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Around the World

A First Look at Children and Youths Who Are Deaf-Blind in the Kingdom of Thailand

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Developing countries often have little awareness of and virtually no services for individuals who are deaf-blind. In some nations, children who are deaf-blind remain isolated at home without education, and adults who are deaf-blind may live without rehabilitation services ("Disability in the Majority World," 2005; SENSE, 1999).

Little is known about the demographic characteristics and clinical profiles of people who are deaf-blind in Thailand, although there have been some anecdotal data on the education of children who are deaf-blind in the region. Multiple searches of available databases on the population, education, and national health of Thailand revealed no data on deaf-blindness. According to Mitchell (1995, p. 7), "the Seventh Educational Development Plan (1992-94) provided for equal treatment for both special and regular education," and the 1991 Rehabilitation of Disabled Persons Act included the categories of *language and speech impairment* and *multiple handicaps*. Nonetheless, there seems to have been no effort to account for people who are

deaf-blind. With no official census, the authors strongly suspect that all cases of persons who are deaf-blind have been labeled and reported as cases of multiple disabilities, and, therefore, it can be assumed that the unique needs and appropriate services related to these persons' sensory loss have not been addressed.

Before 1989, individuals who were deaf-blind were not recognized in Thailand's educational and rehabilitation systems. At that time, the Hilton-Perkins program brought the first team of professional educators to the country to begin working with children who were deaf-blind (Hubbs, 1998; International Programs, 2005). Currently, programs in educational settings, supported by charitable, nonprofit and religious, and governmental projects, provide basic instruction; programs to educate children who are deaf-blind who have additional disabilities have been established in the greater Bangkok areas, as well as in Roi Et, Nakhon Pathom, Chiang Mai, Lampang, and Lo Buri. Despite considerable efforts by governmental and nongovernmental organizations to improve education and rehabilitation programs, no systemic efforts have been specifically targeted to individuals who are deaf-blind. Confounding the challenges, there are no Thai consumer or advocacy organizations of or for individuals who are deaf-blind.

According to the online health data provider, Adviware Pty Ltd. (2005, para. 1), we can extrapolate the number of individuals with dual sensory loss conditions (such as Usher syndrome--a genetic condition that presents with concomitant retinitis pigmentosa and sensorineural hearing loss), but the local genetic and environmental predictors remain unknown, and estimates may "only give a general indication (or even a meaningless indication) as to the actual prevalence or incidence [of the condition]." Adviware Pty Ltd. estimated the possible prevalence of Usher syndrome in Thailand as 3,815 in a population of approximately 62 million.

Here, we present the first organized attempt to examine the

population of individuals who are deaf-blind in Thailand. This study began as a master's thesis in a university rehabilitation program; in 2004, the results were concisely presented at a conference in Asia (Sukontharungsee, 2005). The research activities were overseen by a committee of six professors, emeritus professors, and advisers. The critical role of defining and beginning to understand the prevalence and needs of people with disabilities, especially those who are deaf-blind, is vital to the establishment of services in Thailand. By reporting on the census and surveys conducted with individuals who are deaf-blind and their significant relatives, we hope that a nascent picture will emerge to assist in planning for appropriate programs and services in Thailand, which appears to be poised to expand and improve services for people with disabilities. Ratchasuda College (of Mahidol University) was founded in 1992 specifically to address these needs. It has recently hosted several seminars and workshops on children and adults who are deaf-blind.

THE RESEARCH PROCESS

Identifying individuals who are deaf-blind

With no previous research or data available, we began by contacting institutions for people with disabilities, special education programs, schools for people who are deaf, and schools for people who are blind throughout Thailand, the traditional placement options for people with severe disabilities. The entities contacted reported 130 cases of suspected deaf-blindness. To ensure accuracy, medical specialists in vision and hearing screened each individual, using an eye examination; measured visual acuity using light projection, finger counting, hand movement, and Snellen chart measurements. Eventually, 35 cases were determined to be genuine incidences of deaf-blindness and were included for further investigation on the basis of the criteria for inclusion listed in Box 1. Of these 35 cases, 34 were aged 7-22, and 1 was aged 61. The discussion

presented here focuses mainly on the 34 children and youths unless noted otherwise, since they represent by far the majority of the cases that were found and constitute a reasonably distinct and definable population for study.

Of the 34 children and youths, 12 (35.29%) were aged 7-12, 16 (47.06%) were aged 13-17, and 6 (17.65%) were aged 18-22. These children and youths resided in three of four regions of the country: 18 in the North, 10 in the Central region, and 6 in the Southeast (none was from the South). The majority lived with their parents (70.59%), and the rest lived with other relatives (14.71%) or in an institution (14.71%).

We defined divided sensory loss into four broad categories: deaf and blind (29.41%), deaf and low vision (52.94%), hard-of--hearing and blind (14.71%), and hard-of-hearing and low vision (2.94%). Although the etiology of deaf-blindness in the majority of participants (55.88%) was unknown, other diagnoses were congenital rubella syndrome (9 participants, 26.47%), Usher syndrome (5 participants, 14.71%), and premature birth (1 participant, 2.94%). In addition, the participants were categorized according to whether they were congenitally or adventitiously deaf-blind, as follows: congenital deaf-blindness (16 participants, 10 boys and 6 girls, 47%); congenital deafness, adventitious blindness (16 participants, 10 boys and 6 girls, 47%); and congenital blindness, adventitious deafness (2 participants, 6%).

The participants used a variety of one or more methods of communication. Sign language was the most common form at 58.82% (tactile sign language, 5.88%). Other methods were gestures (47.06%), spoken language (5.88%), and print on palm or paper (5.88%). Table 1 lists the grade levels of the participants.

Statistical comparison to the United States

Although extrapolations and comparisons among countries may

be tenuous, in the United States, the National Technical Assistance Consortium has long maintained a comprehensive and reliable database on children who are deaf-blind (National Deaf-Blind Child Count Summary, 2004). The population of Thailand is approximately 62 million people, compared to 282 million in the United States. Individuals aged 22 or younger in the United States who are deaf-blind represent .0032% of the population. We believe that comparing demographics will allow the reader to gain some insight into the relative situation for children and youths who are deaf-blind in Thailand.

In Thailand, 85.30% of the children and youths in the sample lived with their families while attending school, compared to 88.12% in the United States; however, 35.29% of the Thai sample was not in an educational setting, compared to .34% in the United States. The incidence of significant cognitive delays is large in both countries--47.76% in the United States and 32.25% in Thailand. General patterns of vision and hearing loss and etiology vary widely between the countries, but patterns of age, placement, and anticipated concomitant cognitive involvement are similar (see Table 2 for comparative data on age, vision and hearing loss, and etiology). Of particular concern is the apparent proportion of congenital rubella syndrome in Thailand (26.47%)--a condition that was eradicated in the West through an effective vaccination program (Centers for Disease Control and Prevention, 2005).

Assessing the needs of people who are deaf-blind in Thailand

To gain insight into the needs and preferences of individuals who are deaf-blind in Thailand, we interviewed the 10 individuals who were able to respond to the survey (including the 61-year-old), their families, and their caregivers. According to the survey data, the most frequent social activities of the children and youths included shopping, play with siblings, affectionate behaviors, and communication behaviors. The least

frequent activities were gardening, accompanying a parent to work, and doing homework with family members. Nonfamilial respondents indicated that the subjects who were deaf-blind often joined in school activities (77.14%), but 57.14% did not interact socially with their peers because of communication barriers. Only 48.57% of the sample had friends. Participation in religious events appeared to be significant (37.14%). The primary needs that are specific to individuals who are deaf-blind are presented in Table 3.

IMPLICATIONS OF THE FINDINGS

According to the Ministry of Education of Thailand (2003), "Under the current Thai Constitution, the disabled have a right to equal opportunities for education and career. Disabled children and youth can also access free services, such as basic education and aids. The disabled should be fully integrated in Thai society." For children and youths who are deaf-blind, this remains a goal, since 35% of the surveyed children were not in formal educational settings (see Table 1).

Problems that were highlighted by the research include the lack of interpreters and other rehabilitation personnel, such as social workers, counselors, and others who are knowledgeable about deaf-blindness; more positive societal attitudes; and increased training and availability of teachers and educational programs. Also notable was the lack of the perceived need for advanced technology.

The most frequently cited problems were related to communication. The country does not have a sufficiently large or established interpreting profession, and of the 50 or 60 persons who work as interpreters, only 1 or 2 have formal training in deaf-blindness techniques for communication and strategies (personal correspondence, Sopon Chaiwatanakulwanit, November 20, 2005). With interpreting services generally unavailable, access to education and rehabilitation is limited.

Professional orientation and mobility (O&M) services for children with visual impairment have been long established in Thailand. Schools for children who are blind typically employ one or two O&M specialists, but services for adults are rare in most of the country. Until recently, no O&M specialist had any training in working with students with a dual sensory loss (personal communication, Chalam Yam-iam, October 10, 2005).

Thailand has a growing middle class and a robust economy, but improved socioeconomic status may not have affected individuals with disabilities as it has in industrialized countries. As Kwok (1999) stated, the "economic boom from the 1980s to the mid-1990s was a surprise to many economists, both local and overseas. A decade of fast accumulation of wealth has drastically changed people's way of life. However, disabled people's share of the nation's wealth has not been that significant." It seems significant that 86% of the respondents to the survey said that they grew up in poverty, and 43% reported that they currently lived in poor villages.

Thai attitudes toward disability are changing. Traditionally, incidents of disability were thought to be related to spiritual transgressions (Kwok, 1999). Predominantly Buddhist, people in Thailand often subscribe to "karmic theory--that unfortunate events happen due to a person's former deeds" (Yamey & Greenwood, 2004, p. 459). We hope that recognition of deaf-blindness as a unique disability will lead to an increase in appropriate planning and programs, which may also lead to greater social acceptance of people with disabilities.

Like much seminal research on people with visual impairments and hearing loss, this study has numerous limitations. The primary limitation is that the sample of 34 was small, and the sampling was somewhat selective. Yet we trust that the study will prove to be generative, encouraging further research and action on behalf of Thai children and adults who are deaf-blind. Further efforts are critically needed.

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