

**DISABILITY AND ADULTHOOD IN, MEXICO: AN ETHNOGRAPHIC CASE STUDY****Michael Skivington***University of Wisconsin Oshkosh*

*This study sought to better understand the cultural meaning of adulthood and disability in a large city in central Mexico. Using an ethnographic case study research design that included interviews and observations, this study addressed the research question: What is the cultural meaning and accompanying challenges of becoming an adult with disability in Cuernavaca, Morelos, Mexico? Results indicate that the adult life of a person with a disability is difficult. Corruption, societal rejection, and inadequate school and social services are challenges this population faces. Analyses also revealed that Wolfensberger's (1972) original depiction of the social roles people with disabilities play in society was still accurate in today's Mexico. Research findings and implications for future study are also discussed.*

The United Nations Education, Scientific and Cultural Organization (UNESCO) initiatives of past few decades reflect a growing worldwide concern for the quality of life for people with disabilities. A review of the policy, practice and service documents available through UNESCO detail concerns about access to education and other services for children and adults with disabilities. For example, in a 1993 paper prepared for UNESCO, Hegarty described a variety of concerns regarding the educational needs of children with disabilities. Transition to adulthood was included within these needs as Hegarty specifically pointed to the need to help children with disabilities *become economically active and lead lives that are as full and independent as possible* (Hegarty, 1993, p. 24). Hegarty further described the need for action in *employment, useful work and valued activity; personal autonomy; community involvement, social and leisure activity; and domestic living* (p.51).

Building on the work of Hegarty and others, UNESCO convened the World Conference on Special Needs Education: Access and Quality in Salamanca, Spain in June of 1994. The World Conference, attended by over 300 participants, representing 92 governments, and 25 international organizations, focused on improving the lives of people with disabilities through inclusive education, Education for All, and preparing students with disabilities for their adult lives. The product of this conference, *The Salamanca Statement and Framework for Action on Special Needs Education* (UNESCO, 1994), represented a worldwide consensus regarding the then current situation for special needs education and gave direction for future advances in a variety of special needs education related areas, including transition.

Subsequent UNESCO documents, including the *Convention of the Rights of Persons with Disabilities* (Office of the United National High Commissioner for Human Rights, 1996- 2007) promotes learning and life skills for young people and adults with disabilities. Furthermore, they specifically promote the right to live independently, be included in their communities, and have an education that will allow them to participate in their societies, work and employment, among other rights. Thus, world-wide concerns continue to include the preparation of all young adults for meaningful adult lives.

Little is known about the state of services for and the lives of students and adults with disabilities in Mexico. Mexican responses to the 1993/1994 UNESCO surveys indicated an emerging concern for special education and the lives of people with disabilities, but described very little concrete action taken to improve special education services. The former Mexican president (2000-2006), Vicente Fox, and his administration claimed that special education schools and students would receive renewed priority when he took office in 2000. However, in a recent study of the state of special education services in Mexico,

only forty-two percent of the country has an area school for students with disabilities (Ortiz as cited in Aviles, 2006). Furthermore, only fifty-three out of a total of four hundred and fifty-seven teacher training schools (*Normales*) provide licenses in special education. As a result, it should come as no surprise that out of over one million teachers in Mexico, only forty five thousand are special educators. In addition of the paucity of qualified special educators in Mexico, Mexican funding of special education schools is abysmal, providing less than twenty thousand pesos annually (approximately two thousand US dollars) to each special education school. This fact was specifically noted by the Director of Educational Innovation for the Secretary of Public Education (*Secretaria de Educacion Publica - SEP*), in an official statement provided by the government, when she stated, *we gave them nothing*. (p.1). Clearly, special education in Mexico is not a priority for the Mexican government.

While there continues to be a need for more published research studies about the current state of special education in today's Mexico, in general, even less has been published regarding expectations for adults with disabilities and transition from school to adult life for youth with disabilities in Mexico. However, Mexico's response to the UNESCO survey indicates an interest in more integration of people with disabilities into mainstream society. Mexicans, like people from other countries, are becoming aware that more needs to be done to provide people with disabilities with educational and other life opportunities so they can to live, work, and participate more fully in their respective communities.

The UNESCO work and many of the current efforts identified in Mexico, while important and needed, reflect a medical model of disability. In this model, experts identify and label difference or impairment as disability, locating disability within the person, constructing disability as a distinct, knowable entity. Functional limitations or impairments are the primary causes of the problems individuals' with disabilities encounter. As such, intervention, instruction, etc. provided by experts and targeting individuals with disabilities are the mechanisms used to address the problems caused by the functional limitations (Crow, 1996). However, the actions recommended by UNESCO also appear to reflect an understanding of the social nature of disability in which disability is seen as occurring because of interactions between environments and individuals (Crow, 1996). Because disability is seen as a constructed concept that exists in the intersection of individuals and environments, responses to problems focus on the interactions and not the individual, and include addressing environmental, attitudinal, and policy barriers individuals encounter (Devlieger, Rusch, & Pfeiffer, 2003). Many of the recommendations that have come out of the UNESCO, directed specifically at changing environmental and policy barriers, reflect the awareness of the social nature of disability.

This article reports on part of the results of a study designed to begin to understand the lives of people with disabilities in Mexico, particularly adolescents and young adults, and their preparation for adult roles in Cuernavaca, Morelos, Mexico. As a part of this study, I asked: What is the cultural meaning and accompanying challenges of becoming an adult with disability in Cuernavaca, Morelos, México?

The work conducted in this study reflects my view that disability is a social construction in which cultural beliefs, political factors, economic forces, and local values combine to give meaning to who is identified as *disabled* and what the ensuing personal, political and economic consequences are for individuals identified with disability labels. In fact, I concur with the call by Disability Studies in Education (DSE) scholars to interrogate and reject the all too often taken for granted deficit model lens of special education (Ferri, 2008). In the current study, I used special education not as an endorsement but as an entry point into the lives of people and families with disabilities. In fact, the very nature of the *two-school* system (for lack of a better phrase) is further evidence of marginalization on behalf of the Mexican government. Further, I support the central tenets and approaches to DSE theory. Among these is the contextualization of disability within political and social spheres, and contrasting medical, scientific and psychological understandings with social and experiential understandings of disability (Connor, Gabel, Gallagher, & Morton, 2008). Consequently, understanding how *disability* and its intersection with *adulthood* are constructed and enacted in Mexico is essential to understanding how families and schools prepare children and adolescents with disability labels to live their lives as adults. In choosing my main theoretical, I reviewed DSE theory and Bourdieu's (1986) understanding of Social Capital theory that uses social power and control to reproduce inequity. I settled on the classic work of Wolfensberger (1972) whose work on marginalization and *othering* gave us sufficient support on which to begin to build as more becomes known about the cultural meaning of disabilities in México. Therefore, after I discuss the method employed for this study in the next section, I will discuss the research findings using the historical roles of people with disabilities vis-à-vis Wolfensberger's theoretical viewpoint.

**Method**

I employed an ethnographic embedded single case design (Merriam, 1998; Yin, 2003) to emphasize the perspective of the research participants (Yin, 2003; Glesne, 1999; Merriam, 1998; Creswell, 1998), giving voice to the multiple realities that exist in their environments and within their cultures. In this study, I heard from three cultural groups, a Mexican special education school-community, professionals from a vocational special education school, Mexican families of students with disabilities (both attending the study school as well as schools in other parts of the city), and members of the Mexican communities in which people with disabilities live.

*Setting*

Cuernavaca is located in south central Mexico, and is approximately one hour and fifteen minutes by bus from the Mexico City airport. It is a major regional urban city of around one million people. Cuernavaca, the capital city of the state of Morelos, has characteristics similar to Mexico City (given its close proximity).

The state of Morelos has 18 schools (centers) for children with disabilities. These schools serve a disabled population that is estimated by official governmental statistics to be at 1.9% of the total population of the State of Morelos (INEGI, 2000).

The primary study school, one of the 18 special schools, is located on the south end of the city and is in a poor area surrounded by large weekend homes for wealthy people from Mexico City (*Capitalinos*). The school is set on a large parcel of land at the bottom of a steep hill. There is one gated entrance into the school. The gate remains closed and locked during the school day for the security of the students. Parents and other visitors must ring a doorbell and wait to be let in electronically. That entrance has steps and an accessible ramp. Unfortunately, the ramp is at such a steep pitch that its nickname is the *assassin* (*la asesina*).

The school serves students with all types of disabilities from pre-school through adulthood, enrolling over 200 students with disabilities such as autism, Down syndrome, and intellectual disabilities (mild to severe), and physical disabilities. The teachers represent different professional backgrounds with four of 13 teachers being licensed in special education. Of the nine remaining teachers, five were trained in human communication, three were trained in basic elementary education, and one was certified as an English teacher. The years of experience ranged from one year to more than fifteen years.

**Participants**

The initial participants for this study were chosen using a purposive selection procedure (Merriam, 1998). Because the study was about preparation of youth with disabilities for adult roles, the purposive sample started with individuals who are associated with a special education school. The primary study school was selected as a result of the activities of a pilot study. To gain entry to potential schools, during the pilot study I made contact with a director of a large private school in Cuernavaca. The study school was identified by the director of that school as a school whose faculty and families might be interested in working with me. This school is known as a Center of Multiple Attention (CAM) and was further identified as a Basic School, CAM Basic School (*CAM Basica*). The families, teachers and an administrator from this school served as the core set of participants. However, participants were also drawn from another special education school that had a direct relationship with the primary study school. This public special education school had a vocational training focus. As such, it was identified as a CAM Labor School (*CAM Laboral*). Participation increased as the study continued because of the snowball effect (Ream, 2003), using referral from key informants, and direct and indirect study participants, and included parents and other family members, school-related professionals, and community members.

*Parents and other family members.* Participating parents and other family members of students with disabilities were primarily from the study school; however, some of the community interviews were also with parents and family members of children and adults with disabilities who were not served at the study school. Of the twelve parent interviews at the study school, all were mothers of the children with disabilities, with the exception of one person who was a grandmother who had assumed the responsibility of raising her grandchild. By virtue of attendance at the public school, all families who were interviewed were poor or in some cases very poor people. The earnings of these families were at or below the average 2006 daily salary of a worker in the State of Morelos (including Cuernavaca) of 195.2 pesos per day, roughly less than 20 US dollars per day (INEGI, 2005). The educational levels of the

mothers ranged from a few years of primary education to college graduates. Most families lived in the area immediately surrounding the school and took public transportation to and from the school with one-way trips ranging from a few minutes to over an hour.

Three family interviews were conducted with community members, two interviews with mothers of children with disabilities and one with two adult siblings. The mothers were at a higher level of socio-economic status than the mothers at the study school and were able to provide private education to their children with disabilities. Furthermore, the mothers were also better educated. One had an advanced degree, and had stable home lives and cooperative spouses, even though they identified difficulties presented by having a family member with a disability. The community family interview with the older siblings was different because their sibling with a disability was nearly fifty years old; consequently, this interview provided a unique historical perspective with regard to the treatment and education of people with disabilities in Mexico.

*School-related professionals.* Nine professionals from the primary study school were interviewed. The directors of the CAM Basica and CAM Laboral schools were interviewed. Both directors have many decades of experience in the field of special education in the State of Morelos and both are trained in psychology. The director's interview from the CAM Laboral served as the only faculty interview from that site. Each member of what the CAM Basica school called the *support team (el equipo de apoyo)* was also interviewed individually. The support team at this school consisted of a medical doctor, school psychologist, speech and language therapist, and a social worker. The years of experience for this team ranged from approximately two years to nearly twenty years of experience with students with disabilities. Also interviewed were two classroom teachers and the integration specialist at the study school.

*Community members.* Ten interviews were completed with members of the larger Cuernavaca community. The backgrounds of the interviewees include two veterinarians; two regular education teachers, one of whom worked in a private school and the other in a public school; a business leader; a director of human resources at a hotel/restaurant; the director of a private non-profit group; the founder and director of a private educational clinic; and a taxi driver.

#### *Instrumentation*

The interview protocol for this study evolved from the protocol used in the pilot study conducted in Mexico in the summer of 2004. The pilot protocol, consisting of open-ended questions, was geared towards probing parents', teachers', and administrators' understanding of the special education and transition processes. For this study, the pilot interview protocol was altered to reflect additional or more specific issues that emerged in the pilot interviews and focused more specifically on transition and adult life. Questions in this protocol addressed attitudes of Mexicans about people with disabilities, overall employment opportunities for Mexicans with disabilities, the issues related to their employment, expectations for adults with disabilities in Mexico, and activities or programs related to preparing students with disabilities for their adult roles. The protocol was further modified during the study to reflect emerging trends in the data, allowing for deeper exploration of those trends that focused on school, family and support networks available to adults with disabilities. Questions also included those related to respondent demographics (e.g., education; relationship to people with disabilities, if appropriate; job/role, as appropriate).

#### *Data Collection and Observation*

Prior to beginning participant identification and data collection, I obtained approval from the human subjects review board. To adequately investigate the adult life for persons with disabilities and their preparation for adult life in the selected community, I conducted an in-depth study using extended time in the field. More specifically, I spent nine months in daily, direct participant-observation of all aspects of the special education school and life in the surrounding community of Cuernavaca, Mexico. Participant-observation and interviewing (Glesne, 1999) are the primary forms of data collection for this study.

*Observations.* Observation roles fall on a continuum of interaction between the researcher and the research participants (Glesne, 1999). In this study, the researcher's roles fluctuated from being participant to participant-observer, as allowed in each observation situation. Observations included lunchtime when students and staff were eating and the outside basketball court during the lunch break. The researcher often ate lunch with the other staff members on the outside court and discussed topics of

the day or solicited specific information about the school. Observations also included several classrooms, which included noting the physical environment and the number of students, interactions among the teachers and students, and curricular choices and instructional methods. Other informal observations occurred as I moved about the community in my daily life.

*Interviews.* Informal, semi-structured interviews were conducted of parents, teachers, administrators and local community members connected to one public special education school. Thirty-four interviews, approximately 30 minutes to 1 1/2 hours long, were conducted in Spanish. Each interview began with the reiteration that participation was voluntary, a review of the purpose of the study, and an icebreaker (e.g., tell me about your family). Then, an initial global question about transition was posed, for example, *What will your child do when he or she leaves this school?* Individual questions on the interview protocol were determined by the content of the interviewee's response.

Data collection continued until such time as the information being mined no longer added new angles to the overall picture and the analytic categories had been firmly established (Miller, 1995). Although data analysis is ongoing, the final stages of data analysis began once I left the field.

#### *Data Analysis*

Data analysis occurred simultaneously with the data collection procedures in the field (Glesne, 1999; Fetterman, 1989). Using the constant comparative method and coding, categories were constructed as data became available (Merriam, 1998). Coding included using three interrelated levels (open coding, axial coding, and selective coding) and assisted in identifying and describing the patterns and meanings from the data (Charmaz, 2000).

During open coding I broke the data into concepts and categories, and identifying the nature of the concepts and the relationships the concepts had with one another. As each interview transcript was read I gave labels to the concepts that were emerging. As concepts began to cluster into groups, I moved on to the second level of coding, axial coding (Strauss & Corbin, 1998), re-assembling the coded data into groups of interrelated labels or concepts (categories), identifying connections between categories and any sub-categories. With selective coding, I organized the categories into a large, integrated scheme by identifying the central or core theme (Charmaz, 2000): the intersection between adulthood and disability in Cuernavaca, Mexico. Within the intersection of adulthood and disability in Cuernavaca, Mexico, I included the concept of adulthood in general, the concept of adulthood with a disability, and the community response to adults with disabilities.

#### *Trustworthiness, Accuracy and Credibility*

Thorough and careful analysis of ethnographic data, the use of triangulation, pattern development, and key events can lead to greater accuracy, credibility, and trustworthiness in analysis of the data from the field (Denzin & Lincoln, 2005; Toma, 2006). In this study, I used prolonged field engagement, theoretical sampling, persistent observation, triangulation [*the combination of multiple methodological practices, empirical materials, perspectives and observers* (Denzin & Lincoln, 2005, p. 5)], and the identification of key events to enhance the accuracy and truthfulness of the (Denzin & Lincoln, 2005; Janesick, 1994; Morse, 1994).

In addition to the above activities, at the end of formal data collection, I conducted debriefing meetings. While targeted mostly at data analysis, these meetings yielded additional data that improved my understanding of the phenomena under study. While still in Mexico, the author, a fellow American citizen, and a bilingual secretary conducted two debriefing meetings after all of the interviews and transcripts were completed. Having been born in Cuernavaca, the secretary who transcribed the interview recordings was the natural choice to debrief with as I sought to increase my understanding of and coherence in the translations (both literal and cultural). Transcripts from each of the constituent groups' interviews (parents, schools, and community members) were read for the first meeting. The second meeting focused on the transcripts from family members only. During each meeting, we reflected on the subject matter and, especially on the part of the native born Mexican secretary, offered general impressions of the treatment and education of people with disabilities in Cuernavaca, Mexico. Finally, although the goal of this ethnographic case study was to provide a thick description of transition to adult life for students with disabilities in one Mexican school-community and adult life for persons with disabilities in the surrounding community, it tells the story of this community only. As such, I do not claim to provide readily transferable information.

*Limitations*

Careful consideration was given during the overall design of this study in an attempt to address possible limitations. However, it was impossible to anticipate or control all aspects of this study. Hence, there are some limitations.

Geography is a limitation in this study. The study was conducted in a large urban city named Cuernavaca in the central Mexican state of Morelos. As such, while I have every reason to believe that many of these results would be applicable in other parts of Mexico, I would caution the reader to be discriminating in applying the results in other regions and with other populations.

Another limitation is the researcher as an instrument of data collection. The researcher was responsible for conducting interviews, interpreting data, and making conclusions. Although many steps were taken to ensure the validity of the results (e.g., debriefings with native Mexican Spanish speakers, multiple data sources), my status as a white US citizen should be considered a limitation of this study.

**Results and Discussion**

Contemporary life in Cuernavaca, Mexico, is characterized by wide-ranging experiences involving foreigners (*extranjeros*) who come to study at the many foreign language schools. Citizens of the state of Morelos, where Cuernavaca is located, enjoy many of the cutting edge technologies found in other parts of the world. Cell phones can be heard ringing and most middle class families have either cable or satellite television, with an increasing amount of homes having high-speed internet, at their disposal. Unfortunately, not all members of the community enjoy this lifestyle. With this backdrop of modernity and vibrant rhythms of progress and technology one needs only to look slightly beneath the surface to see another, very different side of Cuernavaca.

Daily life (*la vida cotidiana*) for many is marked by high levels of unemployment and poverty. Highly defined gender, social, and family relationships are another constant. Difficult financial and social situations are further complicated by government corruption and low levels of public funding for projects such as schools and job creation, serious issues frequently discussed by the citizenry. In short, the daily lives of most of the adults in Cuernavaca, Morelos, are consumed with survival – finding the next meal, paying the rent, and making sure they are taking care of their families' welfare. For adults with disabilities in Cuernavaca these difficulties are exacerbated exponentially in contemporary society. Understanding the challenges faced by these adults requires an understanding of the lives of adults without disabilities along with an understanding of the lives of adult with disabilities. Each of these is addressed below. In addition, we offer an explanatory framework that appears to ground the beliefs that under-gird the cultural practices and beliefs identified in this study. Finally, we conclude with implications for practice and suggestions for future research.

*Adulthood in Cuernavaca*

Participants described their conception of adulthood. They told me that adulthood in this community is marked by many roles and responsibilities; working, creating a family, helping out the family of origin, and being a contributing citizen of the United States of Mexico (*estados unidos mexicanos*). Adults are expected to seek and maintain employment or make every effort to do so. Although high levels of unemployment, suffocating corruption, and high levels of migration to the United States undermine this expectancy, the employment expectation persists.

Participants also reported that in Cuernavaca employment for adults is rarely referred to as *permanent* or *stable*. For many, this lack of permanency/stability of work is true regardless of their education or income level. The university-trained professional in Mexico can just as likely be employed as a taxi driver or bus driver than as a practicing lawyer. Meanwhile, the unskilled worker is busily searching for a job in which he can make enough money to make ends meet. These economic conditions can be further exacerbated by the firmly entrenched gender roles that still exist in Cuernavaca today that I discuss in the next section.

Male and female gender roles have changed very little over time in Mexican culture. *Normally, the man is responsible for giving the family money and the mother is one that takes care of the house and children* (Ernesto, community member). As described by Ernesto, women are in charge of the family, children, and the needs for the schools. Males are in charge of making major decisions involving the family. Those decisions include how much allowance (*Domingo*) to give the woman each week. When Conchita, a

mother with a child with disability, was asked by the researcher, why her husband and other men think the way they do she said the following:

*It's the machismo and they think we (women) are inferior. They think that whatever wrong thing that happens, it's the woman's fault.*

She went on to say with regard to having children with disabilities:

*The fathers blame the mothers and think it's our fault when a child with a disability is born.*

Gender roles are further reinforced in the corruption of the *good old boy* networks in government, which are dominated by men in positions of power and influence.

Corruption in Mexico at all levels of government is as famous as the pyramids of the sun and the moon at the site of Teotihuacan. Marches and demonstrations (*manifestaciones*) can be heard on most days in the capital city of Morelos. These protesting groups are diverse, each one asking the government to make good on promises made through formal or informal agreements. Everyone knows about the scourge of corruption, *In Mexico we have corruption; that is undeniable* (Lourdes). Yet another community informant, Consuelo, went into more specific detail about a scenario (that further complicates the issue of social reproduction of disability) in which a person in Mexico may secure employment. The dialogue begins with the researcher's question:

*Q: If you know me even though I have a disability, you would offer me a job?*

*Consuelo: If you are my friend and I like you, yes I'm going to help you. If I don't know you, no I'm not going to help you.*

They openly talk about corruption in cafes and other public places as well as in our participant interviews. Unfortunately, it appears to be very difficult to change the culture of favors, connections, and gift giving.

While there is no pressure to move out and/or begin a family at any *magical* age, Mexicans expect this to happen eventually; meaning each non-disabled man and woman in Mexico will eventually experience the passage into adulthood. However, crossing the threshold into adulthood does not necessarily equate with establishing a separate household. Adults who marry may choose to live with the parents of either spouse and sometimes continue this living arrangement after they begin having children. Cross-generational households also occur, when couples, previously lived independently, move in with grandparents. These types of living arrangements are seen as mutually beneficial. The families of origin and their offspring benefit from pooling their resources, increasing their capacity for amassing economic capital. In fact, the author knows of one case where the son (in his mid-20s) has already finished law school and is living at home to help with the family responsibilities, but he also must live with the family to create the financial basis from which to begin to build his client base.

Finally, adults in Mexican society are expected to be productive citizens. This productivity implies many things including employment and public service, which gives back to society. In fact, several participants mentioned that their professions required them, upon completion of their university degrees, to provide unpaid service to disadvantaged communities. Ironically, this expectation seemed to imply that citizens who finished their college careers were *valuable* and had something to give back to society. There was no mention of similar expectations for people who had completed their secondary or primary educational programs as their *terminal degrees*.

#### *Adulthood for Persons with Disabilities in Morelos, México*

Adulthood for people with disabilities in Cuernavaca is marked by societal rejection, low employment expectations and no independent living options. Mexicans achieve legal adulthood when they reach the age of 18. Legal adulthood in Mexico means the ability to vote and, as in the case of males, eligibility for the military draft lottery. Unfortunately, there are no advocacy or adult services, and in Cuernavaca there appears to be a pervasive belief that persons with disabilities will never be adults. Consequently, there are no systems or pressures external to the family to assure that adults with disabilities are being afforded their rights to engage society as citizens. Unless individual families push to assert and maintain the

citizenship and civil rights and responsibilities of the adult with a disability, these rights and responsibilities seem to disappear. As a result, persons with disabilities have no civil right to access or participate in community settings or services and opportunities, from employment to recreation. Employers, vendors, bus drivers, etc. may refuse to hire or interact with people with disabilities without fear of legal or social repercussions.

Beginning with their families, youth and adults with disabilities are framed within the context of myth and fear. Participants indicated that families often believe in folklore or old wives tales about people with disabilities. Reactions include denial of having a child with a disability carrying through to the belief that adults with disabilities cannot work or function without supervision. These beliefs pose limits to the possibility that the child with a disability will have the opportunities needed to reach his/her potential. In Cuernavaca, families with adolescents with disabilities have no expectations for employment, moving out, increased independence, or even finishing formal schooling. Thus, parental concern about independence relates more to whether or not a child with a disability will ever reach the level of *personal independence* that will make their care less onerous. As a community respondent remarked:

*Normally, the mother is responsible for the care of the child with a disability or older siblings take care of the child with problems. But there is no sense that they will create an independent child. Children (with disabilities) are very dependent on some adult and the family (they) have to work (together). Sometimes, the older siblings have to work with the mother and distribute the time amongst themselves.*

In an attempt to maintain stability in family functioning, Mexican families often seek to keep the adult with a disability in the schooling experience as long as possible. For this reason respondents discussed many cases of adults with disabilities well into age 20, 30, and 40 still in *school* settings. This was not seen as problematic. Rather, in this culture, the gravest situation would be losing the only apparent adult service *lifeline* available to adults with disabilities in this part of Mexico.

Societal rejection was real and obvious. It took many forms and included social rejection on public busses or not being allowed to stay in a movie until its conclusion. Ana described riding the bus (*la ruta*) with her child with a disability. She reported that she and her child were first given strange looks by the other passengers. Then, they would not move over to allow her to sit down even though there was plenty of room. She went on to say:

*Then I would just take him to the other side (of the bus) to avoid having to argue with people. Sometimes, kids (on the bus) attack him with their words or hit him.*

José, a professional in the field of disabilities in Cuernavaca, described similar incidents. The first was when José took a student to the grocery store. At the store they encountered a woman who was so afraid of the child with disability that said she thought something might happen to her. He went on to report:

*We took him (the child with a disability) to the supermarket and a woman was there and she was upset and I had to say to the lady what was happening and that he was a special child and need more time and space to attend to him. The woman got very mad.*

Rejection is based, in part, on the fact that adults with disabilities are seen as a burden to society. According to informants, in Cuernavaca (and quite probably in Mexico in general), if a person isn't viewed as contributing to society, he or she is viewed as subtracting from the society. Adults with disabilities are seen as taking the most away from society because of the perception that they can never be *contributing* members of the society.

Being a non-contributing member is the result of being *unable* to fill adult roles associated with gender-based expectations, especially in the area of employment. Low employment expectations originate from the societal belief that adults (or students) with disabilities are not capable of work. Even if adults with disabilities had proper vocational training, there are simply no employment options in the community – except for a few, rare exceptions. As Susana (a community member) stated:

*Mexico is a very poor country and the employment opportunities are directed to persons without disabilities. Because to employ a person with a disability means that they (the factory)*

*have to dedicate time to their training.....but in reality the companies are trying to survive because of the economic problems of the country.*

The above descriptions for adults with disabilities in Cuernavaca seem to suggest that there is little being attempted to try to ameliorate these difficult issues. This impression would be inaccurate; there are many advocates working on behalf of adults with disabilities in Cuernavaca. However, there are also many obstacles in the way of the self-actualization of adults with disabilities in Mexico, and most of these are outside of the immediate control of many of the constituent groups working to improve the lives of people with disabilities (e.g., lack of publicly funded programs and services). Corruption in Cuernavaca siphons off the resources needed for adults with disabilities. This funding is redirected towards other projects, or the funds simply go missing (understood by the average citizen as equating with *stolen*). Consequently, efforts to improve the lives of people with disabilities, beyond basic education, are dependent on fund raising efforts by private individuals and groups.

*A Framework for Understanding Adulthood for People with Disabilities in Cuernavaca, Morelos*

The lives of adults with disabilities in Cuernavaca can be better understood if one considers the relative roles they play in that culture. In his seminal book, *Normalization*, Wolfensberger (1972) described eight historical roles for or views of people with disabilities: subhuman organism, menace, unspeakable object of dread, object of pity, holy innocent, diseased organism, object of ridicule, eternal child. These historic roles for or views of people with disabilities seem to have particular relevance when attempting to understand the position of adults with disabilities in Cuernavaca, Mexico. Thus, what may look like dated descriptors and subsequent recommendations for practice are still relevant today in Mexico and beyond.

Three of these roles are particularly relevant to the status of adults with disabilities in Cuernavaca (i.e., eternal child, holy innocent, and object of pity). Consequently, in this section they are addressed individually. A discussion of the remaining roles and a section summary conclude this section.

*Eternal child.* In Cuernavaca, most adult children will leave and begin to build a life separate from their family of origin when they are in their mid 20s or mid 30s, and/or they will marry. Children with disabilities are never expected to leave their family of origin and forge an independent life of their own, *there is no sense that they will create an independent child* (Anita). Regardless of their level of disability, and despite the many independence skills most of them acquire, they are never viewed as wholly capable of meeting all of their needs or taking care of typical adult responsibilities. When the parents of adults with disabilities die or become too ill to care for their child with a disability, care for that child shifts to their adult siblings. As Anita stated, *Normally, the mother is responsible for the care of the child with a disability or older siblings take care of the child with problems*. Thus, they are viewed as always being in need of care taking. Furthermore, family members provide young adults and adults with disabilities with extra protection. Participants indicated that they fear that disabled adults will be taken advantage of, made fun of, or otherwise abused, so they keep these *defenseless* individual hidden away from the rest of the world, not allowing them to take the risks normally associated with adulthood (Nirje, 1972). As a result, the role of *child* is never finished for the person with a disability Mexico.

*Holy innocent.* Not only are adults with disabilities seen as eternal children, their lives are seen as representing a message from God. This attribution was commonly made by many of the residents in Cuernavaca in that they frequently referred to people with disabilities as being sent from God for a positive purpose; but, when pressed, they could not identify what that purpose was. The belief was also stated in family views, although its presence was not as prevalent as one might think in a country such as Mexico, with most of its population claiming to be Catholic. Informants who described beliefs that associated the presence of disability with an intention by God tended to be people from lower socio-economic statuses (*de bajos recursos*); families from higher socio-economic statuses were more likely to attribute disability to scientific factors rather than religious factors. Families that reported their belief in a religious connection went through various stages – initially attributing the presence of the child as a punishment (*un castigo*) but later believing that their child was sent by God as an angel or to teach them to live their lives in a more Christian-like manner (e.g., demonstrating greater compassion or patience).

In addition to needing perpetual care and protection, people with disabilities were treated differently and, at times, not held accountable for their behavior. In other words, when a person with a disability would do something socially unacceptable, the *innocence* and *childishness* associated with the disability would

be the justification. Instead of acknowledging the fact that individuals with disabilities are fallible human beings who make errors or intentionally behave in inappropriate ways, these individuals were excused from learning and adhering to the social expectations and mores applicable to their non-disabled peers. As a result, few attempts were made to improve social behaviors, and inappropriate but remediable behaviors were allowed to continue. Allowing the continuation of aberrant or unacceptable behavior highlights the deviance of some people with disabilities and confirms already established biases about the nature of disabilities. Consequences from confirming these biases can vary from pity, devaluation, and social isolation to overt action against the person resulting in victimization (e.g., via violent or fraudulent interactions) or advocating for the complete physical isolation of people with disabilities from the rest of the community (e.g., institutionalization).

*Object of pity.* Pity is so common in the State of Morelos that the motto for the state of Morelos department of special education is *accept me as I am for reasons of justice not of pity (aceptame como soy en razón de justicia y no de piedad)*. The depth of this sentiment is difficult to describe without experiencing it first hand. However, as the author was living in the community and talking with various people (taxi drivers, store attendants, waiters, etc.), he was greeted many times with statements like, *Oh, you are working with those people? Those poor things - to be born that way. Do they have schools? Oh good, well they definitely need help. I'm glad you are here to help them.* Characterizing someone as an object of pity interferes with identifying that individual's strength and potential. Assisting adults with disabilities to exercise their rights as Mexican citizens or to become employees requires educators and service providers to ensure that non-disabled people see the potential and competence of people with disabilities, not objects of pity.

*Other roles.* Some informants expressed fear or unease with people with disabilities or related stories that suggested uninformed community members were uneasy or fearful of persons with disabilities. For example, José, a professional in the field of disabilities in Cuernavaca, took a student to the grocery store. At the store they encountered a woman who was afraid of the child with disability because she thought something might happen to her. The data from this research cannot specifically identify the source of this fear or unease. However, historic roles reveal other potential sources for these feelings.

One source is the characterization of the person with a disability as an *unspeakable object of dread* because the person with a disability is seen as having been sent by God as a direct punishment for the sins of the parents or because the person is seen as a representation of dreadful entity or event, e.g., a reminder of how fragile human life is (Wolfensberger, 1972). Although often associated with pity, viewing a person as an *object of dread* typically moves that pity to fear and rejection. Ana described riding the bus (*la ruta*) with her child with a disability. She reported that she and her child were first given strange looks by the other passengers. Then, they wouldn't move over to allow her to sit down even though there was plenty of room. *I would just take him to the other side (of the bus) to avoid having to argue with people. Sometimes, kids (on the bus) attack him with their words or hit him* (Ana). Other incidents included bus drivers in Cuernavaca refusing to pick up people with disabilities or moviegoers asking to have a child with a disability removed from the theater for making some noises. These behaviors may also reflect the belief that the person with a disability is a diseased organism (and possibly contagious).

The *diseased organism* role describes people with disabilities as people who are sick and who must be cured if they are to move beyond their sickness. At the beginning of this study's fieldwork, it surprised me how frequently people would refer to people with disabilities as being sick (*enfermo*). This way of describing people with disabilities was so common in the Cuernavacan culture that after spending significant time in the field, I began to take less note of its mention. The other way people would assign the *sick* label to people with disabilities would be when parents compared other children to their child with a disability. In these cases, parents would describe children without a disability as being born healthy (*sano*). Although associating illness or disease with the individual with a disability was not done in a pejorative manner, such associations affected services and outcome expectations for these individuals. If the child with a disability could never be cured, then that child would always continue in his or her diseased status and would need continuing care and protection. Furthermore, if the individual with a disability was seen as diseased, it is possible that the disease could be communicated to those who come into contact with the diseased person. Thus, the disease characterization may inspire rejection and fear, although these feelings may be more benign than if the individual with a disability is seen as a *menace*.

*Summary.* Many Mexicans, living in this region of central México, have not reached even a minimal level of understanding of the causes or affects of disability, or the potential of people with disabilities. Consequently, they have not begun to accept people with disabilities. This lack of understanding emerged in interview after interview; with respondents indicating that they thought people with disabilities are treated poorly because most people don't understand them (*falta de información*). They also said that because the general population doesn't understand people with disabilities, people generally feared individuals with disabilities.

Because of the fear, rejection, and erroneous beliefs inspired by the presence of disability, persons with disabilities are cast into powerless positions. Furthermore, their families were forced to deal with negative biases, unfavorable characterizations, and real, and imagined, threats to the emotional and physical safety of their loved ones with disabilities. These affects were felt across socio-economic and educational levels.

#### *Implications for Practice*

People with disabilities in the region of México reported in this investigation are viewed, mostly as eternal children. This belief is reified by parental and school practices that do not include teaching independent living, social, vocational, and other survival skills to children and adolescents who have disabilities. If students with disabilities were taught the necessary skills to engage society as fully included adults, having all of the rights and responsibilities of any adult in México, Cuernavacans might begin to understand the capabilities and potential of people with disabilities. Furthermore, in this region, many individuals with disabilities are isolated from the rest of their communities. Without positive, productive contact, these individuals will never be able to garner the social capital needed to influence the course of their lives.

Enhancing the chances of adults with disabilities to access adult life in Mexico will require significant changes in Mexican schools, including changes to their educational philosophies, curriculum content, educational delivery methods, and settings to ensure that students with disabilities have the opportunities to acquire critical skills. For example, teaching community valued skills would help parents and community members begin to have higher expectations for the adult lives of persons with disabilities. Teaching these skills in appropriate settings, using appropriate assessment and training techniques, and providing needed adaptations and accommodations will further enhance the chances that students with disabilities will successfully acquire critical skills and be able to use and maintain them in community settings.

To implement changes, philosophical changes need to be considered by Mexican special educators and family members. Currently, children and adults with disabilities by and large live in highly restrictive, protective settings. Unfortunately, such settings prevent these individuals from ever achieving their own individual dignity, as described by Nirje (1972). If children with disabilities are to become adults, risks, in the form of *real life experiences* can and should be afforded to them to prepare them for their adult lives. Educators and parents will need the courage to try low-risk tasks at first, and then the courage to increase their tolerance for risk as the developing child with a disability increases their competence.

#### *Suggestions for Future Research*

During the course of this study, there were several issues that arose which were out of the scope (*funnel*) of this study or, because of time limitations, were unable to be explored in depth. One of these issues could shed additional light on the understanding of the topic targeted for this research: business and professionals perspective on hiring people with disabilities. Why do employers choose not to hire people with disabilities? Although this question was asked, and this study began to explain some of the biases, the results of this study are insufficient to understand employer beliefs and biases. Only one employer was available for an interview. I was fortunate to find even one employer to interview given that lack of employment opportunities for adults with disabilities in the workforce in Cuernavaca. Consequently, I can only speculate the employers worried about financial implications. I also believe that the society as a whole is not accepting of people with disabilities so it fits that employers would mirror the feelings of the overall culture, or it may be that employers have never considered adults with disabilities as potential employees. I would also like to see researchers begin to look at the social construction of disability through a Disability Studies in Education (DSE) theoretical framework. Data garnered from a DSE line of inquiry in México would be very beneficial from a political and public policy standpoint.

### Conclusions

Early in the twenty-first century Cuernavaca, Morelos is a society that is still trying to find a place for their adult citizens with disabilities. Many Cuernavacans hold stereotypical beliefs about people with disabilities grounded in superstition and ignorance. They believe that they are sick or crazy and might be contagious. The problems that arise from these erroneous beliefs are compounded by affects of corruption within the Mexican government. With blatant stealing of funds from schools to the buying and selling of teacher contracts, schools for students with disabilities struggle to keep their heads above water. High levels of unemployment may also contribute to the lack of or willingness to understand people with disabilities. With average adults in Cuernavaca working multiple jobs trying to meet the basic needs of their families, there appears to be little room for employment of people with disabilities.

Schools, families, and some members of the community are attempting to change existing conditions. They are trying bridge the gap in services that results from those services not being provided by the government. By providing their own adult services for people with disabilities, these stakeholders hope to supplement existing services. Some schools for people with disabilities offer vocational workshops (sheltered workshops) and other training to adolescents and adults in hopes that they can acquire skills that could be successfully put to use in the community in the open job market. Unfortunately, the prospects of such competitive employment remain slim to none.

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