-determination after we clarified and provided a definition. However, we do not know whether agency staff members encourage clients to speak for themselves or when possible, fill out agency forms. Cultural aspects such as age and status may come into play if parents accompany their children to the various agencies.

Residing on a small island presents many challenges as highlighted by the interviews. Services may not be effective or timely if there is not enough qualified staff. Along these lines, we heard that appropriate and relevant training of professionals to accurately diagnose and treat clients is a significant need. This dovetails with the necessity for coordination and collaboration amongst agencies.

Agency staff highlighted the lack of equipment such as computerized voting machines as a luxury that Americans probably do not even think about when we cast our vote. Yet, in rural societies such luxuries are still absent. Inaccessible public transportation or public parks particularly in rural settings continue to present challenges for people with disabilities wanting to be self-determined.

The reliance on customary healing methods is part and parcel with indigenous cultures and cannot be overlooked. In the same way, language protocols must also be integrated within a responsive system of care that accounts for a culturally determined ideal of independence. Through our interviews we unearthed what appears to be some ambivalence with values and beliefs. Service providers on the one hand are socialized in these traditional contexts, yet many obtain their education from American universities and are employed as public servants following American legislation and laws. While agency staff agreed with the concept of self-determination is it really something that is contextually compatible in this setting? The fact that many staff professionals did not have a comprehensive understanding of self-determination provides reason to pursue this line of investigation. In several interviews we had to re-phrase or define the term itself. Additionally, is self-determination an appropriate value or goal for traditionally collectivist cultures?

Our inquiry also uncovered some areas necessitating additional research relating to the perception of disability. We were especially interested in understanding how people with disabilities in this population refer to themselves. Both staff and consumer survey respondents believed that the various local terms (ma'i, o le atoatoa o le mafaufau ma le tino, gasegase) were used sometimes. In fact, o le atoatoa o le mafaufau ma le tino (not fully developed) is used in public service announcements. Through a western lens this definition of not being whole or half of a person seems appalling, as it overtly promotes power and privilege. Yet, within a culture rich in tradition and religious doctrine, what expression is deemed appropriate? How do these societal values coincide with western laws, rules, and regulations? Do age, gender, and socioeconomic status of both consumers and service providers impact perceptions? And if so, how do these perceptions play out in everyday life?

In his inquiries with the Carolinian atoll dwellers, Marshall (1994) explored the western concept of disability through their ideas about personhood. Personhood refers to the fundamental need of persons to be with other people. The core of personhood reflects the extent that one is able to participate in the hierarchical and interconnected social relationships. The measure of a person's "disability" then, is the degree to which that individual is able or not able to participate in the on-going everyday network of social relationships. Even physical impairments such as quadriplegia or blindness are not necessarily a "disability" in these communities provided that the person with a "disability" can construct new roles that enable active contribution to the household and community. Much like Samoans where life revolves around the aiga or family, factoring in contribution and relationships in the coordination between agencies may facilitate better and appropriate services.

This preliminary study provides insight towards a more targeted study. More research is needed on how culture and language influence the perception of disability and resultant services. We hope to enrich the sparse knowledge of culture and disability related to self-determination. There is a significant gap between what we know from western-based research and paradigms and the actual application across indigenous cultures. Future studies of this nature may inform federal legislation regarding appropriately defining specific activities within a culturally diverse community, as mandated by IDEA or ADA.

Limitations

The authors would like to acknowledge the limitations inherent in this study. Noted previously, sampling for the service providers was purposive. Although necessary and chosen for a specific purpose, it does not represent the wider population and may be selective and biased. Sampling for the consumer group was convenient or opportunistic, based on the ease of access. The parameters of generalizability are highly negligible since only three consumers were interviewed and surveyed. As a result, conclusions drawn represent the three consumers and cannot be generalized across the Samoan community members with disabilities.

We were not able to meet with the Special Education and Early Childhood Education staff from the Department of Education to hear their perspectives regarding services and self-determination. This paper does not provide a balanced view of the issues since we did not obtain responses from these departments.

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