

Tell Us What You Need: Health Care Perspectives of Guam Families with Genetic Diagnoses

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ABSTRACT

Objectives: Guam's geographic isolation and lack of community resources have resulted in unique healthcare needs. In 2006, the Western States Genetic Services Collaborative (WSGSC) conducted a newborn screening and genetics needs assessment in Guam and made recommendations for system improvement.

Methods: This article reports on results from two focus groups conducted with twelve parents of children and adults with genetic conditions. The focus groups were part of a larger assessment of genetics and newborn screening needs completed with families, physicians, nurses, and public health staff on Guam.

Results: The parents identified four needs: 1) Increase access to specialty services; 2) Improve genetics education for providers and families; 3) Create a Guam-based family support group; and 4) Improve insurance coverage for people with special needs.

Conclusions: Although the focus group discussions centered on genetics and newborn screening, the needs identified by parents were much broader and not unique to Guam. Issues surrounding parental support, accessibility of services, and healthcare affordability are prevalent throughout the U.S. The WSGSC has drawn on regional resources and successful state strategies to address the issues identified by the families and to make specific recommendations.

Implications: Since 2006, the WSGSC has implemented a genetics outreach clinic to Guam, helped Guam develop a plan to improve newborn screening follow-up, provided genetics education, and begun a dialogue with Guam insurance companies about genetic testing and newborn screening. The WSGSC continues to collaborate with Guam to improve its newborn screening and clinical services.

INTRODUCTION

Guam is a U.S. territory located in Micronesia and is geographically closer to urban centers in Southeast Asia than the closest U.S. state, Hawai'i. The health care system in Guam is similar to that of the U.S., with comparable medical licensure requirements, health care providers, and public and private insurance companies. However, Guam lacks many government and community

resources, including pediatric specialists, a medi-

cal school, and an academic medical center.

These limitations create obstacles to the develop-

ment and maintenance of successful clinical and

public health programs, especially when com-

pared to the rest of the United States. As such,

two needs assessments have been conducted in

Guam to identify issues specific to public health

and to make recommendations for the improve-

ment of Guam's clinical and public health genetics programs. exploring telemedicine opportunities to improve access to specialty services, increasing educa-

In 2002, the National Newborn Screening and Genetics Resource Center sponsored a review team to assess the Guam Newborn Screening Pro-

gram and identify specific newborn screening needs within the territory (National Newborn Screening and Genetics Resource Center, 2002).

They found that, although personnel in the Guam Department of Public Health and Social Services (DPHSS) were passionate and enthusiastic, they

required additional training and staff to successfully administer the Newborn Screening Program. Guam also needed access to clinical geneticists and

metabolic specialists for medical management of infants diagnosed through newborn screening. The review team recommended dedicating a full-time

staff member to the Newborn Screening Program,

exploring telemedicine opportunities to improve access to specialty services, increasing educational opportunities for parents and professionals, and developing a formal genetics plan for the territory.

Four years later, the Western States Genetic Services Collaborative (WSGSC) sponsored a second review team to evaluate progress made in addressing the newborn screening needs identified in 2002. The WSGSC also expanded the needs assessment to include issues related to clinical genetic services. Results from this assessment were used to: 1) develop a comprehensive plan for genetics and newborn screening in Guam; 2) help focus programmatic efforts; and 3) maximize the use of existing resources to address high priority issues.

The 2006 needs assessment was com-

pleted with 88 key informants, including twelve parents of children or adults with genetic disorders and 76 health care professionals. The data was used to identify specific needs related to clinical genetic services, newborn screening, and genetics education. This publication will focus on the findings from the parent focus groups.

METHODS

Design

Two semi-structured focus groups were held with twelve parents of children or adults with genetic disorders. Focus group questions centered on experiences surrounding: 1) diagnosis of their child's genetic condition, 2) treatment, 3) education about the diagnosis, and 4) telemedicine. Several questions were also asked about specific needs regarding genetic resources and specialty services.

Focus groups were conducted by a researcher trained in focus group facilitation. A second researcher recorded the discussion and documented nonverbal events.

Participants

Participants were parents of children or adults with genetic disorders. The first focus group included seven parents of children or adults with hemophilia recruited through the Guam Hemophilia Support Group. The second focus group included five parents of children with genetic conditions recruited by Guam DPHSS social workers from primary care clinics sponsored by the DPHSS. Incentives worth \$25 were provided to all participants as compensation. Written informed consent was collected from each participant prior to the session. The majority of the participants were English-

speaking (83.3%) Chamorro (58.3%) females (83.3%) between the ages of 18 and 35 (50.0%). Most had graduated from high school (91.7%) and had some college experience (50.0%) (Table 1).

Analysis

Transcripts of participants' responses were analyzed using the long-table analysis method described by Krueger and Casey (2000). This method provided a general methodology for systematically comparing the qualitative data collected from the focus groups. It involves grouping similar ideas or statements into categories and then identifying and labeling the overarching themes of each categorical group. Themes embedded within the newly organized data were identified, and identified themes were compared. Similarities and differences between the two focus groups were noted. A second

researcher reviewed the data and themes and, at the completion of the analysis process, the themes and conclusions were electronically sent to three parents who participated in the Guam focus groups to ensure that the needs identified were accurate and representative of the focus group discussions.

RESULTS

Four major themes were noted within the responses of the focus group participants. Each theme represented a value or need that was consistently emphasized. The four themes were then expanded into more specific needs (Table 2).

Increase Access to Specialty Services

All of the participants (N=12) stated that specialty services, such as cardiology, genetics, and hematology, are not easily available to indi-

viduals on Guam. Each family mentioned that they have had to travel off-island to Hawai'i, the U.S. mainland, or Asia at least once to receive care from specialists. The participants also believed that medical services were more thorough in Hawai'i and on the U.S. mainland.

The biggest concern of participants was the level of medical care their children received. Currently, to be seen by pediatric subspecialists, families must leave Guam for Hawai'i, the U.S. mainland, or Asia. However, the participants explained that, for non-emergent consults, a child can wait between two to three years for insurance companies to process off-island travel requests. Many participants commented that the services, specialists, and treatments accessed by families living in Hawai'i or on the U.S. mainland should be easily accessible to families living on Guam. As one

mother stated, "We're U.S. citizens, but we're being treated like we're living in a third world country!"

Another woman explained that she moved to Las Vegas to ensure that her son with hemophilia received proper care, but recently moved back to Guam because she had no family or family support in Nevada. She pointed out that "we shouldn't have to move...just to make sure our children get simple medical care."

When the researchers presented the scenario of a geneticist and genetic counselor from Hawai'i staffing in-person genetics clinics in Guam, the families were understandably enthusiastic. Parents would like a geneticist and genetic counselor to visit Guam at least twice a year. The families were also very interested in the use of telemedicine for specialty care. They explained that the technology would allow them increased access to spe-

cialty services without the expense and hassle associated with off-island travel. Two parents had participated in a telemedicine session in the past, and they encouraged its revival. The families would like telemedicine to be used for routine care and emergency situations.

Improve Genetics Education for Healthcare Providers and Families

When asked about the medical services available in Guam, parents had mixed reactions. Many thought that the Guam physicians are reluctant to listen and are not open to information raised by parents. One mother said she has to “pick and choose” her child’s physicians from among “the few doctors who will listen to me, and who will try to understand my child’s condition.” The mother of a

girl with Beckwith-Weidemann syndrome explained:

We become the experts in our child’s condition. We’re the ones searching the internet for information and new research...but when I bring the information to my doctors, they won’t listen...We’ve finally found a pediatrician who will listen to what we say. He’ll work with us.

The participants wanted written information to be provided to doctors and nurses. The woman caring for her daughter with Beckwith-Weidemann syndrome showed us a huge packet of articles she carries with her to aid her in describing her daugh-

ter's disorder to new physicians. Families from the Hemophilia Support Group were especially nervous about emergency room staff. One parent mentioned that she and her son had to wait six to eight hours before receiving treatment at the local hospital emergency room, and when they finally received care, she had to help the physicians figure out how to mix the medication.

Parents also wanted increased education for themselves. The majority obtain information about their child's condition from the internet, from off-island specialists, and from the DPHSS staff. However, parents stated that the information they receive is often minimal or incomplete. For example, none of the parents from the Hemophilia Support Group had received genetic counseling about recurrence risks. Parents from the second focus group said it was often overwhelming to search

through the numerous internet sites in an attempt to answer medical questions. Many felt that increased access to medical specialists would directly increase parent knowledge of their child's condition.

Create a Guam-Based Family Support Group

Many of the participants emphasized the need for a Guam-based family support group. The parents believed that this group would allow for an exchange of knowledge and information while also providing support and encouragement. One young mother described herself as feeling "completely alone" when trying to simultaneously navigate through the medical system and deal with the physical disabilities of her child. She said that, had she been a part of a group of parents with similar experiences, she would have felt stronger and less

isolated.

The benefits of organizing and maintaining a strong parent support group were obvious after listening to the experiences of the participants from the Guam Hemophilia Support Group. The families

said that the support group not only provides information and support, but members also routinely share Factor, a substance used to treat individuals with hemophilia. The parents explained that shortages of Factor VIII and Factor IX are common within the territory and, because Factor is essential to keeping their sons healthy, the Hemophilia Support Group has created an informal network of “Factor-sharing.” This system is so reliable that the local hospital will often call members of the Hemophilia Support Group when their supply of Factor expires or runs low. The Hemophilia Support Group has also empowered its members to be-

come self-advocates. As one mother said, “The public health staff has helped the parents a lot, but now we have to start advocating for ourselves... and we are stronger as a united group!”

Improve Insurance Coverage for People with Special Needs

Guam parents had many complaints about insurance coverage in Guam. Several said that private insurance companies will not cover services and treatments for children with special needs. A mother in the Hemophilia Support Group explained that, with private insurance, it is difficult to get coverage for her son’s Factor. However, the Medically Indigent Program (MIP), a locally funded public insurance program, will cover medical expenses, including Factor, up to \$50,000. As a result, many families rely on MIP to ensure coverage of health care costs. At the same time, families are cogni-

zant of the fact that the program is a huge financial burden on the government of Guam. Families are aware of the strain they place on the system but feel trapped because they have no other alternative methods of coverage.

Finally, families worry about insurance coverage as their children transition into adulthood. One mother of an 18 year old son with hemophilia said that, because the private insurance companies will not cover her son's necessary medical expenses, he must remain on MIP. However, to continue to qualify for MIP, her son cannot work full-time. She described this as a "waste" and wondered about his "quality of life."

DISCUSSION

Although the needs assessment focused on issues surrounding newborn screening and ge-

netic services, the participating families identified needs that were much broader in scope including parent support, accessibility of services, and affordability of health care. It is not surprising that families caring for children with special needs

would be more concerned with issues of support and access to care than with newborn screening and genetics. The WSGSC is best positioned to address the needs associated with genetic services, genetics education, and reimbursement for genetics and newborn screening and does not have the resources to address the larger health care issues of children with special health needs.

However, the strategies and recommendations suggested by the WSGSC can be used as a model for improving other specialty services and public health programs in Guam that affect children with special health needs. Specific strategies and rec-

ommendations for genetic services and newborn screening can be found in Table 3.

Access to Genetic Services

Because Guam lacks pediatric specialists including cardiologists, neurologists, and geneticists, parents explained that they must travel to Asia, Hawai'i, or the U.S. mainland to ensure their children receive the services they require. However, the travel costs are often prohibitive, and insurance companies will not always reimburse these expenses. To increase access to genetic services, families suggested that outreach clinics be held in Guam twice a year, and telemedicine be incorporated into health care.

In 2007, the WSGSC responded to the needs identified by the families by sponsoring a week-long genetics outreach clinic staffed by a ge-

netics team from Hawai'i. Twenty-five patients were evaluated, and the geneticist determined that all referrals to the outreach clinic were appropriate for genetic consultations. However, when the genetic tests recommended by the clinical geneticist were ordered, it was discovered that genetic testing is not a covered benefit of any Guam insurance company. This includes simple genetic tests, such as a chromosome analysis, that are routinely ordered and reimbursed in the United States. Genetic testing is an essential tool for clinical geneticists and, without its use, accurate diagnoses can not be made. Due to this obstacle, additional outreach clinics planned by the WSGSC were postponed, and efforts were redirected to improving

insurance reimbursement for genetic testing, newborn screening, and clinical genetic services. To date, one private insurance company has agreed

to add diagnostic testing for positive newborn screening results to their benefits package. Discussions remain ongoing with representatives from this and other insurance companies. The Hawai'i-based clinical geneticist remains available on an as-needed basis for phone consultations with Guam primary care physicians, and a second genetics outreach clinic to Guam is currently being planned for January 2010.

The WSGSC is also evaluating methods of utilizing telemedicine to provide genetic services to Guam. Several pilot projects have studied the use of telemedicine in providing genetic services to rural communities (Abrams and Geier, 2006; Stalker et al., 2006; Lea et al., 2005). All showed high levels of patient satisfaction, improved waiting times, and increased access, suggesting that telemedicine can be used successfully to provide clinical

services to underserved populations. The WSGSC is currently working with telemedicine sites in Guam, as well with the Hawai'i State Telehealth Access Network (STAN), to determine how to best utilize telemedicine for the provision of genetic services.

Genetics Education

Educational opportunities are limited in Guam due to its lack of subspecialists and geographic isolation. Many of the families felt that they and their providers have very little information about genetic conditions and have few opportunities to increase their awareness of genetics. With growing attention being placed on the genetics of common diseases, genome-wide association studies, and direct-to-consumer genetic testing, it will be increasingly important for both health care pro-

viders and consumers to have some knowledge of genetics. To increase the number of educational opportunities available to Guam professionals and families, the WSGSC recommends that visiting specialists participate in at least one educational event. The WSGSC will also work with Guam Memorial Hospital to organize educational opportunities via videoconferencing, and to ensure that alternative methods of continuing education, such as CD-ROMs, Internet sites, and online conferences, are available. Finally, the WSGSC has developed a list of electronic genetic resources for families and professionals and has made this list available on its website.

believed this support group would reduce feelings of isolation and would encourage an exchange of information and knowledge. Caregivers of individuals with chronic conditions often experience high levels of stress, and the need for peer support is frequently recognized (Douma et al., 2006). Although many methods of family support exist, participation in a support group has been shown to significantly increase family functioning and decrease levels of stress (Chien et al., 2005). Having a parent-driven support group on Guam would help families of children with special needs share their experiences, and would provide the structure necessary for successful parent advocacy.

The WSGSC recommends that Family

Family Support Group

Several participating families identified the need for a family support group in Guam. Parents

Voices work with family leaders in Guam to organize a Family Voices chapter within the territory. Family Voices is a national organization of families

Table1: Participant Characteristics (n=12)

Category	N (%)
Gender:	
Female	10 (83.3)
Male	2 (16.7)
Age:	
18-25	3 (25.0)
26-30	3 (25.0)
31-35	0 (0.0)
36-40	1 (8.3)
41-45	3 (25.0)
46-50	1 (8.3)
Over 50	1 (8.3)
Number of children:	
0	2 (16.7)
1-2	3 (25.0)
3-4	3 (25.0)
5-6	4 (33.3)
Ethnic background:	
Chamorro	7 (58.3)
Filipino	4 (33.3)
Ponapeian	1 (8.3)
Language most used:	
English	10 (83.3)
Ilocano	1 (8.3)
Tagalog	1 (8.3)
Education level:	
Did not graduate high school	1 (8.3)
High school graduate	5 (41.7)
Some college	5 (41.7)
College graduate	1 (8.3)

Table 2: Needs Described by the Focus Group Participants

Themes
<ol style="list-style-type: none"> 1. Increase access to specialty services <ul style="list-style-type: none"> Hold in-person genetics clinics in Guam at least twice a year Establish telemedicine consultation for routine follow-up and emergent care 2. Improve genetics education for healthcare providers and families <ul style="list-style-type: none"> Increase communication between physicians and families 3. Create a Guam-based family support group <ul style="list-style-type: none"> Increase support systems for parents and encourage self-advocacy 4. Improve insurance coverage for people with special needs

Table 3: Recommendations and Strategies to Address the Needs Identified by Guam Families

Recommendations and Strategies
<ol style="list-style-type: none">1. Organize week-long semi-annual genetics outreach clinics. The WSGSC will sponsor semi-annual genetics outreach clinics staffed by Hawai'i providers.2. Initiate telemedicine consults for genetics. The WSGSC will work with the Hawai'i State Telehealth Access Network and DPHSS staff to develop a telemedicine program for genetics patients.3. Encourage visiting specialists to provide at least one educational event for families and health care providers.4. Explore alternative methods of education. The WSGSC will work with Guam Memorial Hospital to increase awareness of alternative methods of genetics education.5. Develop a Guam chapter of Family Voices. The WSGSC will identify a potential family leader in Guam and connect him/her to representatives from other state Family Voices. Together, they will organize a Guam Family Voices chapter.6. Guam needs a local leader to advocate for reimbursement of genetic services and testing.7. The WSGSC will continue discussions with Guam insurance companies to increase coverage for genetic services and testing.