

Building Familial Spaces¹ for Transition and Work: From the Fantastic to the Normal
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Abstract: Transition for persons with disability is a process of negotiating difficult situations and barriers set by others and by systems. My strategies to overcome those barriers in my personal transitions through education systems and employment included the creations of familiar spaces in which group support plays a major role. This paper tracks my process through the familiar spaces and gives examples of encounters with barriers along my transition through hospital treatments to schools and then work.

Key Words: spaces, disabilities, transition

Why Am I Having Difficulty Writing this Paper?

When my friend, Steven Brown, and the rest of the good folks at the University of Hawai‘i Center on Disability Studies, asked me to participate in the 2005 Capacity Building Institute, “Enhancing Transition to Postsecondary Education and Employment for Youth with Disabilities through *Culturally Relevant Supports, Services and Education*,” I agonized for days before writing. I took awhile to recognize two reasons why I was having such difficulty writing about my experience as a person with disability who has gone through the issues discussed in the Institute. The first reason is because I simply have not had the time to reflect on what I have done, how I (and those around me) did what we had to do to get me through life on a daily basis. The second reason is that the experience I had and continue to have in Chuuk is quite different from what others in the Institute experienced.

Although we may be able to draw some thematic similarities across our experiences, all the experiences have particularities that make them different. Mine is unique to the cultural practices and contemporary problems of my place. For example, while seeing a person in a wheelchair in all aspects of life is considered the norm in Hawai‘i, it is still “fantastic” and “fascinating” to see the only visible Chuukese person in a wheelchair going to work. In Chuuk, people like me are considered “sick,” and sick people do not work. Furthermore, the job market in Chuuk is so depressed that searching for any job is fiercely competitive. For a person with a visible disability, to work is not “normal.” It is fantastic, not commonplace, and even threatening and unfair to able-bodied folks.

I firmly believe that problems of transitions and work for persons with disability have a great deal to do with the wider social and economic issues the community is going through. It is, after all, the community that defines and produces barriers for persons with disability. So I figure my contribution is to describe the wider cultural challenges and problems that exist in my place and then attempt to offer some reflections about my own challenges in transition and work.

First, let me introduce the place where I am from and set the plot for reflections on my personal transitions. I am from Chuuk State, the most populated of the four states in the Federated States of Micronesia (FSM). The FSM, the Republic of Palau (ROP), the Republic of the Marshall Islands (RMI) and the Commonwealth of the Northern Marianas together used to be the Trust Territory of the Pacific Islands, or TTPI, part of the post World War-II United Nations Trusteeship program. In its efforts to promote a democratic government in the islands, the United

States introduced social, economic, health, and education programs, and a good number of federal programs aimed at promoting positive social changes. After the island nations voted to go their separate ways into the postcolonial era, each maintained close relationships with the U.S. The current relationship, which is called the Compact of Free Association, now in its second term², provides these island nations (FSM, ROP, and RMI)³ with U.S. assistance in grants and federal programs.

But, as the tired old cliché goes, things do not always turn out as planned. Even with all the time and resources poured into these small island nations, development, or planned development, comes reluctantly and slowly. The challenges are enormous. When a visiting staff member of the Joint Economic Monitoring Committee Office (JEMCO) came to Chuuk, he was critical about the status of education in Chuuk State. JEMCO cautioned state and national leaders about the poor status of education in Chuuk.⁴ Moreover, if we measure the success of transition to postsecondary education and employment for student and youth with disabilities by counting the number of students, we will need only a few fingers on one hand to show its success. Maybe just one finger will be needed.

Personal Stories: Change in My Life

I was injured in June of 1980, a few days after my freshman year in high school. I fell off a rock and broke my neck, leaving me paralyzed from the chest down. I was brought to Honolulu, where I spent a whole year, mostly at the Rehabilitation Hospital of the Pacific, “rehabbing.” I would be labeled a C-6 quadriplegic, a label that puts me in an obscured category; I am still unfamiliar with its usefulness. Actually any term that identifies and categorizes my disability seems to be more useful for me outside of my home island, for example in Hawai‘i and in academic circles. In Chuuk, where I have spent most of my life during my disability, the terms, even in their local translations, bear little meaning for me.

I returned to Xavier High School (XHS) in Chuuk after a year in Hawai‘i. The director of the school at that time, Father Francis Hezel, insisted I try to go back to school in Chuuk. He met with my parents and asked if I could return to XHS. Although my parents agreed with the priest that I should return to school, they silently disagreed with him. But out of respect for him, they did so quietly. They wanted me to return home, back to my island, and live out the rest of my life, crippled and house-ridden. That was the cultural norm and practice for persons with disability before and, still in many cases, since I arrived in 1982. Persons with disability are considered sick.

Xavier was, and is still, a Jesuit boarding school for boys, but recently started admitting girls as day students. It sits off by itself on a hill on the northern end of the island of Weno. Its isolation suited me well because it kept me out of full view of the public. Except for one summer, I lived almost the whole three years at the school, which was about an hour away from downtown. Once in a while I would spend hours driving around downtown, but I hardly ever got out of the car or spent time with friends and relatives living away from the school. That lack of public exposure helped my parents to accept the priest’s request to allow me to return to school.

The compromise I struck with my parents was I would have a relative or two stay with me at the school as my attendants. The school designed a support system for me when I returned to Xavier. The director of the school invited two of my uncles to come and live with me in one of the faculty units. The school also arranged to keep them occupied and employed when I did not

need their help. They were given jobs in the Maintenance Department. To assist my uncles, a number of student volunteers helped with my daily routines.

We started with a group of four or five friends, who were mostly my classmates. These guys were willing to handle my personal care needs, such as helping me in the shower and using the toilet, getting dressed, and other hygienic tasks. Other students volunteered to push me around to classes, the cafeteria, study sessions, and church. There were layers, or levels of help, available to anyone who wanted to take part in my care.

Eventually, I would come to rely more and more on the student volunteers. By my senior year, I depended solely on the support of the student help. At Xavier, graduating classes are small, and students tend to be very close with each other. Lifetime friendships are established in these tight-knit small classes so, for me, the support group we created at the school still exists today.

Four months before the end of my senior year, I visited Guam and the University of Guam (UOG). A number of my friends and relatives were there. So I started making plans to go to UOG. Again I had to deal with my parents. Luckily for me, the same uncles who stayed with me for a while at XHS now attended UOG. Four of my high school friends also were at UOG, so they helped form the core of my support group there. My parents reluctantly allowed me to go to the university in Guam.

The transition to Guam and UOG was more difficult than I expected. The challenge was far greater than I faced at XHS. First, unlike XHS where I was asked to go back to school and some system was set up for me, UOG was not ready for a young kid in a wheelchair from Chuuk who wanted to be a fulltime boarding student.

The university did not have any system set up to deal with a student with disabilities who wanted to live in the dorm. There was no help provided for assistance. The staff and management of the housing department were not at all familiar with my needs, much less the laws that applied to them. As a result, they became not only passively unhelpful, but they actively put barriers in the way of being helpful. For example, they would not allow students who lived off campus to come in at night to help me until I took up the issue with the president of the university.

For the first two years, I received no educational or instructional support services for students with disabilities. It was especially difficult for me because I could afford only a manual wheelchair. Sometimes I would be stuck in places and not make it to class. There was no functional system to offer any support. One professor refused to move his class from the second floor until the Vice President of Instruction intervened two weeks after the semester had begun.

I had to set up my own system, or network, of help. I started training students and non-students to be attendants. Since I could not pay everyone who helped me, I had to rely on a group of volunteers of friends and relatives. I managed to pay for room and board for one live-in attendant and relied heavily on this volunteer group. I approached and recruited friends who were comfortable doing different things for me: pushing me around campus, transferring me in and out of cars, and driving me around. They helped me with my daily routines: showering, dressing, and cooking. They spent the nights as my roommate and turned me in bed to prevent pressure sores.

Interestingly enough, we considered at one point hiring a nurse or an aide, but quickly ruled out the idea. I was not comfortable having strangers handling my care. However, I became close with a nurse friend whom I allowed to help in my daily care. The circle of friend helpers I created in Guam was similar to the one I had at XHS. My friends from XHS with me at UOG continued to help me and helped train others who were willing to help.

During my junior and senior years the Student Support Services opened at UOG. There I got some instructional support, but more importantly, I found a lifetime ally and fellow advocate, the director of the program, Yoichi Rengiil, who would help me land my first professional job as a radio announcer.

Beside Mr. Rengiil, I also won the support of the Special Education department professors who advocated for me. These professors had to remind the UOG officials of the applicable federal laws we knew the university was violating. We also recruited the Dean of Students. Along with Mr. Rengiil's help we were able to bring Jane Jarrows, disability advocate, on campus to meet with university officials. One of the UOG officials we targeted was Dr. Roy Suda, the Vice President of Instruction. To show my challenges of being wheeled around campus, we asked him to push me around one morning. We had to give up the experiment after my first two classes because we were concerned about his health. Then he realized what we had to go through everyday. Not only did that create awareness, it gave us a breakthrough with the officials.

When I left UOG in 1992, only one building had an elevator, and there were hardly any decent ramps. I visited the same school in 1998, and there were three or four new buildings with elevators and ramps in all buildings, with proper regulation design.

Wanting to Work

Besides getting an education, and because of getting an education, I naturally wanted to work. Often, many persons with disability opt to stay out of the work force because of the many challenges they encounter. I believe it important to find work that I not only enjoy doing but find rewarding. Nothing is more demeaning to persons with disability than being forced into a situation where the only type of work available to them does not provide adequately for their needs and yields little to no satisfaction.

First "Job"

I remember the first job I had. I was "hired" by the maintenance department of the high school to help out in the shop. I specifically asked to work in the shop because I loved being around machinery. The shop had an electrical saw workers used to cut wood. That is what I wanted to do. However, the head of the maintenance department, a Jesuit brother, would not allow me near the machine in fear I might injure myself. So, for a whole summer, I was paid 25 cents an hour to sort old rusty screws and bolts. I was not even sure if anybody actually used those old items, but the maintenance department was supposed to keep me busy and "employed." I hated that job so much I missed enough days in my first month of work that I was eventually "not expected to show up."

My First Paycheck

When I was a Freshman at the University of Guam, I received my first paycheck as a college work-study student. It took a good number of days searching university offices for anyone to employ me under the university work-study program. I managed to convince an old friend in the Education division to hire me as an operator on the university distant-education

radio network. One of the most satisfying moments of my life was when I received my first paycheck. I was so happy I sent it home to my grandmother.

Meaningful Work

Working at the radio network was getting less enjoyable over time because the supervisor began to treat me unfairly. She would write me sealed notes complaining about many personal issues, which I felt too uncomfortable to counter. So I grew more and more resentful towards my work and the place. However, during lunch hours I managed to attach myself to a group of fellow communication majors who were trying to revive an old radio station at the university. There I found one of my passions in life, radio announcing. I thoroughly enjoyed being on the air.

However, this situation presented a predicament that often confronts everyone. Many times, because of a lack of choices and options, we find ourselves working in jobs we cannot stand, or doing for free the work we love to do. I spent three years doing volunteer hours on the school radio before I was able to land a paid radio job on one of Guam's radio stations.

I applied with several stations and encountered discrimination that would break my interest for long periods of time. Then I would regroup and search for jobs again with other radio stations. One general manager told me straightforward he would not hire me because he thought I would not be able to use the bathroom facility in the building. Another did not know I was in a wheelchair and was excited after hearing my demo tape. He called the school radio station and asked to see me. However when I showed up in his office, he uncomfortably informed me he had already offered the job to another applicant. The truth was the job was filled two weeks later. Finally, my friend Yoichi Rengiil, who knew one of the general managers, helped me land my first professional job. I was given a slot for a graveyard shift. The General Manager even hired a helper to work with me. I was the happiest Disc Jockey on the radio from midnight to six o'clock in the morning, with a strong following to boot. The General Manager promoted me to other shifts six months later.

Choice of Work and Career

After I realized there was no money in radio, I went back to school. I needed to leave Guam because I wanted to experience a new place. I arrived in Hawai'i in 1992 and enrolled at the University of Hawai'i at Mānoa (UH-M). I have always wanted to be a history teacher, so I picked UH-M because of the excellent mix of Hawai'i's racial histories. I started rebuilding my network of support. I convinced the UH-M housing office to allow a cousin to room with me in the dorms even if he was not a student at the university. Other members of my support group were classmates and friends from school and the community. I found help also at the KOKUA program (UH-M's Disabled Students Services Office), which helps students with special needs. I earned my graduate degrees from the UH-M and went back home in 1997 to teach history and culture studies.

I was hired to teach history at the College of Micronesia-FSM Chuuk Campus. In 2002, I became director of the Chuuk Campus. I enjoy working at the College's Chuuk Campus. I am doing what I enjoy doing in the place I love, teaching people I genuinely love. They are my people. My family, friends, and students are part of my support group.

Reflections

I want to offer some reflections on the discussions above. First of all, at the beginning of every turn of events and experience for me there is always *uncertainty*. If there is a concept that dominates my life as a person with disability, it is the series of uncertainties that surrounds every major turn in my life. As a matter of fact, a major part of my “rehabilitation” process, especially the more meaningful ones, has to do with undoing these uncertain blocks by familiarizing myself with their challenges and devising ways to overcome them.

Most of this rehabbing was done after I left the Rehabilitation Hospital. One common issue of all uncertainties is that they are not common; therefore, we have little prior knowledge of how to deal with them. We need to familiarize ourselves with the challenges of disability.⁵ To do that, people with disabilities need to be visible. We have to be “out there” in the mix of life stating what our needs are and fighting for them. There is no institutionalized rehab technique for uncertainty; it can only be overcome with persistence and visibility.

Secondly, it is very important to build a support network. Call it a circle of friends, because that is exactly what it entails. Over time, keep casting that network wider and wider. You will need the help of everyone, even those with whom you do not see eye-to-eye on other issues. I have learned the best support systems are the ones that are least regulated and least official. In other words, a system of help that is mostly voluntary. People are effective if they help out at the level and form in which they are comfortable. Disabled persons need the helping hands and healing nature of familiar/familial bodies to help smooth the rough edges of uncertainties in life.

With the first and the second, what you are doing is called advocacy. We need to keep the issues fresh as much as possible. Awareness is achieved and maintained when issues are actively discussed—in other words, maintaining active public discourse.

Like I stated at the beginning, the problems of transition are enormous in a place like Chuuk where general economic and cultural challenges are pervasive. The poor condition of education affects all children. In Chuuk, successful transition (by all students) through all the levels of education, from primary to secondary to post-secondary, is a feat accomplished by only a handful. Since a western education was introduced in Chuuk after World War II in the 1950s, only a handful of Chuukese have earned graduate degrees. Only two have earned Ph.D. degrees.

That poor education system thus presents added challenges to children with special needs. Furthermore, their right to exist and participate in those limited systems is not secured. Culturally, they are labeled as sick, and public education is not considered the appropriate place for them. Until recently, no law protected their rights to full education. But even now that we have that law, it is not well enforced.

So, now you understand what I meant when I said to show the number of students with disability from Chuuk who have managed to transition from high school to college, you would need just one finger.

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¹ The concept of familial and familiar spaces as healing vessels is a concept borrowed from fellow Micronesian historian Vicente Diaz. This was part of his presentation at the Pacific History Association conference in Hilo, Hawai‘i 1996. Subsequent personal communications through many years helped me with this concept. I have also used this concept in another paper, “Chuukese travellers and the idea of horizons.”

² The U.S. negotiated three separate Compacts with ROP, RMI and FSM. Although these Compacts exist in in perpetuity, U.S. funding assistance expired in the first fifteen years. For RMI and FSM, the funds ended in 2003. Those funding provisions have been renegotiated in what is now called the Amended Compact.

³ The Northern Marianas elected to become a Commonwealth of the United States in 1975.

⁴ Although the report focused primarily on primary and secondary education, those of us who work at the post-secondary level are not without our share of the problem.

⁵ I often say it is better to be stared at than be ignored. I would rather people stare at me so they could see me and see what I need rather than ignore me and my needs.