

## **Vietnam's children's experiences of being visually or hearing impaired**

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This paper focuses on the experiences of visually and hearing impaired children in Vietnam, a country where lay-based cultural beliefs predominantly shape understanding of any form of disability. The practice of ancestral worship informs a belief that disabilities are a punishment for wrong deeds in past lives, and as a result people with disabilities are often marginalized. Such reactions are sometimes taken to extremes: circumstantial evidence suggests that disabled children are even likely to be killed at birth. Others might simply be hidden away or rejected into the local orphanage. This paper discusses the therapeutic support on offer to children attending two types of educational settings, and explores how the wider school and local community considered and treated such children, examining the chosen forms of intervention in each institution from an ethnographic perspective. The first was a mainstream school with a specialist vocational training unit for visually impaired children, and the second was a specialist school for children who were hearing impaired and who were taught only to lip read and speak.

**Keywords:** Vietnam; hearing-impaired; visually impaired; children; ancestral worship.

### **Introduction**

The purpose of this paper is to examine the embodied experience of what it means to be a disabled child living in contemporary Vietnam. Drawing upon my ethnographic fieldwork, it reports on the experience of being disabled among visually impaired and hearing-impaired children. It then explores why it is possible for physically disabled children and their families to experience such pronounced feelings of marginalization and stigma in the Vietnamese context. To this end, my findings highlight the importance of addressing local belief systems when introducing external support programs aiming to improve the quality of a child's life and the embodied understanding of self. This sense of embodiment is informed by the seminal work of Merleau-Ponty (1962) and medical anthropologists such as Helman (1984) and Kleinman (1988) all of whom have pointed out that the physical sense of the body is directly shaped by cultural influence.

*Background*

My research interest in Vietnam now spans two decades. Twenty years ago I was a social worker working with a Viet-Kieu community in London. Discussing members' experiences of illness and the taboo subject of disability partly informed and inspired my journey to Vietnam where I initially lived for two years between 1996 and 1998 as an anthropologist adopting participatory observation as my central research tool for understanding local meaning attached to the body. After returning from Vietnam I lived in the USA, between 2000 and 2006 where I became immersed in the West coast Viet-Kieu community and a community of Vietnamese children adopted by American families, some of whom had been put up for international adoption after being rejected by their parents on the basis of having a physical impairment. This paper is informed both by my initial fieldwork, which combined extensive participatory observation among children with open-ended interviews among child focused professionals, and by an on-going monitoring of child rights focused developments in Vietnam leading up to 2012 when Vietnam established a nationally recognized sign language.

*Vietnamese children and the international arena*

On the face of it, a revolution in attitudes towards children has taken place across the globe, stimulated by economic growth and internationally led child rights programs (Burr, 2006). In the late 1980s, under a nationally led social policy named Doi Moi, Vietnam established a social oriented market economy (Vuong et al. 2011). This dramatically altered the socio-political landscape by stimulating the re-establishment of relations between Vietnam and the USA and opening up the country to western led international aid programs. Today the World Bank refers to Vietnam as a middle-income country and its average income per month is estimated to be \$120 (Mont, 2013). The communist based communes have been disbanded and the two-child policy relaxed. Yet Vietnam is still a one party state (Burr, 2006, 2013; Gammeltoft, 2008). It is also a state which oppressed and often banned traditional rituals and celebrations during the Cold-War era.

In this paper I focus on the impact of these macro-economic and geo-political forces on Vietnam's health sector, and specifically the impact on children who have some kind of disability. The majority of Vietnamese doctors and teachers were trained by their communist allies, and despite the subsequent introduction of Western led bio-medical practice on the one hand and communist inspired social reforms on the other, the Vietnamese people continue to incorporate a myriad of different folk beliefs. Thus, despite four decades of rule by a one-party communist government and the resulting attempted oppression of traditional practices, the dominant belief systems, particularly in the more rural north of the country, remain a blend of Confucian based ancestral worship (Oldstone-Moore, 2003) and Buddhism

(Hirschman and Vu Manh Loi, 1994; Rydstrom, 2006). While Buddhism supports the belief that we on earth have been reincarnated from a previous life, ancestral worship incorporates the belief that it is the acts of deceased family members that inform the quality of lives of the living.

## **Methodology**

The central research method informing this paper is that of the anthropologist using the technique of participant observation, in which the emphasis is on allowing critical categories and meanings to emerge from the ethnographic encounter. To develop an understanding of what it is like to live in a particular setting, the researcher must become a participant in the life of people in that setting, while maintaining the stance of an observer, someone who can describe, and write up field notes objectively. This process usually requires anthropologists to become such a familiar presence in people's daily lives that life goes on around them virtually as it would if they were not there. To meet this aim I spent six months visiting both visually impaired and hearing impaired children in their schools. I also interviewed a selection of people whom I met during fieldwork, and as an anthropologist the interviews leaned towards being semi-structured and open ended rather than formal and questionnaire based. (Burr 2006:4).

## **A moral understanding of the body**

It is primarily this belief in reincarnation and the deeds of family ancestors that has created an environment in which bio-medical understandings of the body continue to co-exist alongside culturally specific folk beliefs about sickness and health. Drawing upon medical anthropology I highlight that while this might seem at odds with a Western based bio-medical healthcare model, closer inspection of lay beliefs confirms that there continue to be universally held culturally biased ideas about the origins of illness (Blue, 2014). Helman (1984) also suggested that Western concepts of self or personhood that are autonomous and bound by scientific understanding, only present one way of conceptualising the body. In a similar vein, my fieldwork strongly points towards a moral understanding of the body taking precedence over any other explanation for disability.

This moralistic response to the body has also been highlighted by other writers such as Sontag (2002) who examined her experience of being treated for breast cancer in the USA. She describes how her diagnosis of cancer coalesced into a discussion about a person's basic human qualities and the extent to which they could be described as strong and pure enough to win the battle. So this reaction to being physically imperfect seems to be universally understood as both a medical condition underpinned by biological understanding of the

human body and by myth, magic and folklore.

*The structure of Vietnam and its hidden disabled*

In Vietnam multiple influences co-exist or undermine each other. As established earlier in this paper it is commonplace for lay beliefs in myth and folklore, shaped by ancestral punishment, to add an additional layer of complexity to an understanding of illness and disability. This is reinforced by household based practices of laying gifts on the ancestral table. In this context where a child is disabled, ancestors may be called upon and given generous offerings so that a cure becomes possible or be called into question when a child becomes ill (Gammeltoft, 2008). The following traditional practice illuminates this point: when a child is born, only immediate family members are allowed to visit for the first thirty days of its life: this is because it is believed that stronger spirits of adults might harm the fragile soul of a newborn (Burr, 2006: 29). With this in mind it is possible to appreciate that where a disability such as blindness and deafness might not be immediately apparent, later discovery of these could be blamed on a failure of parents and ancestors to protect the vulnerable new born from spirits. Such practices point towards disabilities, both physical and mental, creating profound and culturally specific feelings of shame and marginalization (French, 1994; Jaye, 2004). In this environment disabled children are profoundly stigmatized for their imperfections and their disability can be treated as an embodiment of ancestors' wrong doings (Burr, 2006; Gammeltoft, 2008).

**Disability from an international aid perspective**

I interviewed aid workers as part of my fieldwork, and during an informal interview with the head of an international NGO based in Hanoi, which had tried to find out more about disabled children's lives, was given the impression that those who do survive babyhood often lead very limited lives in which they are more or less confined to the family home. The director of this NGO also told me that her local workers had been refused entrance to village houses where it was commonly known that a disabled child resided (Burr, 2006). The anthropologist Tine Gammeltoft (2008:831) also found a very similar pattern of behaviour during her research in Vietnam where parents spoke to her about bearing a shameful fate as a result of having a disabled child.

**Disability as a threat to livelihoods**

In an environment where the urban/rural divide of opportunity is significant, where there is limited welfare support, and children's labour is a necessary contributor to the household

income, physically able children are essential to the overall wellbeing of the entire family unit. Mont and Cuong (2011) writing for the World Bank highlight this sense of futility and also the lack of monetary based resources available to redress the poverty created by raising a disabled child. The aid worker whom I interviewed spoke in a similar fashion about the desperation brought on by having a disabled child and pointed out that at its worst a newborn's life may be put in danger, or a child may be hidden away or neglected so that they purposely do not thrive (Burr 2006: fieldwork notes). In light of this last point it is of significance to highlight that 70% of the population still live in rural areas, where access to formal health services are challenging and where it is therefore difficult to gain accurate information about the exact circumstances of disabled peoples' lives (Mont and Cuong, 2011).

In the Vietnamese context where the Confucian value system dictates a collectivist belief system, the motive for hiding a child, preventing it from thriving, or even ending its life, might be rationalized and re-configured as a noble sacrifice to the collective good. This is not as farfetched as it might at first appear, but in order to understand what this means, it is essential to have an appreciation of the lengths that individuals will go to in order to maintain family honour.

### **A collective sense of self**

My first immersion into collectivist ideas about identity occurred when I was travelling through Vietnam by myself a couple of months after moving to Hanoi. While visiting a northern town called Hai Phong, I fell into conversation with a man who had long since returned to Vietnam disappointed and full of shame after being repatriated from the refugee camps for Vietnamese boat people in Hong Kong. He spoke with a clear sense of duty about the personal sacrifice he was forced to make for his family, and explained how during the cold war era, families with the means to do so would opt to send one member of the family out of the country to establish family links and develop and gain access to western based resources. In his case he had only gotten as far as the refugee camps in Hong Kong and had not subsequently qualified for a visa to re-settle in Australia, the USA or Canada. Yet he had been a young child when he was smuggled out of the country to eventually find himself locked up in Hong Kong. Having grown up in the camps, he spoke of feeling a misfit when returning to live in Vietnam, and with no qualifications or work, he felt the stigma of having let the family down and of ultimately harming his family's honour. In turn members of his immediate family also had little time for him and considered him to be a failure. Conversations such as this one, highlighted how fearful and distrustful families had been during the introductory phase of Communism. Rather than give in to living in a totalitarian state, family members were forced into making difficult decisions which would result in parents asking individual children to escape overseas as a protective measure in support of

the long-term wellbeing of their wider family. Experiences such as these are well documented. Anthropologists Nancy Scheper-Hughes, in her seminal study of child death in favelas in Brazil (1992), and Katherine Dettwyler, in her study of children growing up in rural Mali (1994), found similar collectivist based reactions to living in challenging circumstances. Likewise in their work a collectivist response to individuals was in response to those who were considered a threat to the status quo or the general wellbeing of the wider community. In Scheper-Hughes' ethnography, she describes how newborn babies would be immediately re-embodied as little angels and deprived of their mother's milk so that they would die. Rather than recognise such responses to individual infants as a coping strategy for managing over-population (when giving birth to babies whom a family could not afford to feed), such infants were instead purposely dehydrated so that they could fulfill a destiny to return to heaven. Dettwyler's ethnography recorded a similar reaction to over-population and children being born out of wedlock when examining the growth and development of twins in rural Mali. Her findings showed that it was the physically stronger twin who received preferential treatment. On returning to the same village a few years later, she wrote that it came as no surprise to learn that the less strong twin had succumbed to a sickness and that in the aftermath of her death her unmarried mother, with now only one physically able and working child to care for, had received and accepted a marriage proposal. In all such cases, it is not an underlying medical condition, but the dominant societal values, cultural norms, socio-political and economic circumstances which decide the fate of children. Such experiences point towards all embodied experiences being societally, rather than bio-medically defined. Yet disabilities still tend to be formally treated using a predominantly medical understanding of the body. Dominant funders of intervention programs in Vietnam include UNICEF which has adopted an approach of addressing the mass inequalities facing disabled children by highlighting a need for disabled children's rights under the UNCRC banner to be adhered to (see UNICEF, 2014)

### **Disability understood through a western lens**

This individualistic and rights based focus finds its origins in Western understanding of the self which became more pronounced during the age of Enlightenment in the seventeen and eighteen hundreds when the resulting Cartesian principle dictated a separation of the social and physical understanding of the body. Within this approach, the bio-medical body is treated as a physical object that needs fixing and diagnosed using clearly defined medical terminology (Kleinman, 1983). As Jaye (2004) points out, the lived embodied experiences of individuals is experienced within particular historical, cultural, political and societal frameworks. Theorists within medical anthropology have a long-standing reputation for considering illness and general responses to the body in this way (Merleau-Ponty, 1962). Yet, it was not until the 1970s that a grassroots-led political movement began to highlight some of the social problems by only focusing on a bio-medical discourse when treating children with

disabilities. During this period, social commentators such as Michael Oliver (1991) argued that a social model of disability was highly relevant and could be used to challenge disabled people's daily experiences.

Thus, within an applied understanding of human experience, a social and medical model of disability emerged as two distinct approaches. Since the 1970s this split has become an established norm, yet Shakespeare and Watson (2002: 22) argued that we had to move beyond this understanding in order to embrace what they refer to as an embodied ontology. While I support their shift away from the social/medical split towards a more integrated model, I would also suggest that their argument for disabled people to define and shape their own experiences, are culturally-bound and can only be made possible within societies which have already established strong anti-discriminatory practices. Vietnam's socio-political, economic and cultural environment is such that many people do not have enough autonomy to make the choice about how they see themselves that would make embodied ontology possible. As I show next this is as a result of a number of inter-connecting factors.

### **Vietnam: a social model of disability.**

When I first arrived in Vietnam it still modeled its support of disabled people on a combination of pre-communist beliefs based on destiny and on intervention programs that had not been updated by external influences or rigorous research since the start of the cold war. The finite resources that Vietnam had to offer were also focused on providing services to people affected by Agent Orange, which had been used as a form of war-time weaponry by the Americans during the Vietnam/America War. The effects of this toxic defoliant are still being felt 40 years later (see for example newspaper report by Snejana Farberov in 2013).

During this period in the mid 1960s and 1970s there was a brief trend preventing the use of sign language so that people who had impaired hearing could focus on learning to lip read and speak, and thus be better integrated into mainstream society (Lou, 1988:75). Today an individually-based combination of oral and sign training has been accepted as the most beneficial approach. But when I was living in Vietnam, the minority of deaf children who went to school were only allowed to communicate by lip-reading. Teaching was adult-centred and any form of signing was actively discouraged. It was not until 2012 that Vietnam established a nationally recognized sign language, and as a result, people with hearing impairments still exist very much on the margins (Vietnam News, 2012).

Such evidence points towards disabilities being defined by lay beliefs and therefore a social model and not a purely physiological and medical understanding of the body (Linton, 1998). The hidden away, less than perfect child, well documented by anthropologists such as Gameeltoft (2008) and myself is still being directly affected by traditional beliefs, lack of

resources and, in the Vietnamese context by the choices people feel compelled to make when internalizing the need to have a child who will not contaminate the family reputation with their imperfections, or deprive the family of the resources they need in order to have some quality of life (Burr 2006, Gammeltoft, 2008).

### **Field notes from Vietnam**

For the purpose of this paper, I draw upon my fieldwork observations among two groups of Vietnamese children, a group of hearing-impaired children who attended a specialist school and a group of visually impaired children who attended a mainstream high school. Set within a country context, in which the majority of disabled children were never likely to attend school, the children who I met were very privileged. Living in the city gave them immediate access to specialist schools. They had not been hidden away, and in the case of the visually-impaired children, had moved from rural villages to board at a school primarily training them to become qualified masseurs so that they could return to their villages to live independently and earn a living. Yet my findings show that any sense of privilege was superficial, because while at school the children suffered from social isolation and discrimination. They also received outdated and inadequate service provision because of Vietnam's isolation during the cold-war and the shortage of social care funding.

### **A fieldwork introduction to hearing-impaired children**

During my first summer in Hanoi I enjoyed taking long and aimless cycle rides around the city, going wherever my bike took me. It was on one such ride that my attention was drawn towards an animated and very excitable group of children wildly waving their arms in the air and hanging on to and off their companions' bicycles as they did so. The group was in its own little bubble and such was their chaotic reign of the road that it took me some moments to both navigate my safe passage and to realize that the group were using sign language among themselves. At the time I was struck by the joy that they took in being in each other's company and by the way in which they seemed to be in a private world of their own creation. I resolved to find out where they were going, and what their relationship was to each other. But it was not until September that year and the start of a new school year that I was to spot them again. This time, they were coming out of a side road in school uniform and this enabled me to locate them.

By the autumn I had located the two schools and asked a Vietnamese friend to provide me with an introduction. The first school that I went to was the specialist school for deaf children who broadly ranged in age from six to sixteen. The children who I spent time with were about twelve years old and had been together as a cohort for five years. In the first class I was

struck by how noisy and disorganized the lessons were. The children were meant to be doing some sewing but spent the entire lesson signing among themselves while the teachers spoke very loudly from the front of the class room, regardless of how well their hearing-impaired charges were receiving this or paying attention.

A fundamental mismatch existed. The teachers were not only not signing to the children but, during that instance, punishing children by sending them to the back of the room to face the wall when they were caught signing among themselves. In this instance it was self evident that the teachers had little regard for their charges. At the time I noted that the teachers' reactions were in keeping with, what I was beginning to recognize as an emerging and very local discourse on disability and bodily imperfection based on ancestral punishment. This was not the only overt form of marginalization taking place.

During the break, I interviewed a teacher and learnt that the school did not teach signing. Instead, it was following a system of teaching the children to lip read: an approach which became fashionable during the 1970s across schools in Europe and North America (Marschark and Spencer 2010), . Today the dominant approach is to incorporate an ability to lip read into a formal signing system. Not so for the children I met, and, it was not until 2012 that a native signing system was formally introduced into Vietnam (Maddell, 2013).

On the face of it, this lack of willingness to sign and to lip-read was out of date, echoing a technique that had been in fashion in the West prior to the fall of Southern Vietnam and the isolation of the country during the Cold War. But it was also an approach which self evidently did not seem to be working: the children were not engaging with lip reading. When I asked the teachers about this during the break they spoke about the children being lazy and unwilling to learn, thus echoing a Confucius based traditionalist approach to education. It was then that I asked about how the Vietnamese tonal system was incorporated into the teaching on lip reading. Instead teachers spoke to me about how it was a challenge to teach children how to lip-read and to incorporate tones into the lip reading process.

### **Tonal language systems**

Tonal languages are complex and hinge upon a person being able to pick up quite subtle changes in the tone of a word (Yip, 2002). Thus an uplifting tone on a word will give it an entirely different meaning to the word with a flat tone to it. A different vowel at the end of a sentence will also give a word a completely different meaning. In that context a person who has impaired hearing is simply not going to be able to understand anything that is lip read, because they are unable to pick up the subtle linguistic nuances. I sat with the group after the school break and watched the teachers resume a teaching style, which focused on shouting out words while children continued to sign under their desks. The children were clearly signing, in fact their every actions were demonstrating that this was what they wanted and

needed to do. But this also increased their social isolation. In fact, their actions had further exacerbated the children's sense of isolation, because having ignored the children's desire to sign, the children had then gone on to develop signing systems unique to their particular class. This meant that each cohort had developed their own unique method of talking with each other. These children existed not only on the margins of society but also as separate entities within their school. Thus once the children left school their full ability to be understood would probably be confined to a very small group of people. At the time, in my fieldwork notes I had absent mindedly scribbled 'margins within margins', arguably a neat shorthand for what was happening and one which is reminiscent of Paul Farmer's arguments about structural violence (Farmer, 1984).

### **Children in the school for the visually impaired**

At the school for the visually impaired there were similar problems of extreme forms of structurally based separation among the visually impaired children. These children were being taught in a high school. The high school had a separate boarding school for the visually impaired children and specialist teaching on the subject of massage. But other than that, the children were expected to join sighted children for their lessons during the school day. Once again, the effects of lack of resources and the inevitability of large class management, was evident: for example, it meant that the visually impaired children did not have any resources written in Braille. This meant that the visually impaired children were reliant on the teacher and other students to read information off the board for them and were expected to attend classes in which the majority of children were sighted.

I visited the school on a daily basis over a six month period and during my time at this school, I joined up with a different child each day and followed them through their normal routine. My fieldwork observations highlighted how marginalized the children were, keeping my distance in the crowded corridors I watched as the visually-impaired children were jostled and jeered at, teased and shoved. Sitting in their dormitory later on, surrounded by children lying on their bunk beds, I learnt that the classes in massage were the most enjoyable classes, partly because the children could learn together and not in isolation. A fashion for integrated learning in mainstream schools had been established, but the necessary resources had not been put in place to make it a real success.

### **Ly's experiences:**

The frustration and limitations experienced by the large number of children whom I met can be summed up with reference to Ly's story. When I met her, Ly was seventeen years old and boarding at the school for the visually-impaired. Her English was virtually fluent and partly

because of this she had garnered the support of a small group of elderly American Christian women who had raised enough money to send Ly to a specialist teacher training college in the USA. During a car journey with the group the women explained that Ly would be returning to Vietnam to offer her teaching skills to the next generation of visually-impaired children. Clutching my hand, Ly whispered urgently into my ear that if she got to the USA she would never be returning to Vietnam, and that her world in that country was one of shame and punishment and not one of happiness. Her destiny had to lie elsewhere because the alternative was too grim and she explained that by escaping her fate she would bring much needed honour upon her parents, whose status within their village would subsequently rise once she was permanently in the USA.

## **Conclusion**

The central point of this paper has been to highlight how restricting disabled children's lives can be and to show that the experience of disability is socially bound and not medically bound. This paper indicates that a Vietnamese response to disability is defined by locally created action and secrecy. It also outlines the importance of understanding lay responses to the body and the extent to which particular belief systems resonate with and hold meaning for a particular group of people. In this instance it is the practice of ancestral worship, which dominates in creating meaning for the embodied self. It would make sense then to use such ideas as a starting point, for exploring disabilities, and the possibility that an individual's bodily imperfections are likely to shame their entire family group. In this way the paper shows the importance of first addressing local responses to disabilities and then drawing upon local expertise when designing intervention programs, such as the 2012 native sign language program. The paper points towards the continual need to support grass roots based disability programs and highlights why it is so difficult to overcome feelings of punishment and guilt when the dominant discourse on disability is defined by traditional practice.

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