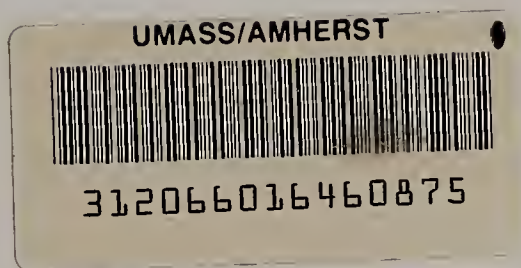


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Disability in the Cape Verdean Community: An Analysis of Health Care Services

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Synopsis

The purpose of the present study was to examine the barriers to health care services that Cape Verdean families with children with disabilities encounter and the kind of outreach methods health care providers attempt to employ. A broad range of providers working with Cape Verdean consumers were asked a wide range of questions relating to disability, health care, culture, access and the current and future needs of Cape Verdean families with people with disabilities. Providers from around New England were interviewed within either a focus group or individual interview format. This was Phase II of a two part project funded through the MDCC.

Phase I is examining the perceptions and meaning of disability to Cape Verdean families and is being funded through Northeastern University. This phase of the study is scheduled to be completed in June of 1998.

For our current project we were able to interview 31 providers from a broad range of fields including: community activists, vocational rehabilitation counselors, medical providers, home health care aides, disability activists, a representative from the Cape Verdean Consulate, academic scholars, and outreach coordinators from various community agencies. The study encompassed communities where Cape Verdean populations have been long time residents such as Boston's Roxbury and Dorchester communities, New Bedford, Brockton, Fall River, Taunton, Wareham and Hyannis.

Some of the major themes developed by the providers were: 1. Misidentification and census inadequacies: Cape Verdeans are not counted in general census and even less in disability statistics; 2. Racial/ethnic identity issues as very important to this identification; 3. Lack of knowledge and recognition of the Cape Verdean Community; 4. The complexity of language and communication: Crioulo, Portuguese - written versus oral traditions; 5. The complexities of understanding disability: disability as being "sick"; 6. Disability as Stigma; 7. Family as critical: Individual service provision versus working with families.

In general the need to expand culturally and linguistically sensitive services continues to be a major concern for many providers. Outreach into the grassroots community was also seen as vital. Becoming involved as an active community member was felt to be a critical strategy for anyone interested in developing a collaborative relationship with Cape Verdean families and people with disabilities.

Grant Report

Summary of Grant Accomplishments

The current project was able to reach a wide range of providers who are involved with the Cape Verdean community. We were able to meet and make connections with providers and advocates who are currently engaged in working with Cape Verdeans and learn about their perceptions, concerns and ideas regarding the provision of health care services as they are specifically focused to people with disabilities. The Cape Verdean community has been a well established community in New England, with many roots dating back to the 1800's. And yet, one of the major concerns from providers was how little recognition there is, either of the population here in New England or of the Republic of Cape Verde itself. A critical component of this identity is that of Cape Verdean independence which occurred in 1975. Cape Verde had previously been a colony of Portugal. The complexity regarding these issues are still reflected in some of the major issues presented by providers around racial and ethnic identity: "Who are we? Are we Cape Verdean, black, white, Portuguese, African or what?" Some of the answers depends on which generation you speak to, whether the client (and provider) are immigrants or first, second and even third generation, etc. This was also reflected in concerns around how Cape Verdeans are identified, with many Cape Verdean providers feeling that they are misidentified and not "counted" in any official census data, which has significant implications regarding how to again "count" disability in this community.

Providers expressed a general lack of appreciation or recognition of the Cape Verdean Culture. This included not understanding the language; providers either not taking the time to find out about the importance of cultural connections within the Cape Verdean family and how these are replicated in the Cape Verdean community. These "connections" were viewed quite consistently as extremely vital in being able to establish respectful, meaningful and non-imperialistic connections, that is, where outsiders are not just coming in to tell the people in the community what they should be doing. Understanding the complex history of Cape Verde itself (which has required us to learn about Cape Verdean history and its complex cultural connections and struggles both on the Islands of Cape Verde and here in the United States) was discussed as absolutely vital in order to be able to "contextualize" health care, disability and the Cape Verdean agency in seeking appropriate services. Some providers expressed the belief for example the services to the disabled are a luxury when compared to more "basic living issues, for example finding employment, food and clothing and adequate living areas for Cape Verdean families, thus, "issues within disability" taking a more second place level.

Providers consistently spoke of the important of family and community. Anyone interested in providing services to a person with disability within the Cape Verdean

community must be prepared to interact, collaborate and help the entire family. As with many other cultures, there is a strong emphasis on family and the “individual” model of service provision and empowerment goes strikingly against this “familism.” Connecting with the community was seen as a vital corollary to empowering family and working with people with disabilities. Meeting people in the community, in social clubs, Cape Verdean restaurants, churches, was discussed as being a crucial element to anyone from the system who was interested in truly establishing “collaborative relationships” and developing strategies. Strict “office” work, where the provider expects all contacts will occur, limits the authenticity of the provider and the desire to truly serve this diverse community.

Another finding was the importance of language as a cultural connection. This in particular will be an outstanding component to service provision for older and recently immigrant families and people with disabilities. Although the government language is Portuguese, the grassroots language, that spoken by families and communities is Crioulo. This has been a language of resistance against colonialism and has significant emotional and political implications. On the direct clinical level, some families will come in seeking services from providers who speak only Crioulo and this needs to be address. We were able to meet several providers who spoke Crioulo well, some who spoke a little and the rest who did not speak Crioulo.

Within the family, providers felt that the concept of “disability” was a personal, private and highly subjective matter. There was not as yet, a very strong “disability consciousness” as has been developed in mainstream disability literature. It is important to stress the need for caution in enforcing the disability culture movement that was created within a different sociocultural context. Most providers felt that people with disabilities were generally integrated within the family and made to feel like integral family members. There was however, the perception, that disability was kept within the family and not made a public issue. A common term used was that of “coetido” which translates to “poor thing.” Some felt that “disability” was not even a well defined term, for many families viewed a family member with a “disability” as having a “sickness” or being “sick,” and the need to frame issues within this label. The term “developmental disability” was even more confusing. Some providers identified disability with accidents or other “acquired deficits” and not with earlier, developmental issues. There was also the complex sense of at times disability being perceived as a stigma and that the asking for services necessitated both being “identified” as well as confronting a system, which was considered some families as “making trouble,” as opposed to feeling that they were entitled to disability services and other resources

Along with some of the specific findings regarding disability and its perception within the community was the very significant connections that many of the providers had within the Cape Verdean community. This was seen in communities like New Bedford where activists, school professionals, newspaper editor, service providers, etc., knew each other and had some connection, either personal or professional within the area

of disability. An important issue stressed by many providers was the concern regarding trust and commitment. We were asked a number of times regarding our intentions and issues regarding how this research was going to actively help providers, families and most importantly, Cape Verdeans with disabilities. "First impressions count," is what we were told as we embarked on trying to interview various providers to the Cape Verdean community.

Barriers to Implementation

Several important barriers were encountered in doing an analysis of service provision to people with disabilities within the Cape Verdean Community. A complete analysis of all of the individual interview and focus group transcripts is still taking place. This is expected to take several more months to complete. The transcripts are rich with qualitative data regarding many different aspects of life in the Cape Verdean community. Another limitation has been the at times difficulty in getting collaborators to focus more specifically and intensely on developmental disabilities, and although connected, more general social service issues at times took center stage. This again reinforced the issue brought up by a number of providers that when a community is dealing with basic issues, the more complex sociopolitical issues of services and empowerment for people with developmental disabilities and the creation of a disability movement (consciousness) takes second place. Basic survival issues are always first and foremost.

The project also has separated the "providers" and "consumers." This in some ways leaves unchallenged and re-created the very notion of "providers" speaking for those they serve, as opposed to people with disabilities having their own voice - a voice that may run counter to the perceptions, ideology, and practices of people who are in the helping professions. Although Phase I of the project has and will interview families and people with disabilities in the Cape Verdean community, the very act of "separating" the groups in our opinion, sets up and reinforces this false and non-productive hierarchy. A barrier to implementation - the giving of voice to people with disabilities in the Cape Verdean community - was in many ways reproduced by the very methodology that we developed.

Time and financial limitations are part and parcel of any specific and highly focused research project. Our ability to logistically cover many significant areas of the New England Cape Verdean Community was clearly limited by specific time constraints. Our project limitations regarding New England - and whether this specifically meant only Massachusetts - also set up some tension regarding reaching other Cape Verdean population. A major Cape Verdean population center is located in Rhode Island (Newport and Providence for example). When speaking about Cape Verdeans, this is another population center that needs to be integrated in any research study regarding any type of disability outreach for Cape Verdeans. In addition time and financial limitations

prevented the researchers from coordinating outreach workshop for both providers and families as outlined in the original proposal.

Specificity regarding "type of disability" will be an ongoing limitation and a possible focus for our continued research project. As noted above, for many Cape Verdean providers, the question regarding what type and level of disability was an important one. Children, adolescents, young adults, middle age and senior Cape Verdeans with disabilities, all present common, yet also age and disability specific needs and concerns. In an exploratory study such as this, the "specificity" that is required in order not to "lump" all people with disability together, was lost in asking questions about developmental disabilities or disability in general.

The significance of school and educational programs was stressed by many providers and yet we were able to interview only a few direct service providers connected with schools. The need to interview and collaborate with senior supervisory and administrative personnel, those who in many ways set and guide policy regarding the development of services to Cape Verdeans, was not fully elaborated in this study.

The ability to identify Cape Verdeans with disabilities and make contact, will require a concerted outreach effort, one that relies on providers to supply names of families, but, one that also relies on our going out into the street and knocking on doors and asking people directly. Our need to establish this type of connection is vital to both establishing trust and a real commitment to the Cape Verdean community in New England.

Linkages

Connections were made with several different agencies and contacts. First and foremost was our establishing relationships with various significant Cape Verdean groups. Connections were made with New Bedford High School, the Cape Verdean Consulate in Boston, The Minority Community Action Coalition (John Andrade) in New Bedford, The Cape Verdean News, and the UCP Center in New Bedford, which will assist with further client contacts and the provision of a meeting place. We also established major contacts with the Massachusetts Rehabilitation Commission and the Department of Mental Retardation and plan to disseminate a great deal of our continued work through these agencies. Attempting to make more connections, particularly through the schools and other service centers will continue to be a goal of our research. The significant linkages have also been established at an individual, personal level. A continued research and service interest exists at Rhode Island College, which is the home to the largest archive of Cape Verdean information in New England.

We are also attempting to establish linkages to Cape Verdeans in the Republic of Cape Verde. This is seen as a critical “link” to connecting Cape Verdeans here and with those in Cape Verde. We were told by a number of providers that to understand anything about Cape Verdeans here in the United States, we need to be willing and able to learn about Cape Verdeans on the islands. This would clearly include exploring the meaning of disability in Cape Verde itself, the nature of services being provided, government policy regarding disability rights, and genuinely connecting with the narratives and life stories of people with disabilities as they too establish themselves as part of this developing nation. We are currently seeking funding to travel this summer to Cape Verde to continue to examine families with people with disabilities as well as the service provision system in place in Cape Verde. This has required one of us to begin to learn Cape Verdean Crioulo and our continued seeking of economic support for this research proposal.

Additional Resources

We were able to receive additional resources from several sources. Northeastern University has awarded a small grant to study and interview Cape Verdean families. This was presented as part of the “matching grant” to the MDCC grant. Meeting places were provided by the Commonwealth of Massachusetts Archives in Boston, the Department of Mental Retardation, New Bedford office and the Minority Community Action Coalition in New Bedford. We have also been offered the use of the archive materials at Rhode Island College in our continued research efforts with the Cape Verdean community. Other community members have given their time and expertise in assisting and mentoring us in this community research project.

In terms of continued funding for the project, we have requested funds from Northeastern University and will also be applying for a small travel grant through a local foundation for our proposed trip to Cape Verde to study families and people with developmental disabilities.

Recommendations

The following are some recommendations and suggestions regarding disability and service provision within the Cape Verdean Community in Massachusetts:

1. ***Learning Culture*** - The need to learn about Cape Verdean culture, history and language is vital. Providers of services to this continually growing and well established community must be willing to engage the historical, social and political complexities of this diverse community in order to be able to both understand families and people with disabilities and contextualize their services.
2. ***Community Connections*** - Establishing “linkages” is absolutely vital if we as people who are interested in helping those with disabilities are truly committed to this

endeavor. Providers were very clear - almost across the board - *to learn about us and our people, you have to come to us*. The traditional expectation regarding client/provider and services being focused in an “office” or agency, goes against a more collective/collaborative orientation for this community. If we are to reach families and people with disabilities, providers must be willing to spend time in the grassroots community organizations - social clubs, cultural gatherings, churches, local news agencies, social activists centers - in order to learn not just about people with disabilities, but to collaborate and learn from Cape Verdeans themselves.

3. ***Establishing Partnerships*** - Attitudes are important. Entering into the community with an open, learning and collaborative spirit is essential. A more traditional - we will teach them how it is done attitude - will not be conducive to establishing the authentic partnerships needed to develop culturally relevant and respectful programs and outreach to families and people with disabilities.
4. ***Training and Recruitment*** - The need for recruitment and training of young professionals who are of Cape Verdean descent is a pressing need. Speaking Cape Verdean Crioulo and understanding the language, they serve as a vital bridge - link if you will - to the majority population and this historically complex community. Unfortunately, there are few service providers and more care and commitment is needed to mentor young and talented Cape Verdeans to enter the service professions - social work, special education, teaching, psychology, early childhood education, etc. Funding, scholarships and grants are needed to encourage people to continue to serve their community. As with many ethnic minority communities, many of the talented and gifted young people are quickly picked up by the more upwardly mobile professions - medicine, law, and engineering to name a few - while the social service fields remain relatively unattractive. Cape Verdean youth need to be guided and mentored into the helping professions and the field of developmental disabilities needs to become an attractive field for Cape Verdeans.
5. ***Data Collection*** - Specific population data is required. The State of Massachusetts census counts is inadequate for general population due to its rigid racial categories, which exclude Cape Verdeans. This of course has implications with regards to any statistics on Cape Verdeans with disabilities. Future attempts at population estimates will require an intensive grassroots, door-to-door counting of people with disabilities. Specific disability counts and range of disabilities must also be obtained both here in New England and in Cape Verde as well. The major agencies involved in service provision can take a leading role in this important venture.
6. ***Networking*** - The need to network and bring people together is also crucial to being able to establish consistent relationships and a sharing of information of policy, legislation, available services, entitlements, and just establishing and reinforcing the

sense of community among the providers, researchers and activists serving the Cape Verdean community.

7. *Families as crucial units.* Any attempts to give voice to people with disabilities within the Cape Verdean community must situate the family as a basic unit. The Cape Verdean family - nuclear, extended, community - must be given a central role within research, service provision, and policy determinations. There are many significant narratives that need to be heard - both here in Massachusetts and in Cape Verde - these stories need to be told.
8. *Flexibility in research paradigms* - Any research within the Cape Verdean community must be done with a collaborative spirit, and be flexible to the needs and cultural context of the community. Qualitative and quantitative methods and combinations of various techniques must be considered in order to give voice to the concerns and issues facing the Cape Verdean Community.

Post Project Impact/Conclusion

The project has had significant impact in bringing to awareness the need for dialogue around issues of disability within the Cape Verdean Community. As noted above, Phase I of the project will deal more directly with the voices of families and people with disabilities. There is a clear need for the development of a more concerted effort to organize people with disabilities. In many ways, providers presented a picture of people with disabilities similar to that seen within mainstream clients thirty years ago, before the advent of the disability rights movement. Although cared for and loved within the family and Cape Verdean community, Cape Verdeans with disability remain outside the mainstream environment and isolated. To some degree this mirrors some of the elements of the Cape Verdean community in its relationship to mainstream structures: although being a well established and historically significant community, remaining invisible to many mainstream systems and organizations.

The Cape Verdean community and its leaders have and continue to work hard to change these issues and to bring the Cape Verdean culture to the forefront. This is also a vital issue if we are to collaborate in the development of services for people with disabilities in this community. The project we feel has been the beginning of an important dialogue and the creation of more questions than answers. It is clear that more intensive interviewing of families, providers and policy leaders needs to take place. It is also clear that these different groups need to be brought together in the development of a collaborative, collective, non-hierarchical working relationship.

The ability to bring different agencies together is crucial. Many funding sources on both the state and national levels are looking towards projects that can bring together multiple agencies and peoples in a common goal. We feel that the project has begun to

engage this type of dialogue: bringing many different elements of the Cape Verdean Community together and bringing to awareness the critical importance of discussions around families and people with disabilities. We are hoping to be able to bring many of these groups together in a large conference in order to present other works - both research and service oriented - being done and to united the many dedicated people within this community. We have been greatly honored by the help that we have received in this beginning effort to understand disability in this culturally diverse community.

