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BANGLADESHI FAMILIES WITH MENTALLY RETARDED MEMBERS IN NEW YORK CITY: A STUDY OF NEEDS AND AVAILABLE SERVICES

by

MD. MOHSIN ALI

A dissertation submitted to the Graduate Faculty in Social Welfare in partial fulfillment of the requirements for the degree of Doctor of Social Welfare, The City University of New York.

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Abstract

BANGLADESHI FAMILIES WITH MENTALLY RETARDED MEMBERS IN NEW YORK CITY: A STUDY OF NEEDS AND AVAILABLE SERVICES

by

Md. Mohsin Ali

Adviser: Professor Irwin Epstein

This study makes an assessment of the needs of the Bangladeshi families living in New York City, with mentally retarded (MR) relatives, and gathers information about the services currently available for them.

Recently there has been a significant increase of Bangladeshi people in this country, especially in the Metropolitan New York area. Although the Bangladeshi population is growing rapidly, little systematic research has been conducted about the needs and available support for this new immigrant group.

Many Bangladeshis are struggling to maintain their ethnic beliefs, cultures and family values in America. They are scared of the decline of American moral and family values. Yet, many are able to put their differences aside and engage in building a new Bangladeshi community combining positive family values of both America and Bangladesh.

Many Bangladeshi families in New York face problems with caring for their MR relatives. Their ignorance, cultural practices, family values and financial paucity prevent them from seeking, accessing and utilizing services available for MR people in New York.

Often, service providers also are not aware of their problems. There is a great need to link these Bangladeshi families with the service providers in New York.

This study reports on an investigation into the needs of the Bangladeshi families with MR members and an attempt to acquaint them with the available and relevant services. To gather information, a questionnaire was prepared; a search was conducted to find services; and a resulting list of available services was prepared. In order to identify and contact the families with MR relatives, an advertisement was published in the Bengali weekly newspapers published in New York City and flyers were distributed throughout Bangladeshi grocery stores. Imams (prayer leaders) of the Bangladeshi mosques and other community leaders were also involved in the process. One government agency and one private, non-profit agency engaged in providing services for this population was interviewed.

It is suggested that service providers and the community as a whole educate families about the services available to them. The professionals who provide these services can help families gain wider access to services by helping them meet eligibility requirements.

Since the views about MR people are changing and more community integrated programs are developing, Bangladeshi families with MR relatives are now able to come forward to seek, access and utilize the available services. However, in order for this to occur, the Bangladeshi community leaders must also take initiatives to find families in need and encourage them reach the services designed for their MR relatives.

To facilitate this, an organization dedicated to Bangladeshi people can be established. This organization could find, counsel and train the Bangladeshi families with MR relatives

and provide preparatory services to the Bangladeshi MR people for helping them access existing service providing agencies in New York.

Preface

The main purpose of this study is to make an assessment of the needs of a sample of the Bangladeshi families living in New York City who have mentally retarded (MR) relatives. There is a significant number of Bangladeshi immigrants to the USA and many of them have settled in New York City. Some of these families have mentally retarded family members. Most of these families face a number of problems which prevent them from adjusting to the circumstances in a new society. Consequently, their survival as well-functioning families is at stake. These families need immediate support for their MR relatives from the institutions in New York City, so that they can meet the needs of their MR relatives and their families as well as prepare themselves for survival and adjustment in this new society.

Another study purpose is to find and describe existing services presently available in New York City for the MR persons, rendered through different government and non-government sources. Additionally, the study will explore the ways of accessing these available services and will discuss the available services which will best and most adequately meet the needs of these Bangladeshi families.

Many of the Bangladeshis who came to America with immigration and non-immigration visas from 1972 to 1995 settled in New York City. Most of them came to America within the last 10 years. Many are living as single individuals but have families in Bangladesh, primarily because it usually takes a few years to obtain visas for entire families. Some, though, were able to immigrate as a family.

Most of the Bangladeshi immigrants who live in the New York Metropolitan area are concentrated in specific areas, such as Astoria, Jackson Heights, Jamaica Estates, and Richmond Hill in Queens; McDonald and Church Avenues in Brooklyn; Parkchester in the Bronx; and First and Third Avenues in lower Manhattan. A few live in Staten Island. Of those who are professional people, such as physicians, pharmacists, dentists, engineers, etc., the majority live in Nassau, Suffolk and Weschester counties.

As new immigrants. Bangladeshi people face problems, such as language, cultural and emotional barriers, similar to those of other groups coming from developing countries. As members of a small community, they struggle for survival, both culturally and financially. This is particularly true for families with MR relatives who face additional problems in their daily lives, because of their special needs.

Like other Asian groups, Bangladeshis seldom use mental health services in the United States. Very little is known about the need that may exist for services within this ethnic group. Research on this particular group of people has not been done at all. Nonetheless, the problems faced by these families interfere with their adjustment to their new society. As a result, they do not get enough attention from MR organizations or from MR service providers.

Services for the MR persons and their families are almost non-existent in Bangladesh (Annual DSS Report, 1992). Although, these services are available in New York City, families are generally not aware of them to meet some of their essential needs and struggle alone to find solutions to their complex problems. At the same time, the larger society in the city is unaware of the needs of Bangladeshi families and, therefore, cannot reach out to them with available support and services. The burden of these families, however, could be lightened with appropriate help from the service providers in New York. Thus, there is a great need to find these Bangladeshi families, assess their needs and finally link them with the available resources. Bangladeshi families will greatly benefit by accessing the resources if their awareness is enhanced. It is believed that once these families begin receiving benefits, many more will emerge and become part of this society.

Culturally, Bangladeshi people are comparatively close with their friends and relatives, but the families with MR relatives are usually isolated due to the stigma and shame associated with mental retardation. These families do not usually want to associate themselves with the larger society, however. It has been noticed by Darling (1979) and Faber (1968) that following the diagnosis of a condition as mental retardation, families are likely to reduce their contact with neighbors, friends, and extended family members. They observed that the recognition and acknowledgment of MR in a relative is the first painful task that confronts each member of the family. The greatest problem is to understand what is unfolding and how to handle the problem. For most families, it is only the beginning of a long and arduous journey.

Hansen (1984) observed that the family is usually guilt-ridden and feels a keen sense of failure for having "produced" an MR child. He noticed that the relationships within the family are affected when an MR person lives at home. Everybody's daily lifestyle is turned upside down. Perhaps even more difficult for family members is to deal with the embarrassment over their MR relatives' behavior. Constant anxiety is fueled by the seeming irrationality of the MR person's behavior. Not only must relatives put up with unpredictable and possibly frightening behavior, but they must deal with it 24 hours a day - without any hope of respite. These families can soon become emotionally, mentally and financially exhausted. Hansen also observed that the families and service providers are generally unaware of each other. Therefore, it makes connecting them with services impossible. This creates further stress on the rest of the family, which is already strained by an overload.

The Group for the Advancement of Psychiatry (1986) found that the immense grief of these families over lost dreams and hope for a promising child or a beloved sibling and the suffering of the family members are cruelly aggravated by alienation from friends and neighbors, severe financial drain, and by the failure to access desperately needed resources. Families with MR relatives cannot carry the responsibilities single-handedly, and they are unable to meet these overwhelming demands. In order to cope successfully with the MR relatives, families need all the support they can get, not only from one another but also from the helping professions, from the mental health system, and from institutions at large. They need information and resources for treatment, care, and rehabilitation of their MR relatives. They need periodic respite from the 24 hour responsibility and from worry over the unpredictable behavior of their MR relatives. Without that help and guidance, the task of caring for these people is enormous. In fact, MR people are often the sickest, neediest, and most difficult patients.

There are many agencies operating in New York City which are especially dedicated to providing support and services to the MR individuals and their families, but these agencies are not, however, aware of the problems and needs of Bangladeshi families. Accordingly, this research project will seek out these families, help them assess their needs, find the available resources from government and private sources and explore the opportunity to match and link these needs with the services available.

Family care-givers are chosen as respondents in this study, because they tend to be on the front-line: available and willing to provide the necessary help and support to an MR relative. So, a program aimed at helping the Bangladeshi family care-givers will be developed during the course of this study. It is hoped that more information about the families' specific needs for providing services to their MR relatives will be obtained.

In addition to the main objectives of this study, as explained in the earlier paragraphs, this study will try to fulfill a number of expectations for the Bangladeshis by making a pioneering effort to provide baseline information regarding the Bangladeshi families living in New York City who have MR relatives, including the other Bangladeshi population in America and in New York City. Finally, this study will create a model for further in-depth studies in the area of needs assessment of the Bangladeshi families with special needs in this new society.

In order to conduct and complete this study successfully, a number of steps have been taken from planning to writing the final report. These steps are described in five chapters.

Chapter One discusses the attempts made to assess the actual number of Bangladeshi people who have emigrated to and are presently living in the USA and in New York City. This chapter discusses the family and gender among American Muslims in general and Bangladeshis in America (most of whom are Muslims) in particular. A vivid discussion is made here regarding the conflicts and contrasts of American and Bangladeshi values, culture, religious beliefs and social customs. This chapter focuses on the attitudes and family values of the people of Bangladesh as they pertain to the MR people, including what is done or not done for the MR in Bangladesh. This chapter provides the definitions and classifications of mental retardation (MR) as well as discusses MR as a global problem. The history and existing conditions of MR people in America and in Bangladesh is also discussed. Finally, this chapter discusses the needs of MR people for family and community integration.

Chapter Two describes the research design and the methodology that were used in the study. The theoretical concept of need is discussed in this chapter in relation to the practical needs of the target population of this research. The methodological issues of questionnaire construction, interviewing procedures, methods of data collection, data analysis, reliability, validity and others are discussed in this chapter as they relate to the research design. This chapter also discusses the issues of research ethics, human subjects, informed voluntary consent and the possible risks and benefits for the participants.

Chapter Three discusses the results of the interviews which are shown in the tables. This chapter makes an estimate of the number of MR Bangladeshis living in New York City, and in this context, MR estimates are discussed. The types of needed services as felt by the participants are analyzed in this chapter. A prioritization of the felt-needs is given in terms of MR services currently available in New York City for this population. A conceptual discussion of how needs are established is also presented.

Chapter Four discusses the current types of services which are available to MR people in New York. A discussion is presented on the problems that English-speaking Americans face in accessing and utilizing these services. The service delivery systems and their gaps are also described here. This chapter concludes with a description of the additional problems that the Bangladeshi MR people and their families face in accessing and utilizing these services.

Chapter Five discusses the type of organization that could be developed to best serve the needs of the Bangladeshi MR people and their families in New York. In order to do this adequately, the chapter describes the current Bangladeshi community activities, family structures, economic situations and how the Bangladeshis are organized in New York and their connections to home country. The types of services that would be most appropriate for such an organization to offer initially are detailed. How such an organization could articulate with the existing MR agencies is also explained. The discussions in this chapter also include an analysis of the cultural limitations to serving Bangladeshis through existing organizations and the ways to overcome these strains. Finally, the implications for those respondents, who said that they left their MR relatives back in Bangladesh are discussed in this concluding chapter.

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Chapter 1: Bangladeshis and Mental Retardation in New York

Migration of Bangladeshi People into America

Informed sources reveal that a small number of Bangladeshi people of basically working class background jumped ship in Detroit, Michigan in the 1930's and 1940's and took up various occupations ranging from shopkeepers to security guards. The second generation was also not highly educated and had similar occupations (Ahmed, at. el., 1996). All these Bangladeshis were citizens of the then undivided India and many of them were Muslims. Many immigrants ended up in South American countries believing they had arrived in "Nay Yark" or "Amrika" (Naff, 1992:145). However, the Johnson Reed Immigration Act of 1924 effectively curtailed immigration by establishing quotas for emigrants from many foreign countries. As a result, immigration from Bangladesh (which was a part of India until 1947 and Pakistan until 1971) was also limited by the exclusion laws of 1924 (Kahn, 1983-84; Aswad, 1993). Immigrants from Pakistan and other Asian countries increased due to the fact that quotas established by the Johnson Reed Immigration Act of 1924 and by the McCarran Immigration Act after World War II were abolished by the Immigration Act of 1965. This new Immigration Act gave preference to all countries, to relatives of US citizens, and to professionals and others with skills needed by the United States (Haddad, 1986:2). Many of the immigrants who came under the new Immigration Act were more highly educated than their predecessors.

Many came for university education and stayed. In addition, a number of Bangladeshi students and professionals also began arriving in America in the 1950's. Bangladeshis immigrated as Asian Indians up to 1947 and as Pakistanis from 1948 to 1971.

Since the 1960's, many South Asians, who originally came as students or tourists, chose to remain in the United States. The 1986 immigration data shows that the majority (61%) of the Bangladeshi aliens who adjusted to permanent resident status were students. In 1982, 90% of the total population of Bangladeshi immigrants were professionals. Over the past 7 years, citizens of Bangladesh have also entered the United States through programs aimed at Opportunity Visa (OP-1:1990-91) and Diversity Visas (DV 1995 and 1996) which were called "Visa Lotteries". Many of the lottery visa winners are less educated and most of them have settled in the big cities such as New York, Boston, Dallas, Houston, Chicago, Los Angeles, San Francisco, Atlanta, Miami, Philadelphia, Detroit, Newark, Jersey city, etc. These less educated immigrants found jobs in these cities in small businesses such as: gas-stations, restaurants, small construction companies, small stores, security guard companies, car services, etc. The data also shows that male immigrants have outnumbered female immigrants. For every Bangladeshi woman that immigrated in 1986, there were almost two Bangladeshi men (Ahmed, Kaufman & Naim, 1996).

The above changes in the immigration laws have led to a significant increase in the influx of Bangladeshi people into the United States with many of them settling in New York City. They presently constitute a sizeable ethnic community in this city.

According to the reports of the Visa Office of the Bureau of Consular Affairs of the US Department of State and the Immigration and Naturalization Services (INS) of the US Department of Justice, about 35,817 Bangladeshi people received immigrant and 156,196 received non-immigrant visas and came to America from 1972 to 1995. The non-immigrant visas were mainly issued to students, tourists, business people, diplomates and for other temporary stay. Many of the non-immigrant visa holders decided to stay in this country and attempted to change their visa status from non-immigrant to immigrant. A total of 11,040 Bangladeshis got their non-immigrant status adjusted to immigrant visas from 1981 to 1994. Although many failed to change their visa status, they remained in the US illegally for years even after their visas were expired. These Bangladeshis were not counted by the Visa Office or INS or by the US or NY State or NY City Census Bureaus. They will continue to stay uncounted until somehow they get their status changed to immigrant. The numbers of American-born children of these non-registered Bangladeshis are not known and not included in the above estimates. In addition, a total of 8,059 Bangladeshis were granted US citizenship during the period of 1972 to 1994 (Reports of the Visa Office, 1974 to 1995 and the Statistical Year Book of INS, 1973 to 1994). The annual figures from 1972 to 1995 of Bangladeshi people awarded US visas are given on following page.

Table 1

Annual Figures of Bangladeshi People Awarded US Visas

Year	Immigrant Visas	Non-Immigrant Visas	Adjustment of Visas	Awarded Citizenship
1972	17	98	-	-
1973	122	795	-	8
1974	97	1,483	-	25
1975	382	1,212	-	39
1976	410	1,385	-	55
1977	362	1,766	-	86
1978	449	2,124	-	78
1979	382	2,610	-	132
1980	423	3,395	-	146
1981	607	4,519	-	207
1982	504	4,852	182	223
1983	504	4,226	301	273
1984	590	4.178	306	275
1985	873	4,857	373	337
1986	1,239	7,185	437	296
1987	1,293	7,091	410	334
1988	1,129	9,570	354	419
1989	1,373	10,864	813	496
1990	3,811	8,963	980	696
1991	6,202	9,804	4,651	874
1992	2,248	12,888	1,202	967
1993	2,928	16,889	544	942
1994	2,977	7,582	487	1,151
1995	6,895	17,860	-	-
1972-95	35,817	156,196	11,040	8,059

No specific figure is available for Bangladeshi people who got their immigration status adjusted from 1972 to 1981, because of the fact that Bangladesh was put in 'Other Group' category as the number was so insignificant to project them separately. There might have been more than 800 visas adjusted during this 10 year-period.

Those who came to America prior to 1972 from Bangladesh were not recorded in the above estimates, because until 1971, Bangladesh was still a part of Pakistan. Therefore, there is no way to know how many people of Bangladesh origin came to America prior to 1972. Those Bangladeshis who came prior to 1972 and their descendants have been living in America for a long time. They have increased the number of Bangladeshis in America significantly. They are not included in the above estimates.

There is a popular saying among Bangladeshis that once a person sets his/her foot on American soil, he falls in love with American dollars and does not want to go back to his/her home country. Perhaps the only exceptions are high government officials, rich business persons and important political, social and entertainment personalities. Many of those who wanted to stay have gotten their non-immigrant visas several times. Although some of the non-immigrant visa-holders went back to Bangladesh after visiting America; still many continued to stay without immigrant visas. Among Bangladeshis in America it is believed that at least 30% of those who came to America with non-immigrant visas continue to live in America, trying to change their status to immigrant. Some have succeeded and many are still trying. So, there might be about 46,800 Bangladeshis who are living in America with non-immigrant visas. In addition, Bangladeshis who came prior to 1972 and their descendants might have been about 6,000. The descendants of those who came here after 1971 might have been about another 7,200, if the growth rate of the Bangladeshi population in America is estimated at a rate of 3% per year for an average of 10,000 people over the last 24 years, the American-born Bangladeshis might be estimated at 7,200 from 1972 to 1996. The death rate of Bangladeshis in America is not significantly different from the death rate of those who are still living in Bangladesh. With all these statistics and assumptions, it could be estimated that there might have been about 107,657 Bangladeshis living in America including 46,800 (43.5%) non-immigrants up to 1995. The figures of immigrant, non-immigrant and visa adjustment are not yet available for 1996.

Nonetheless, there is also no way to determine the exact number of Bangladeshis living in New York City. The 1990 Census report of New York City did not show any count of Bangladeshi people. But it has been a popular assumption that most non-immigrant aliens live in the big cities. Besides, new immigrants, who are from low income groups, tend to stay in the big cities because of easy access to job markets and public transportation.

New York City is the Gateway to America for the Bangladeshis and most Bangladeshis prefer to stay in New York. At least half of all the Bangladeshis living in America are living in New York City. In brief, there are about 27,500 immigrants including their descendants who came after 1971 and about 3,000 immigrants including their descendants who came prior to 1972, who are living in New York City as immigrants. There are possibly another 23,400 Bangladeshis, who are living in New York as non-immigrants. In total, there are approximately 53,828 Bangladeshis currently living in New York City. This is about 50% of the total Bangladeshis living in America. It can be mentioned here that there will always be a huge number of Bangladeshi aliens who will continue to live as non-immigrants and no census could count them in. Thus, no accurate number of Bangladeshis living in America and in New York City could be determined at any given time.

Contrasts of Values and Attitudes of Bangladeshis in America

Bangladesh is predominantly a Muslim country and most of the immigrants from Bangladesh are Muslims who brought Muslim faith, culture, custom, heritage and superstitions with them. As a Muslim country, Bangladeshi people share the Muslim values of other Muslim countries. Muslim values are similar in almost all the Muslim countries across the globe. There are also dissimilarities among the different sects of Muslims in the ways they perform their religious activities. Especially, the Sunni and Shaiti -- the two major sects of Muslims have their major differences. Bangladesh Muslims, however, are predominantly Sunni and share universal Sunni values.

At the same time, Bangladesh is an Asian, Third World developing country. Hence, Bangladesh also shares the conservative rural underdeveloped Asian and Third World culture, values, superstitions and customs. It also has a universal peaceful co-existent society and community with different religions such as Christian, Hindu and Buddhist. Bangladesh is financially poor and scientifically and technologically a backward country. Therefore, the Bangladeshi people face the conflicts of cultural values both as Muslims and Asians.

Like people in other Asian communities, Bangladeshis who come to the United States bring with them a unique value system which often stands in stark contrast to the values upheld in America. Chen & Yang (1986) found that although Asian countries such as Bangladesh, India, China, Japan, Pakistan, etc., certainly have different histories, philosophies, religions, economies, cultures, and most obviously, languages, these countries share some similarities, especially in values. These values include strong kinship ties, interdependence, and a great respect for age and authority.

Haddad and Smith (1996) discussed the Islamic values among American Muslims, most of which are maintained by Bangladeshi Muslims. They noticed that Muslim is the fastest growing religion in America and the Bangladeshi Muslims are part of this development. Recent scholarly interest in Muslims in America has been growing, as has the literature on their religion, community organization, ideas, political activities, family patterns, cultures, and adaptation to life in the United States. However, political and social integration or lack of it in the new country profoundly affect immigrant community and family life.

Abraham (1989) indicated that American culture and attitudes are marginalizing Muslims politically and culturally and simultaneously producing opposing forces for integration and isolation within the mainstream of society. Political pressures and discrimination by members of the dominant groups have affected the community and family lives of other minorities as well. This marginality has led to the strengthening of family and community life in most Islamic groups. Most Muslim immigrants, however, like European white immigrants, have worked hard and reached the middle class (Haddad and Smith, 1996).

As recently as the 1960's, America was considered a nation of three major faiths: Protestant, Catholic, and Jewish (Herberg, 1960; Kennedy, 1952). Although Muslims have been in the United States since the early part of this century, their numbers have increased greatly since World War II. Today's Muslim population is estimated at about nine million, who are affiliated with about 600 mosques. They include immigrants and their descendants from many nations as well as converts whose families have lived in the United States for many generations. This estimate does not include the African-American Muslims in the United States (Haddad, 1986:I). As Muslims continue to immigrate to the United States, they are rapidly becoming a significant fourth religious community that needs to be understood and accepted by other Americans.

Ahmed, Kaufman & Naim (1996) mentioned that South Asian Muslims (including Bangladeshi people) are relative newcomers to the United States and little has been written about them despite their increasing numbers. Highly educated, often with careers in medicine, engineering and science, they live primarily in the larger cities. Though still a small group, the number of Bangladeshi people are steadily increasing as well. Almost all Bangladeshis and Pakistanis and 11% of Indians are Muslims. Consequently, it has been estimated that the South Asian Muslims population in the United States is to be well over 300,000 in 1991 (Aswad & Bilge, 1996).

According to Ahmed, Kaufman & Naim (1996), many of the immigrant families from Bangladesh, Pakistan and India consist of highly educated professionals---physicians, dentists, engineers, scientists, lawyers, and university professors. Most of the immigrant generation's marriages have been arranged, but conflicts in adjustment to American life have resulted in some divorces. The foregoing authors also show how families take pains to socialize their children in the Islamic faith and to find the Muslim spouses of appropriate ethnic and educational background. These families face many of the problems that confront family members spread over a wide region as they strive for better education, jobs. and economic opportunities. There are major problems in disciplining children. Mothers usually shape their children's behavior. A mother also guides her daughters' behavior in order to uphold her family's honor, but in American society traditional parental authority is difficult to maintain.

Sharma (1994) noticed that, unlike the nuclear family that exists in the United States, the traditional extended family in South Asia includes several family members: parents, children, grandparents, married sons and their wives, and grandchildren. Although families which come to America tend to be smaller, simulating the American nuclear family pattern, they are in fact in close contact with their extended family who still lives in the home country. The nuclear South Asian families in America are still influenced by their cultural and social heritage.

Sharma stated as well that the traditional family structure in the Indian sub-continent is hierarchically arranged with diffierent family members possessing unique roles. Conflicts within the family are minimized since each member has a specific and exclusive role which is unlikely to interfere with the roles of other family members. By contrast, American society values openness and role flexibility in relationships in ways which may counter South Asian, including Bangladeshi, ways of relating. For example, for most Bangladeshis, displaying anger openly, especially toward those who are older or in a higher position of authority, is not socially acceptable behavior. Communication and authority within such Bangladeshi family systems tends to flow vertically from top to bottom.

Marriage, family boundaries, and care for the elderly and sick people are all influenced by the Bangladeshi concept of family. Most marriages are traditionally arranged by the parents and divorce is very rare, as it is generally not a viable alternative. Family problems are usually confronted within the boundaries of the extended family and are not disclosed to outsiders. There is a strong concern for the welfare of all family members, including sick members. Parents support their children for as long as needed. Children, in turn, especially males, are expected to care for their parents and other sick members until their deaths (Barazangi, 1996).

The first and second generations of Bangladeshis in America face several dilemmas associated with ethnicity, role conflict and marital problems. The intensity of these conflicts is exacerbated by the generation gap and the length of stay in the United States. Like many other Muslims, Bangladeshi Muslims perceive a significant change in American values, and serious lowering of ethical standards, since the hippie, sexual and feminist revolutions. They perceive Western feminism focusing on individual freedom and opportunity for the individual woman rather than for the welfare of women as a larger group. Moreover, western feminism emphasizes sexual rather than cultural identity. The consciousness-raising for Western women is based on the desire to avoid exploitation by the males, while for Bangladeshi women, of greater concern is the avoidance of exploitation by outsiders. Western feminism is often anti-male in ways that Bangladeshis consider degrading and undesirable. Western feminists apparently value sexual liberation and identity of sex roles in ways that are repugnant to Muslims including Bangladeshis. Sexual behavior that may strike an American feminist as liberated may strike a Muslim woman as just another form of slavery. Accordingly, Haddad and Smith (1996) found that very few Muslim women expressed a desire to change places with an American woman. Muslim women see American women as having more social freedom than they themselves have, but, this freedom has many dark sides. American women are respected less by men and the society at large. In addition, the fact that the way elderly American men and women end up at senior citizen homes, a complete isolation from the family (her children, grandchildren and other kin) is unthinkable in any Bangladeshi families (Haddad and Smith, 1996).

In a Bangladeshi family, parents and grandparents are taken care of at home for all their lives, no matter how poor the family is. According to Muslim women (Haddad and Smith, 1996), American women are not well-treated by their husbands and they are forced to work outside the home whether they want to or not. Bangladeshi men see themselves working a lot harder than American men for their women and women are not forced to work. According to Muslim women, the American women have more freedom but they do not have a good life. They have no marital security. Their husbands have girlfriends while they are married. Their husbands leave them and their children. The woman has to raise the children by herself. At the end, most American women end up with a very hard painful life unlike the Bangladeshi women. Most Bangladeshi marriages are guaranteed for life and even if there is any divorce, the husband always takes the responsibility of the children. The parents or brothers give shelter to the divorced daughter or sister until an alternative arrangement is made.

The American practice of dating between young men and women has been of particular concern to Bangladeshi families, because the heart of the concerns of the Muslim families is the matter of male-female relationships before and after marriage (Haddad and Smith, 1996). American culture runs counter to traditional Bangladeshi views of the propriety of these relationships. The easy interaction between men and women, young boys and girls spending time together late into the evening, women dressing in ways that are considered unduly provocative, living together and producing child without marriage, unmarried teenage pregnancies, legalization of abortion, underage single mothers, drugs, carrying guns, gang fights, mugging and such other social and family problems are totally unacceptable to the teachings and practices of Bangladeshi families. The Bangladeshi parents of teenage sons and daughters are very worried that their young children might be forced to join their American peers in the schools and playgrounds to participate in such unacceptable activities. Out of this fear, many Bangladeshi parents are either going back to Bangladesh with their whole families or sending their young-adult children to Bangladesh and raising them there until they get married.

In the eyes of many Muslims (Haddad and Smith, 1996), American society has an extremely loose family structure where children do not respect their parents; husbands and wives do not respect each other; there is no glue in the society, only freedom. Americans are perceived as being raised to be most concerned about themselves only, while Bangladeshis are raised to care for one another. The Bangladeshi women comply with the rules of the cultural system in which they must live, whether they like all of them or not, because to defy them means to lose the support structures the culture provides. Without this structure, they feel vulnerable and empty. Loss of family, for them, is the greatest loss. Although the American women have more freedom and legal rights than Bangladeshi women, the price of trade off is very high (loss of respect, emotional support and security provided by their traditional system). Many women expressed their views (Haddad and Smith, 1996), that women everywhere have it harder than men. Though the symbol of a better life for Bangladeshi women is not the life of American women, they view American women as deserving some of the respect and support that they and other Asian and Muslim women have.

Bangladeshis in this country look with increasing alarm to what they see as the rapid decline of the ethical-moral principles of American society and find reassurance in affirming the importance of maintaining the values of their own religion. They observe the increase of drug usage, rising crime rates, growing lack of respect for elderly family members and for the institution of marriage, the problem of AIDS, and many other elements in American society that they deeply fear. They turn to family, culture and religion as a refuge and a guarantee that they and their families will not suffer the consequences of such deep societal problems. They belong to a kind of universal family and share in a unity that depends on mutual cooperation. "It is basic and fundamental, it is a sacred spiritual unity that represents full awareness of fraternity and brotherhood by every individual in the community. Such unity is divinely conceived and implemented, and the community is seen as the locus for a spiritual and ethical bonding not available in humanly instituted social systems" (Haddad and Smith, 1996).

Bangladeshi families, like other Muslim and Third World Asian families, indeed have high regard and great esteem for the West and its civilization, but there are elements in the West of which they disapprove. Among these are the moral laxity including easy mixing between the sexes, the availability of pornographic materials, dating patterns, and what is euphemistically called "premarital relations." These practices are viewed as unhealthy, immoral, and destructive. All of these concerns, then, are part of the conversations taking place on many levels throughout the Bangladeshi and other Asian and Muslim communities in the United States. The importance of family, of the respective roles of women, and men in society, of socializing children in order that they might avoid the problems of Western society, of finding appropriate ways to care for the elderly--all of these issues necessitate formulating responses to the pressures of American society that neither compromise the ideals of Bangladeshi culture and religion nor take refuge in what some consider to be an unwieldy and unrealistically conservative dogmatism.

But many Bangladeshi Muslims, perhaps the majority, do not immediately see an incompatibility between the values of their culture and religion with those of Western life. Like liberal Christians and Jews or those who have no relation to organized religion, many Bangladeshi Muslims differentiate between religion and state, religion and culture, and religion and customs. They relegate customs to local ethnicity and can, therefore, freely shed them. Generally, they operate successfully within the American society. For others who struggle to maintain differentiations, life in America can present significant challenges. The new Bangladeshi immigrants are less often concerned with forming and maintaining a religious identity as they are with basic survival, making a life in this country and finding ways to integrate successfully into what they have come to hope is truly an 'American melting pot' (Haddad and Smith, 1996). Despite the fact that the number of Bangladeshi people continues to rise rapidly, research on this particular group has not been done.

Conflicts of Values in Health-Care Setting

The ability and willingness of the Bangladeshis to access and have a favorable experience with the American health-care system is dependent on a number of factors. These factors include English language proficiency, family finance, socio-economic background, level of education, religion, and other cultural values. Differences in customs, values, and beliefs between Bangladeshis and mainstream Americans represent sources of potential conflict and misunderstanding in the health care settings. These conflicts involve religious beliefs and practices, family roles, sexual roles, knowledge and superstitions, and social mores.

Family and kinship ties in particular can contribute to the conflict in seeking health care services. Members of the extended family are expected to take part in all aspects of family members' lives, including financial matters, marriage, family birth, illness and death. The sharing of experiences with immediate and extended family is a necessity, not a luxury. In times of crisis, family members are expected to show support by their presence and the offering of financial support. The strong affinity and need for immediate family support is apparent when a family member is cared for in a hospital setting. Moreover, within the extended family, there is a sense of openness and shared experience (Kulwicki. 1996).

Family members express pride in their families and are protective of their members. An aspect of this pride and protectiveness is that family members may be secretive about illness or health matters that are perceived to bring shame and dishonor to the family. Family members might be secretive about family histories of mental illness, mental retardation, genetic or reproductive disorders, and chronic illness such as cardiac disorders and seizures. A major reason for this concealment is that knowledge of these health matters may interfere with the marriage possibilities and other social relationships of the family members. Information regarding such health problems may be withheld from health care professionals for fear that they will become public and ultimately bring harm to the family (Kulwicki, 1996).

Bangladeshis have great respect for their elders like other Muslims as well as Third World Asian people. Children are raised to be obedient to parents and elder sisters and brothers, and never to question elders. Talking back to parents or elders is considered a sign of a poor upbringing. Because the elderly are held in high esteem by the family, family reject medical advice for institutionalization of the elderly or handicapped persons. It is the duty of the family to provide care for elderly, sick and handicapped in the home, typically until death. Even when the family lacks the resources to provide proper care for an elderly or disabled relative, there is a feeling that life outside the family is not worth living (Sengstock, 1996).

Bangladeshis maintain strict sex-role differences. Bangladeshi males, traditionally, are the providers and in charge of social and political affairs. Women, on the other hand, are the child-bearers and rearers and are in charge of house-hold activities. In the health care setting, the male is responsible for any final decisions and signing consent forms and surgical permits. Sex-role differences extend to the notion of the male being the protector of family members from outsiders and the female being the nurturer and carer for family members. Bangladeshi traditions, like those of Muslims of other countries, value female purity and virginity prior to marriage. Usually, the male who is the father or an older brother is expected to protect the family honor by ensuring that female members of the family preserve their chastity and purity. In the health care setting, this extends to the notion of protecting females from being exposed to strangers of the opposite sex. Male kin may feel embarrassed and powerless when female kin are examined by male professionals. Consequently, to protect the family honor, some males may forbid their sisters, spouses, or daughters to be examined by male doctors or other medical personnel (Swanson, 1996).

Under certain circumstances, Bangladeshi patients are more inclined to resort to traditional healing practices. Traditional healers are often consulted in the treatment of mental disorders, depression and schizophrenia, because conventional medical intervention is often experienced as inconclusive or ineffective. They also resort to traditional healers to treat illnesses caused by evil-wishers who cast the evil eye and who use sorcery. Victims of the evil eye are generally thought to be children or young adults who are healthy and considered beautiful, and thus vulnerable. Hatred, jealousy and envy are expressed by casting the evil eye. The evil eye is believed to cause vomiting, gastrointestinal disorders and, on rare occasions, death. Hatred is usually expressed through the use of spells or sorcery. Illnesses caused by sorcery are often manifested in mental and emotional disorders, seizures, etc., (Kulwicki, 1996).

Bangladeshi religious people, like other Muslims and people of other religious faiths, believe that illness may befall an individual because of his or her loss of faith in God. The most common illness attributed to this is madness, which is perhaps, the illness most feared by the Bangladeshis. Since humans are considered the highest form of life because of their possession of a rational faculty, loss of reason is the most serious illness that can befall them. The only cure for illness caused by possession is for victims to reaffirm their belief in God. This may be done directly or through the assistance of a religious intermediary or folk healer. The treatment for such mental illness is by some form of exorcism of the evil. Many Bangladeshi religious people, like other conservative groups, believe knowledge of illness caused by possession is outside of the realm of the medical or mental health practitioner and, therefore, seek a remedy from a folk healer (Kulwicki, 1996)

Lower Utilization of Mental Health Services by Bangladeshis

The popular myth that Asians are the "model minority" has led to a belief that Asian-Americans have fewer mental health problems than other groups in America. One often-cited explanation for the lower mental health and mental retardation (MR) service utilization rate among Asian-Americans has traditionally been that Asians have fewer adjustment difficulties than the majority group (Sharma, 1994). Sharma found that the concept of professional services is alien to many Asians, including Bangladeshis. Many turn to such traditional sources of support as a family. In Bangladesh, as in many other Asian countries, having a mental retardation problem is equated with insanity and being cursed by God. Moreover, there are many stigmata attached to receiving outside help, including social embarrassment, if the help received is publicly known.

Research has consistently shown that Asian-Americans seldom use MR services (Sue & Sue, 1990; Sue & Kirk, 1975; Chu & Sue, 1984). Sue & Sue (1990) point out that the lower utilization of mental health services by Asian-Americans as compared to their Anglo counterparts has been reported for some time. The idea that barriers to utilization may exist and that services should be sensitive to the needs of minorities is widely accepted by many clinicians. However, little is known about the help-seeking attitudes of the Asian immigrants, especially the Bangladeshis.

Few Bangladeshi immigrants use mental health services. According to Fischer & Turner (1970), psychological mindedness and the utilization of mental health services are closely tied to one's socioeconomic status. Thus, in comparing national survey data, Kulka, Veroff & Douvan (1979) found that despite an overall increase in the use of mental health services across the broadest socioeconomic spectrum, individuals with a low socioeconomic status continued to seek professional mental health services less often than those with a higher socioeconomic status. Hall & Tucker (1985) noted that those with higher socioeconomic status may espouse more positive views toward the mental health profession. Better educated individuals are more likely to seek mental health services. The ability to pay for treatment, which is directly related to an individual's occupation, is a consistent predictor of utilization. The financial burden of seeking help also limits access to services. Thus, socioeconomic status has an important influence on the decision to seek help from mental health services. Most Bangladeshis, except the professionals, fall in this lower socioeconomic status of people who have very low mental health service utilization rates. People with a greater knowledge of mental health services tend to have higher rates of utilization. For all the reasons mentioned above, Bangladesh people have very limited knowledge about the mental health services in New York, which results in lower utilization of mental health services.

Bangladeshis, like other Asians, do not generally have a clear and accurate understanding of the nature of MR services that are available. Seeking help may be difficult, not only because of the stigma attached to MR, but because seeking help with mental problems is often perceived as reflecting quite negatively on the family (Shon & Ja, 1982).

American MR concepts are still quite new to Bangladeshi immigrants, in whose country the practice of seeking help from MR service providers does not exist. Such concerns are typically taken care of within the extended family system. Since MR professionals do not exist in Bangladesh, knowledge about the types of problems for which one might seek help in the USA is limited. Moreover, people tend to seek help from those who have similar social and cultural backgrounds. American counselors who cannot communicate with the understanding of a client's cultural background are therefore perceived as less effective in providing help (Chen & Yang, 1986).

Within the past several decades, many social scientists as well as administrators of social welfare agencies have expressed concern over the delivery of mental health services to ethnic minority individuals and communities (Karno & Edgerton, 1969; Abad, Ramos & Boyce, 1974; Sue, 1977; Delgado & Scott, 1979; and Rodriguez, 1983). Specifically, contemporary social work literature reflects the profession's concern with delivering culturally compatible services to racial and ethnic minorities. The use of existing services by minorities is often disproportionately low. The delivery of services has been described as culturally incompatible to the ethnic minority individuals and the communities they serve and, consequently, as underutilized (Vazquez, 1994).

According to the report of the National Institute of Mental Health (1980), minority groups are under-represented in MR related services. It follows that the

Bangladeshi people, are not adequately represented in these services. The major reasons are primarily:

- absence of their native professionals and therapists
- process and manner in which services are offered
- emphasis of socio-emotional issues over educational or vocational concerns
- stigma and shame associated with mental retardation
- unresponsive and inaccessible systems
- inconvenient location of services
- lack of knowledge of services
- use of alternative and traditional services and resources
- cultural beliefs regarding mental retardation and its course of treatment (Flaskerud, 1986).

Bangladeshi immigrants, like other Asian immigrants, are a growing group in the United States who often face psychosocial difficulties associated with adjustment to a new cultural and technological environment. Sharma (1994) mentioned that immigrants can experience high levels of distress and some may even need assistance from MR professionals. Despite the potential need of MR services, little is known about the utilization of MR services by the Bangladeshis in New York.

In fact, Sharma (1994) noted that there are no published statistics on the need for MR services that exist within the South-Asian communities. If one draws from the literature on other Asian-American groups, such as Japanese and Chinese Americans, there is reason to believe that a hidden need for services in the communities of the Indian sub-continent, including the Bangladeshi community, might also exist. Furthermore, if one considers the finding that immigrants generally tend to experience more psychological distress, the possibility of hidden need in the Bangladeshi population (mostly immigrants) in the United States would be even greater than for the non-immigrant population.

Definitions of Mental Retardation

In order to discuss the utilization and delivery of mental retardation services, it is necessary to agree upon a definition of mental retardation. Stark and others defined mental retardation as impairment in intelligence from early life, slow mental development during the growth period, delayed learning ability and lack of social and behavioral adjustment. Mental retardation is not a disease. It is a disability--a disability of a permanent nature (Stark. et. al., 1988).

Mental retardation is defined by the American Association on Mental Deficiencies (AAMD) as: "significant subaverage general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested during the developmental period" (Grossman, 1973).

R. B. Dever defines mental retardation from an educational perspective as "the need for specific training of skills that most people acquire incidentally and that enable individuals to live in the community without supervision." (Grossman, 1973).

US Congress has also defined mental retardation and developmental disabilities, the definition is contained in the Public Law (PL 94-103):

"Developmental Disabilities refer to a severe chronic disability that is attributable to a mental or physical impairment or combination of mental and physical impairments that are:

* Manifested before age 22;
* Likely to continue indefinitely; and
* Resulting in substantial functional limitations in three or more areas of major life activities."

(Jane West, edt., 1991 & Goldman, 1987).

Developmental Disability is also defined by the NYS Mental Hygiene Law as a disability which is attributed to:

* Mental Retardation, Autism, Cerebral Palsy, Epilepsy, and Neurological Impairment;
* Any other condition of a person found to be closely related to mental retardation; and
* Originates before the person reaches age eighteen

Developmental Disabilities are of 5 types which are: Autism; Cerebral Palsy; Epilepsy; Neurological Impairment; and Mental Retardation. (Grossman, H.J. 1973, Lowitzer, C. October, 1987).

Classifications of Mental Retardation:

Mental retardation has been classified by the following organizations:

- American Association on Mental Deficiency (AAMD)'s Classification of Mental Retardation
- World Health Organization's International Classification of Diseases, Clinical Modification (ICD-9 CM); and

- The American Psychiatric Association's Diagnostic and Statistical Manual (DSM-III). (Grossman, 1973, Lowitzer, 1987, & AJP, 1972).

These organizations have classified mental retardation as follows: Profound: IQ below 20, Severe: IQ range is 20-35 i.e., mental age of 2 years. The individuals of these two categories are also known as "Custodial" who require constant care or supervision throughout their lives.

Moderate: IQ range is 35-54, i.e., mental age between 3 to 7 years. These individuals are called "trainable mentally retarded" (TMR) who can be trained under close supervision. They can develop self-protection and master limited skills but they need close attention.

Mild: IQ range is 55 to 70, which is equivalent to average 8 to 12 year-old children. They are known as "educable mentally retarded" (EMR) who can learn to read and write and do simple arithmetic, but they also need special attention and care within a normal schooling system. Mildly retarded individuals may be identified as "slow learners".

Unspecified: IQ is unknown. This group is not usually used. (Stark, at. el., 1988).

Mental Retardation: A Global Problem

According to Richter (1982), mental retardation is a global problem which constitutes part of a general disability. It has been estimated that people throughout the world with all types and degrees of disabilities number approximately 490 million, or 12.3% of the world population. By the year 2000, it has been estimated that the number will have reached 846 million (13.5% of the world population). In 1975, three quarters of the disabled population lived in the developing countries. By the year 2000, more than four-fifths of all disabled people will live in developing countries. According to the statistics of the World Health Organization (WHO), about 3% of the world population is mentally retarded. Mental retardation is now a world-wide problem. In this regard, Jayasuriya (1988) argued that there is no evidence to suggest that mental retardation is less common in developing countries than in developed ones. Yet the resources available for caring for the mentally retarded are limited by harsh realities, the lack of knowledge, technology and finance in the developing countries.

Historical studies have revealed that from ancient times, crimes and exploitation have continued world-wide against mentally retarded people. On this subject, Rahman (1985) noted that the history of mankind is also a history of oppression, humiliation and neglect of people with MR. Even today people with MR often become exploited, oppressed and abused.

In order to create an awareness of such a global human problem of disability and its dimensions, the United Nations observed the Year 1981 as the International Year of Disabled People. Daniel (1985) reported that on December 3, 1982, the United Nations General Assembly unanimously proclaimed 1983 to 1992 as the U.N. Decade of Disabled People and adopted the World Program of Action concerning this group. The General Assembly urged the UN, its agencies, nations, organizations, communities, institutions, and people of goodwill everywhere to cooperate in achieving the Decade's goals, which were to:

- increase participation of disabled people in all social activities
- expand opportunities for education, training, and jobs
- remove all barriers to full participation
- increase acceptance of disabled people in society
- prevent disabling diseases and accidents
- restore sight, hearing, and movement
- expand community-based rehabilitation services
- conquer major disabling conditions
- involve everyone - from every country and culture - in cooperative efforts at local, national, regional and international levels to conquer or prevent disability and release human potential for the benefit of all.

It can be suggested here that a society is best judged by how it provides for the weak, rather than how it rewards the strong. The best index of a society's health is the way it assists its individuals with handicaps. The test of any civilization is the measure of care and consideration it gives to its weakest members. One of the weakest groups in our society today, worldwide, is the mentally retarded population.

The American Experience

The U.S. has a 200 year-old history of treating people with MR. Traditionally, policy with regard to treatment has been to remove MR people from their families and communities and place them in large residential facilities. At times, these people have been left to themselves until it was time to eat or use the toilet (Rivera, 1972; Rothman & Rothman, 1984).

Prior to the twentieth century, MR people lived at home with their families as there was no real alternative due to the lack of services. In the late nineteenth and early twentieth centuries, however, the institutional model evolved. The institutions basically provided custodial care with the clients separated from their families and from society at large. Most of these facilities were built in secluded areas. It was assumed that the MR population was incapable of learning or of leading productive lives. They were provided with food, shelter, and very little else. They received no vocational, social, or self-help training. This was common until the middle of the twentieth century. It was not until the Willowbrook Consent Decree was signed into law that the system of treatment for the MR people began to change (Rivera, 1972; Rothman & Rothman, 1984).

In 1947, the Willowbrook Army installation was converted to a "State School" for the MR people. Overcrowding began almost immediately. In 1972, the now famous "Willowbrook Expose" was shown on ABC's "20/20." The conditions at Willowbrook were exposed for public attention, and they stirred national outrage. Shortly thereafter, a class-action law suit was filed by a parent group against the State of New York (NYSARC & Parisi, et. al, vs. New York State). The suit claimed that conditions of overcrowding, filth, abuse, and inhumane treatment prevailed at Willowbrook (Rothman & Rothman, 1984).

The result of the law suit and exposure was the Willowbrook Consent Decree signed into law in 1975. The Decree mandated the immediate improvement of conditions at Willowbrook, as well as the eventual movement of the Willowbrook residents back into the community. The four major areas of concern that the Decree addressed were: programming, staffing, environment, and community placement (Rothman & Rothman, 1984). The provisions of the Decree were as follows:

> **Programming** must include an individual plan of care, development, and services prepared by an interdisciplinary team after screening and testing.
>
> **Staffing** must include minimum staff to client, clinician to client, and supervisor to client ratios.
>
> **Environment must** include a living unit that offers clients' privacy, dignity, comfort and sanitation; a living unit that is sectioned off so that no more than eight residents live or sleep in one unit. Every building must be kept clean, odorless and insect-free.
>
> **Community Placement** must include the development and operation of a broad range of non-institutional community facilities and programs to meet the needs of Willowbrook residents.

By 1981 Willowbrook was reduced to an institution of 250 or fewer beds. The Office of Mental Retardation and Developmental Disabilities (OMRDD) of the State of New York accepted responsibility for the development and operation of hotels, halfway houses, group homes, sheltered workshops, and day care training programs until other governmental or private agencies developed and operated such facilities and programs.

The Willowbrook Consent Decree is noteworthy in that it specifically described the conditions and treatment to which the MR people were entitled. For the first time, the rights of the MR persons were protected by law. Since 1975, the rest of the states have signed similar laws using the Consent Decree as a model. In 1981, the Consent Decree was extended for an additional five years. There were simply not enough services available at the time to absorb the residents into the community. (Rothman & Rothman, 1984).

Despite its limitations, the program for MR people in this country is one of the world's largest in terms of the dollars spent per person, and the magnitude of federal, state, and local governments' involvement. Quality of care is inspected routinely by the well-trained quality assurance professionals, administrators and support staff. The regulations include provisions for the protection of individual rights, management and operation of programs, as well as involvement of parents and individuals in planning and decision making. In this regard, New York State has been in the forefront of individualization of programs as well as continued research (Rothman & Rothman, 1984).

MR in Bangladesh

Bangladesh is an independent country with an area of about 56,000 square miles, situated in South Asia. It was a part of undivided India (known as East Bengal) until 1947, and became a part of Pakistan (known as East Pakistan) when India was divided into Pakistan and India after the British rule was withdrawn. In 1971, Bangladesh was separated from Pakistan following a war of liberation. Bangladesh has an agrarian economy. Per capita income is about US $ 191. The present population of the country is about 110 million with a 2.16% annual growth rate. The literacy rate is 24% (Introduction to Bangladesh, 1991).

Since Bangladesh is a newly liberated country, its professional treatment and care of people with MR has also a very short history. According to the Progress Report of the Department of Social Services of the Government of Bangladesh, the MR population was estimated at about 3.3 million in 1991.

In Bangladesh, where the country and most of its families are burdened with the task of survival, MR constitutes a special problem. Unfortunately, there is no organized service for this group. The reason perhaps is that the government and society are so overwhelmed with a multitude of social, economic, political, and general health problems that the issue of MR has not received the attention it deserves (Zaman, 1988).

Moreover, in Bangladesh there is no standard scale now to measure and identify the MR population and classify them into specific categories and/or functioning levels. As a result, no specific treatment services have been developed. Thus, the area of MR needs and services remains neglected and is still an unexplored facet of Bangladesh society.

Nonetheless, without conducting a scientific study of MR prevalence and incidence, the Bangladesh government is providing services to the MR people through two departments. The Department of Health provides some temporary medical treatment services through the psychiatric and/or mental health units of different government run hospitals. These hospitals are mainly located in the cities and urban areas. Generally these treatment services are for outpatients. Short term hospitalization (up to 3 weeks) is provided, but rarely. There is only one mental hospital in Bangladesh where long-term mentally ill and MR patients are kept up to two years. Only the patients of rich and middle class families can afford such hospital services. Poor people do not have any hope of being served by these facilities, although they are not modern, scientific, specialized nor consistent in their treatment of mentally ill or retarded patients.

In addition to hospitals, the Social Service Department of the Government of Bangladesh also provides services for those vagrant mentally ill and retarded patients who have escaped from their homes or families and who do not have homes or families and are wandering the streets in villages and cities. Officers of the Social Service Department are instructed to pick up these vagrant MR people from the streets and place them into government shelters where they are provided with food and clothing. Unfortunately, however. the government does not have any program for scientific diagnosis, medical treatment, identifying social, behavioral and intellectual deficiencies. There is no program for their intellectual, social. recreational. cognitive. personal hygiene care, daily living, travel, literacy and vocational skills development.

A few not-for-profit organizations in Bangladesh founded, in the late 1970's and early 1980's are trying to organize programs for the MR people in the non-government sector with the financial help of European countries. One of these organizations is the Society for the Care and Education of the Mentally Retarded, Bangladesh (SCEMRB) founded in 1977 with the initiatives of some parents and well-wishers based in Dhaka. This organization's first project was a school for the MR children, "Willes Little Flower School" started in 1978. In 1982, the Bangladesh Institute for Mentally Retarded (BIMR) was founded with the help of a Norwegian donor agency, NFPU. BIMR has started programs such as mother and children group training, special education classes, vocational classes and sheltered workshops, community and recreational trips, Saturday week-end club, home-based rehabilitation program, outdoor clinical services and early intervention. Of the vocational programs, activities such as carpentry, weaving, textile, embroidery, sewing, knitting, leather work, bakery and food production are very popular. BIMR has the dual functions of providing direct services to MR people and acting as a resource and training center for its branches. The branches of BIMR were started in the different parts of the country and by 1990, 27 branches were opened, of which 3 are in Dhaka city and the other 24 are in the district cities. BIMR has been launching programs for parents and community awareness campaigns and rural outreach programs. BIMR is also deeply engaged in publicity in order to make people aware of the problems of MR and to ask them to cooperate in dealing with problems in any way possible.

SCEMRB has established its priorities which are: a school for the MR children. Early intervention programs are essential both at homes and in schools. Special education is to be designed to prepare children for vocational classes within a 7-year program. MR children are provided training to reinforce their social skills and encourage their increased independence. A Sheltered workshop is planned for those who would complete 2-3 years vocational activities.

This plan includes the placement of the MR individuals in the community after they develop the required skills to merge themselves with open employment opportunities. Residential services, however, are not seen as a priority by SCEMRB. Instead, it prefers only a 4-5 bed small group home for the young adults (Directory of SCEMRB, 1990).

In Bangladesh, the argument is frequently heard that so much has yet to be done in the field of education for the "normal" population that it is not possible to give any educational priority to MR children. But the MR children have the same moral and constitutional rights to education as all other children. While the existing education infrastructure is only able to cover less than 50% of all children, MR children, under the constitution, should have their due share of the scarce educational resources available. On the other hand, government does not have much experience with the needs of MR people. The Bangladesh government's third five-year plan (1985-90) was the first to explicitly express an obligation toward the welfare of the MR people, although other groups of disabled people have been recognized in this manner since the early 1960's.

The government has recently become involved in some programs for the mentally retarded. A fully equipped building has been provided by the government out of its own resources for the newly established "Institute for Mentally Retarded Children" (IMRC). In addition, a "National Complex for Special Education" has been established with the government resources and with the technical and financial assistance from Norwegian government and non-government organizations. Until now, the government has preferred to assist non-governmental organizations (NGO) working for the disabled with investment in the physical infrastructure leaving operational costs to the NGO concerned (SCEMRB, 1988).

The National Institute for the Mentally Retarded (NIMR) was founded in early 1980's. It's objectives are: promoting training and education; disseminating information on scientific and technical knowledge and skills about diagnosis, treatment, programming; delivering modern clinical services; and providing better program management for the MR people.

Mental Retardation Needs Family and Community Integration

In Bangladesh as well as in the United States, the greatest barrier to rehabilitation of MR persons is, perhaps, the public's negative attitudes to such individuals. The view of the service providers is, however changing, as the label "sub-normal" is changed to "person with learning difficulties," acknowledging handicaps is gradually becoming more acceptable. The past attitude of segregating the MR people is fast waning as it becomes recognized that they should be integrated as much as possible in the family, community, and society. The Willowbrook Consent Decree of 1975 of New York State is the greatest example of changing public attitudes towards the MR people. The celebration of the Decade for Disabled by the UN is another great step of acknowledging and accepting MR people in society.

To accomplish these goals, Konig (1982) noted that MR people need help from "normal" people in their immediate environment for care and treatment services in order to learn better skills to adapt themselves and live as independently as their functioning levels permit. At the same time, MR people and their families need help from the community. In fact, they need community-based services. The advent of community-based services explores the opportunity to develop more effective ways of reaching individuals heretofore unreachable. Community care means providing a service as close to the home of the disabled person as is reasonable. It means providing a comprehensive and coordinated service in the least restrictive setting, preferably in their own home, with their family, and within their own cultural environment. When this is not possible, however, some sort of group home needs to be provided, especially for adults (Haque, 1989). Therefore, whenever possible MR children should be kept in his/her home and culture and be allowed to study in school with other "normal" children. Placement in large, congregate institutions should be the last resort.

It is a fact that the mother and father are the first and the most important teachers for the child, particularly for the MR child. The most essential people in the life of an MR child, are both of his/her parents, even if, in most cultures, the mother is the primary person, the first source of love and nurturance, and also the first teacher (Gohli, 1981). According to Intagliata and Willer (1981), our families, to a large extent, have made us what we are. The family has always been the basic unit of society and will continue to be so in the future. Every child, whether normal or orthopedically disabled, blind, deaf, or mentally retarded, establishes his/her first contacts, goes through his/her first experiences and develops both physically and mentally within the family unit. The MR child is especially dependent on his/her family for his/her survival and well-being.

According to Miller and Miller (1977), the crucial role of the parents should be to strive for the integration of the disabled child into the mainstream of society. The parents themselves should evolve a larger role and become an integral part of their child's daily functioning life. This in turn could result in parents becoming more articulate in expressing, from a holistic point of view, what they want for their disabled child. Miller and Miller (1977) continued that if the disabled are to be integrated into the mainstream, all facilities for their growth should also be integrated into the mainstream." Vanier (1979) mentioned that from the very beginning, parents are the real volunteers in relation to their MR children. Therefore, the parents should learn how they will work with their MR children in order to establish effective community-based rehabilitation services.

Rodriguez (1987) advocated the use of social supportive relationships for community integration in addition to the provision of other necessary services to MR people and their families. He said, "In supportive relationships, we are there for people in need. We communicate an interest and a desire to be helpful. We show empathy for the painful dilemmas that they face; we offer reassurance and hope; and we express confidence in the person's strength and competence to surmount the present problems." He argued that in supportive relationships, feelings and emotions play a larger part than cognition. People receiving emotional, moral and material support feel validated as human beings, stronger and more competent and hopeful about the future.

Rodriguez also advocated the involvement and use of information and referral services as well as continuous outreach efforts to overcome barriers to outside support. He concluded that the most effective way to provide human services is outreach services. Kusher & Davidson (1978) found that the recipient must initiate the request for service about an information and referral system; but many do not. The reasons included their unawareness of the availability of services; their fear of unnecessary outside contact; denial of their problems; apathy towards service; receiving of misinformation about the available service, etc. Toseland (1981) held similar views that information and referral services require that the clients take the initiative in contacting agencies, whereas outreach methods are characterized by vigorous efforts to locate, contact, and engage potential clients (Kanter, 1984).

Litwak (1977) argued that such a linkage system effectively reduces the distance between the agencies and the clients. He explained that many have addressed a wide range of linkages to close distances. These linkages include the use of indigenous workers, local information centers, or other outreach services. Litwak and Dobrof (1977) suggested that agencies and clients should utilize linkages to increase the frequency of their contacts. Similarly, Watkins and Gonzales (1982) noted that the key element in the use of MR services is the establishment of linkages between services and the population targeted. These linkages are created by active outreach services. However, outreach cannot be effective until it reaches the clients (Vazquez, 1994).

In summary, it can be said here that the Bangladeshi people are a new but growing community in America, and that they have become a sizeable ethnic group in New York. Many of them are struggling to maintain and upholding their Islamic, Asian and Third World beliefs, culture and values in this Western culture, but they are scared of the degradation of American social and family values. Many also are able to put their cultural differences aside and trying to adjust with the mainstream of American society. Many are engaged in developing new Bangladeshi community by incorporating the good values of both cultures.

As mental retardation (MR) is a global problem, it does not maintain the boundaries of man-made countries. MR problems strike both Bangladeshis and Americans. Therefore, the Bangladeshis in New York also face the MR problems of their relatives. But they are unaware of the services available for the MR people in New York as such services did not exist in Bangladesh. Likewise, MR service providers in New York are not aware of the existence of the MR needs in the Bangladeshi community. Bangladeshis take care of such MR problems at home. Their ignorance, financial paucity and cultural practices prevent them from seeking and accessing help for their MR relatives from the larger society. Since views about MR people are changing and more family and community integrated programs are developed for this population, Bangladeshi families with MR relatives in New York should now come forward and join the community of families of other MR relatives in order to access and utilize the available services for rehabilitating their MR relatives in New York City more successfully. This study is intended to contribute to this process.

Chapter 2: Research Design

Selection of An Appropriate Research Design

The research design is the logical sequence of steps that connects empirical data collected to the initial questions that drive the study. Ultimately, it guides the study to its conclusions. As an action plan, the design guided the researcher in collecting, analyzing, and interpreting observations. It helped determine whether the obtained interpretations could be generalized to a larger population (Patton, 1990; Yin, 1989).

The purpose of this research must be made clear first, because the purpose is the controlling force in any research project. Decisions about design, measurement, analysis, and reporting all flow from purpose. The purpose of this study is to assess the needs of the Bangladeshi families living in New York City who have MR relatives as well as to help these families find and access available MR services. In order to achieve these purposes, a formative research design was developed and implemented. More specifically, a need assessment study was conducted to identify the specific needs of these families and to find services for their retarded members so that they could increase their abilities to cope, to receive and to utilize those services which are currently available.

Alternatively, basic research designs seek knowledge for its own sake, i.e., to understand and explain how the world operates. These designs would not help achieve the purpose of this study as directly. Similarly, summative evaluation research determines the effectiveness of human interventions and actions (programs, policies, products, etc.) which can only be applied to on-going programs. This approach as well is not suitable to the purpose of this research. Likewise action research aims at solving specific problems within an on-going program or organization which cannot meet the purpose of this study (Patton, 1990 & Whyte, 1989). Consequently, none of the foregoing research strategies were selected for this study.

Instead, formative designs are intended to contribute knowledge that helps people understand the nature of a problem so that human beings can more effectively control their environment. The techniques of formative research are expected to help in the collection, analysis, and interpretation of data for achieving the objectives of this research and for translating the research objectives and interventions in measurable indices. Formative research is expected to serve the purpose of improving a specific program, policy, group of people and services and/or products as well as to improve human endeavors of these families, their relatives and community friends. In this study, a formative design is intended to improve human intervention for a specific group of people (the Bangladeshi families involved) by focusing on specific programs at specific points in time (Patton, 1990 & Whyte, 1989).

Methodology

In addition to the selection of a formative research design, techniques of needs assessment were employed following Bradshaw's and Thayer's (1977) suggestions. Subjects of this study were identified and a set of questions was prepared for interviewing the subjects. Data were collected and analyzed by using both qualitative and quantitative methods. Reliability and validity of the data and other relevant criteria were assured following the suggestions of Robert Yin (1989). In addition, in this chapter, the issues of ethics of social work research, human subjects, informed voluntary consent, statement of information for the subjects and risks to the subjects are also discussed.

Techniques of Needs Assessment

Needs assessment for the families of MR members was done following the concept of Jonathan Bradshaw (1977) who linked the concept of social need with the idea of social service. He observed that the history of social services is the story of the recognition of social needs. Social services are society's responses to themselves. In this study, the needs of these families represented the social needs and some sort of organization of society should be present there to provide social services to meet the needs of these families. From the economic point of view, Bradshaw's concept of social need is a social demand which becomes effective when it is backed financially and it becomes ineffective and non-existent when it is not. But, Bradshaw continued to point out that with respect to social services, there is normally no direct link between service and payment. And, social needs continue to be needs whether they are financially supported or not (Bradshaw, 1977). Accordingly, the needs of Bangladeshi families with MR children constituted social needs whether they are financially supported or not.

While speaking about social needs, Bradshaw (1977) observed four different types of needs; normative, which are identified by experts; felt-need, which are felt by those in need; expressed need or demand when it is not only felt but also demanded and comparative need, which is deduced by the outside observer i.e., when the same need is met for one area or group of people but not met for the similar other people. The needs of the families of mentally retarded members were felt-needs experienced by family members every day. These needs were not fully expressed, since they are new immigrants, unaware of the available services, and had no knowledge of reaching them, they could not express or demand services from the society that they are living in now. Similarly, their needs could be normative and comparative as this study identified their needs from the vantage point of an outside professional who observed their needs and compared their unfulfilled needs with those who were receiving services for the similar types of problems. Although, they were mostly invisible and unknown to professionals and outside observers, this researcher, as a native Bangladeshi, observed their problems both from outside and within the Bangladeshi community. Their needs, however, still continue to be at the stage of felt-needs and remained unexpressed.

Similarly, Thayer (1977) observed that the existence of a problem might indicate a set of undesirable circumstances in which there is a need for help of some sort. Such need is an identified problem and a diagnostic need. To help alleviate such an identified problem is the prescriptive need. A need is only met when the help or service provided brings the intended change in the conditions of the recipient. According to Thayer (1977), the everyday problems of the families to take care of their MR members create undesirable situations and required help of some sort. MR persons and their families require both diagnostic and prescriptive assistance until their needs are met by bringing the intended change of their conditions.

This study attempted to identify the diagnostic and prescriptive needs of the Bangladeshi families with mentally retarded members, and help them locate the available services, so that they could access and utilize them to bring the intended change to their conditions.

Subjects of the Study

The target population (subjects) of this study is comprised of those non-retarded Bangladeshi adults living in New York City who are providing care for a MR family member at home (son, daughter, sibling, or other kin). They were identified through a survey of families with MR members. There was more than one adult member in every family, but the whole family was considered as 'one unit or subject.'

Location of the Study

The location of this research study is the City of New York which includes the boroughs of Manhattan, Queens, Brooklyn, The Bronx and Staten Island.

Survey Questionnaire

For the survey, an interview guide and questionnaire was prepared to identify Bangladeshi families living in New York City who have MR members and to assess the needs involved in caring for them. (The interview guide and questionnaire appears in Appendix B). The questions which were asked of the care-givers are described below:

The first question concerned the respondent's sources of information on this research project: newspaper advertisements, flyers, community leaders, imams of the mosques, and friends & relatives who provided information.

A second question asked for information on family members, male or female. This question also asked if the family had any member(s) who could be considered MR. In this regard. an idea about the characteristics or definition of mental retardation, as well as the levels of functioning of the MR family members were given.

A third question asked if the participating families had anyone living with the family who could provide extra care to their retarded members. This question asked to find if the family needed any help from outside care-givers so that the family members who are currently giving care could be free to rest or work and earn for the survival of the family.

A fourth question concerned professional services such as: medical, psychiatric, psychological, nursing, psychosocial, etc. were being received or not. These are the basic professional services an MR person needs on a regular basis. The subjects were also asked if their MR family members were currently receiving any of these services, such as training in independent living or in vocational skills, which might be learned in special schools, day treatment programs, day training centers and sheltered workshops.

Subjects were then asked if their retarded family members are presently residing in any residential facilities. There are many group homes where MR persons of different functioning levels reside and are given care. For example, intensive care facilities are open for profoundly retarded persons; community residences are available for people functioning at a moderate level; and supported apartments are available for high functioning persons.

In view of the fact that many families were taking care of their MR members from birth. they learned certain skills and a general knowledge of how to provide care by doing but. for the most part. they did not have any formal training in this area. Therefore. one question in the interview asked if they felt that they needed further training to take care of their retarded members.

In addition, the subjects were asked questions about their needs for assistance in gaining access to other specific and specialized services, mainly medicaid, medicare, social security disability benefits, job placement services (for the retarded members), placement for residential services, day programs and special schools, respite services, in-home-training, home attendant, transport services, etc.

Subjects were also asked questions about any other needs that were not covered by the above questions, questions which they may need answer in order to take better care of their retarded relatives.

Finally, the subjects were asked about their religious faith in order to determine whether their religious faith influenced their decisions on exposing knowledge of their problems to the larger society to seek outside help for their MR family members.

Information on Available Services

Since most of the Bangladeshi families living in New York City have recently immigrated from Bangladesh, they face barriers in language, culture and differences in emotional responses and/or attitudes to MR. In addition, they are likely to need information about available services for their retarded family members. In this regard, a search was undertaken during this study to identify potential providers of MR services presently available in New York City.

A government and a private agency, both currently engaged in providing services to MR people in New York City, were contacted in order to find different types of services currently available in New York City for MR people. When interviewed, social workers from each agency were asked questions about what services their respective agency is currently providing to MR people and what criteria their agency has for recruiting MR people for the services. Moreover, a list of available services has been prepared, based on the individual needs of each family.

Ways of Recruiting Respondents

To inform potential respondents of the availability of researcher to provide guidance to services, advertisements were placed in the five Bengali weekly newspapers (Thikana, Probashi, Bangalee, Sangbad and Parichoy) published in New York City, and flyers were distributed through Bangladeshi grocery stores. Moreover, Imams (prayer leaders) of the Bangladeshi mosques and other community leaders were involved in identifying the Bangladeshi families with MR members. (Copies of the advertisement and the flyer are given in Appendix A). In addition to the above initiatives, the researcher also spoke to the Bangladeshi people in social gatherings and urged them to help find families with MR relatives. Efforts were taken to use Bangladeshi friendship networks such as family relations and community social, cultural, religious, professional, regional, non-profit, charities and business organizations to find such families.

Informed Voluntary Consents

To gain access to information from members of Bangladeshi families with MR members who responded during the search, a signed informed voluntary consent form was obtained from each of those families who agreed to participate in the study. Before answering any questions. families were asked to read a statement of voluntary consent. When they agreed to the content of the statement, they were asked to proceed to respond to the questions. For those who could not speak or read English. the reseacher translated the statement to Bengali, the native language of all Bangladeshi people including the researcher. A copy of the statement was given to them to take home, so that their relatives and friends could read it and consult with them for making their independent decision to participate in this research.

Methods of Data Collection

Data were collected in a single stage survey conducted during January 1996 to June, 1996. To maintain the anonymity of the subjects, code numbers to indicate the borough in which they live were assigned to each family. For example: in the code 1:Q1, 1 was the serial or family number of the total list, and Q1 was the serial or family number of the Borough of Queens.

The researcher collected both qualitative and quantitative information in the survey, and those data were processed using both the qualitative and quantitative methods of data analysis. Responses were analyzed and presented with qualitative quotes, absolute numbers and percentages.

First Contact with Potential Respondents

The first step in identifying target families generally came through telephone contact. Most people called directly and talked to the researcher. A few left messages on the answering machine, while still others were contacted through Caller ID technology. The researcher also heard from a few individuals who gave him the telephone numbers of their relatives or friends and requested help for them.

During this initial contact, the definition of "mental retardation" used in this study was discussed to determine if the individual and the family were appropriate to the study. Originally, thirty four families were deemed appropriate for the study, and their phone numbers and home addresses were recorded for further contact. After some initial discussion on the telephone, 5 families expressed reservation about further contacts and they were excluded from the study. Thus, the research sample was reduced to 29 families.

Interviewing Procedures

Prospective respondents were called back by the researcher, and asked if they would like to meet him and discuss their family needs. Appointments were made to meet with these respondent families in their homes or in the home of the researcher, at the respondents' convenience. Whenever possible, the appointments are private, without distractions from the environment. After exchanging greetings in traditional Bangladeshi ways, the researcher began by talking about the respondents' homes and relatives back in Bangladesh and about the socio-economic conditions of Bangladesh. Some common information was also exchanged between the families and the researcher: the length of time they have lived in the US, and various problems encountered by members of the Bangladeshi community in New York. This exchange of information was designed to put the respondents at ease and to establish rapport with the researcher.

The researcher then discussed the objectives of the research. The families were initially told that the responsibilities of the researcher would be to assess their family needs, then find the sources of available resources for support and services to meet those needs. They were also told that although they would be informed about available resources, it would be their responsibility to contact those sources. The researcher went on to say that after the project was completed, it might be possible for the researcher to link them with service providers if this proved necessary. It was made clear, however, that the researcher could not guarantee services for their family members. The families were also told about their rights and obligations associated with participation in the research, of their human and ethical rights to withdraw from the research at any time without giving prior notice, about the confidentiality of their information, and about the protection of their identity from disclosure.

When these assurances were given, the content of the informed consent form and the needs for the research project were then discussed. After discussion, the families were asked if they wanted to participate in this research project purely on a voluntary basis without any monetary benefit. Those who signed the voluntary informed consent form were accepted as active participants in this research effort. Upon receiving written and signed consents. the researcher continued to discuss the procedures of the project with those who signed.

Sampling

No randomized or probability sampling of the subjects was employed in this study. All eligible and willing subjects were participants in this study. Consequently, generalizability of the findings is problematic. However, given the difficulty in finding eligible subjects and the absence of previous studies, a purposive/convenience sampling strategy was chosen (Patton, 1990).

Methods of Data Analysis

Smith (1990) suggested that in formative research there are essentially two strategies of collection and data analysis: quantitative and qualitative. Previously, Epstein and Tripodi (1978) had noted that, although quantitative research methods have dominated research agendas in social work, many have argued that the qualitative method would be more compatible with practice. All three - Smith, Epstein and Tripodi - have demonstrated that the combined use of quantitative-qualitative methods has brought better results through the utilization of the fruits of both. (Smith, 1990; Epstein and Tripodi, 1978). All three noted that quantitative analysis is appropriate to summarize the data in closed-ended questions; but qualitative data analysis helps summarize opened-ended questions as in personal interviews, i.e., process notes about the program, and in the descriptive case records.

By using the quantitative method the researcher sought to maximize the objectivity of the study and the external validity of the findings, i.e., how many families were currently receiving services, how many needed what types of specialized and professional services, how many needed in-home and out of the home services, what types of needs were associated with different levels of functioning, etc. Numerical data were statistically analyzed according to frequency distribution, and measures of central tendency for further descriptive analyses. Parametric statistics, however, were not considered appropriate for use, because the study was not based on random sampling. Consequently, the data generated by this present investigation were not suitable for parametric statistics and generalization from the findings were approached cautiously.

By using the qualitative method, the researcher hopes to validly describe the respondents' subjective experience by tapping the deeper meanings of having an MR child in an alien culture. This human experience was conveyed in expressions of suffering, pain, stress, financial drain, social isolation, rejection, abuse, shame, guilt, long episodes of non-stop anxiety, over-burdened physical work, and the many other problems faced by the respondents every day. Such painful descriptions of the lifelong problem of Bangladeshi immigrant parents with MR children could not be rendered in quantitative form. Use of the qualitative method brought to light those inner feelings, experiences and inherent strengths needed to deal with a practically and emotionally stressful situation.

Despite epistemological differences in these research approaches, this researcher used both quantitative and qualitative methods as legitimate complements to each other throughout this project. Both of these methods were used within this same study and thus the benefits of each were exploited wherever possible in order to derive the most valid and reliable picture of the needs of this population.

Weaknesses and Strengths of the Study

There were a number of acknowledged weaknesses and strengths manifested in various aspects of this study. They are as follows:

Weaknesses

- There is no other study available on this issue involving the Bangladeshi community in the US. Therefore, there is no baseline data or other available information for reference and support for this research.
- Most of the Bangladeshi families are new immigrants and are struggling for survival, both financially and culturally. This made for difficulty in recruiting subjects.

- Bangladeshi families with MR relatives are reluctant to discuss their problems due to the perceived stigma attached to MR. Here again was an obstacle to recruitment of potential participants.
- Consequently, the study population offers an exploratory look at the problem, with issues of generalizability unaddressed.

Strengths

- Bangladeshi people are concentrated primarily in a few specific locations in New York City and they were initially reached rather easily and directly.
- Bangladeshi grocery stores, mosques, literary forums, community gatherings, and Bengali news media such as Bengali weekly newspapers, and TV programs in New York City were convenient and effective sources of communication with Bangladeshi community.
- As the researcher is himself a Bangladeshi native, from the same cultural and social background as potential respondents, he has easy access to Bangladeshi families. The long extensive professional social work experience of the researcher also helped greatly to motivate and lower the barriers with Bangladeshi families in their search for information.
- The foregoing factors facilitated the recruitment of participants and the gathering of information that is thought to be an authentic expression of the experience of participants.

Reliability And Validity

This study followed standard guidelines for ensuring reliability and validity of the collected data. Research is a process of applying scientific procedures to accumulate reliable and valid evidence on the manner and extent to which specified activities produce particular effects. Reliability and validity of data are essential to the conduct of research.

In reliability, the concern is how much of the variation in the measured phenomenon is due to inconsistencies in measurement, rather than true differences in the phenomenon being measured. The goal of reliability is to minimize the errors and biases in the study data. (Yin, 1989). In an effort to promote reliability, this researcher followed a number of operational steps to standardize data-collection procedures in order to accumulate reliable information and to minimize errors and biases. As such, all the data were collected directly from the subjects, by the researcher, through face-to-face interviews in the native Bengali language that the subjects and the researcher speak most comfortably. Initial responses, both qualitative and quantitative were restated by the researcher to the subjects to ensure the reliability of the researcher's written notes. In addition, many subjects gave responses in writing.

Validity refers to the degree to which an instrument succeeds in measuring what it purports to measure (Yin, 1989). Face validity was promoted through rigorous development of a clearly defined research instrument and systematic analysis of participant responses. By matching qualitative and quantitavie respones, the validity and reliability of findings was enhanced. However, as stated earlier, the external validity of the findings cannot be tested, statistically.

Ethics of the Study

The researcher was aware of the principles of social work ethics and carefully maintained them in this research project. Everyone involved in this research was treated fairly, equally, and with respect and dignity, regardless of their religion, disability and socio-economic and political status and backgrounds. They were greeted in Bangladeshi ways such as "offering Salaams for the Muslims and Namaskars for Hindus." They were addressed as "Apni." the Bangladeshi word used to address respected persons. Salaams and Namaskars were also offered at the end of each session instead of customary American "Good-bye." In addition, many other Bangladeshi customs were honored during the interview sessions to create an environment of respect and comfort for participant families.

Human Subjects Issues

Throughout the study, the confidentiality of the identified subjects was carefully protected. Each subject was assigned a code and their names were not used. Measures were taken to protect the subjects from any physical or psychological abuses and from social, legal or other impediments. In obtaining a voluntary and non-binding written informed consent from each participating family, no fear or intimidation was used in any way. The subjects were told about their rights to refuse to participate in the study and to refuse to answer any question at any time, even after they agreed to participate.

Statement of Information for the Subjects

The Statement of Information was prepared as a part of the guidelines to be followed by the researcher. After making the first contact with the selected subjects, the researcher read a "Statement of Information" to each and every selected subject, several times if needed, until the subjects indicated that they understood what was read to them. The subjects were also given a copy to be read by themselves. Everyone was given a copy of this statement to keep with them so that they could read it at home and discuss their rights and obligations with other family members.

The statement was given and read out to every subject before their Informed Consents were taken. They were given enough time and opportunity to think and discuss it with family members. friends and relatives before making a decision to participate in the research project. The statement appears in Appendix C.

Risks to Subjects

Because of the precautions taken above, the study did not result in any physical, emotional or legal problems for any subjects. However, as a result of the social and cultural superstitiousness, the ignorance and closed societal ties in Bangladesh society, many subjects might have felt somewhat uncomfortable about disclosing the fact that they have MR member(s) in their families. Having a retarded person in a family is not viewed as socially desirable by other members of the society. It created problems for marriages and other social relationships. Being of a different culture, often Bangladeshi families with MR relatives are not aware that this country provides services to MR people and their families as a matter of course. Although, there were no legal, psychological or physical risks, they might perceive a social stigma, as to some of the other groups of people in this situation.

There was a great necessity to seriously take into account such risks; even if they did not actually exist objectively, because these families had suffered for years without any help from others in caring for their retarded members. Many, if not all, are financially and emotionally exhausted. As a result, sometimes whole families become crippled. They need help from others, especially from the larger society. They need financial, medical, nursing, psychiatric, psychological, psycho-social, technical, moral, emotional, counselling and other social support to care of their MR relatives and to provide the survival of their families.

Families with MR members should be motivated and encouraged to come forward with their problems and have access to services and other support, which are currently available for this population in New York from government and non-government sources. These families need to be exposed to information and the fact that there are thousands of families in New York City who are in similar situations and feel shy and uncomfortable. They must be taught to be assertive in going about the business of obtaining services and support that are available from different sources.

It should be mentioned here that as the researcher, I understood these perceived risks and fears personally. I am from Bangladesh and understand their sensitivity. I talked to them personally and worked with them to alleviate their fears with empathy and by sharing my personal experiences of 9 years of social work with the MR in the US and that families need not be fearful of any social, legal, psychological, or physical reprisals by availing themselves of services, either immediate or long range. If I felt that someone was not comfortable, even after talking to him, I would stop interviewing the person and refer the person to the available services. The person would not be recruited as a subject. However, this did not happen. All who agreed to participate appeared to be comfortable with the research project after the interview began.

In fact, this feasible and practical approach gave these families who are no longer living in Bangladesh, an opportunity. They are now members of American society where they don't have closed societal ties and fears of discrimination. In this context, they could join other families with MR members and share their pain, sorrow, and suffering with them as well as avail themselves of the opportunities for treatment, services and supports made available for them from different government and non-government sources in New York City.

This does not imply, however, that they found easy access to services as a result. The latter involves a long process, much paper work and communication with a number of agencies and people over a number of months. Usually, there is a big demand for these services. Sometimes, needy people need to wait for years to gain access to the services. And, even in the United States, resources are limited.

Final Report of the Study

The findings and recommendations of the study are put together in a final report which is this Dissertation. The report will be available to the interested professionals and relevant organizations and members of the Bangladesh community.

Chapter 3: Study Findings

Finding Bangladeshi Families with MR Persons In New York

This study has made an extensive effort to accurately estimate the number of Bangladeshi people who immigrated to the United States and who are living in New York City. Public and University Libraries have been searched and United States, New York State and New York City Census reports as well as reports of the Visa Office and the Immigration and Naturalization Services have been reviewed. In addition, contacts have been made directly with the responsible officers of the Visa Office of the Department of State and the Office of the Annual Demographic Statistical Reports of the Immigration and Naturalization Services, Department of Justice, Washington, D.C. The respective officers of those Departments, who provided what information is available, were very cooperative and helpful. They spoke over the telephone, faxed and mailed that information, immediately. Thus, the information of the immigrant visas, non-immigrant visas, changes of visa status from temporary to immigrant and citizenship for Bangladeshi people were obtained from 1972 to 1995. But no figures were available about the number of Bangladeshi people who came prior to 1972 when Bangladesh was a part of Pakistan and prior to that when a part of undivided India. Nor was a figure available about the number of the American-born Bangladeshis to date. Similarly, there is no accurate number available of Bangladeshi people who came with non-immigrant visas and continue to live in the United States. By the same token, no definitive number of Bangladeshis, who are currently living in New York City, could be determined. The approximate total Bangladeshi immigrants in America today has been generally estimated to be 107,657 including about 53,828, who are living in New York City. (Reports of Visa and INS offices, 1972-1995).

Efforts have also been made to calculate the number of families who have MR members living in New York City. The result was slow and discouraging. Only 34 families were identified, of which 29 families have agreed to participate in the study. Although, as it has been said earlier, about 3% of the total population are MR in Bangladesh, it is not possible to determine whether 3% of the total Bangladeshis living in New York City are retarded. Many immigrants did not bring families; others brought part of their families. Many left MR relatives in Bangladesh antaicipating problems in obtaining US visas and in providing care after coming to this new country. Financial survival is the main issue for many of these immigrant and non-immigrant families. Also, because of the fears of humiliation, isolation and loss of family prestige, many families did not come forward to expose themselves to this study as the families with MR relatives. It is also true that efforts to locate all Bangladeshi families who have MR relatives were not entirely successful. Therefore, the accurate estimates of the number of families with MR relatives cannot be determined. Ultimately, however, it is hoped that more families will come forward to avail themselves of needed services when these services are known to them and when they find courage, confidence and assurance that they will not be humiliated, isolated or neglected by service providers.

Findings of This Study

The findings of this study are presented below both in quantitative and in qualitative forms. The quantitative data are presented in tabular form with frequency distributions and percentages. Each table with specific numerical data is analyzed and explained with detailed descriptions.

The first intereview question asked how the respondents became aware of this project. Possible sources mentioned in the question were: the Bengali newspapers published in New York City, flyers distributed throughout the Bengali grocery stores, community leaders, Imams of the mosques or friends/relatives. These sources and their data are presented in Table 2. Of these 5 sources, 12 out of 34 (35.30%) respondents received information from the Bengali weekly newspapers. The 5 Bengali weeklies in New York City play a vital role in disseminating information to the community people. Ten of the respondents (29.41%) learned the information from their friends and relatives. These findings show that Bangladeshi people are very close with their friends and families and share MR relevant information with each other. Distribution of flyers in grocery stores accounted for the third source. Six (17.65%) respondents got their information this way. Dozens of grocery stores, therefore, play an important role to pass information by posting and distributing flyers. But the Imams of the Mosques and the other community leaders placed fourth in the information role. Only 3 (8.82%) respondents heard of this study through the mosques while the other 3 (8.82%) respondents received the information from community leaders. This suggests that the Imams of the mosques and the community leaders do not play important roles in making community people with MR children aware of information to serve them. In other words, Bangladeshi people do not always go to the mosques and their community leaders for help or receiving helpful information about personally sensitive subjects.

Table 2: Sources of Information For This Study

Sources of Information	Frequency	Percentage
Newspaper Ad	12	35.30%
Friends & relatives	10	29.41%
Flyers	6	17.65%
Mosques	3	8.82%
Community Leaders	3	8.82%
Total: 5 sources	34 Respondents	100.00%

Although Bangladeshi people in this society keep in touch with their relatives and friends, they do not appear to expose personal problems such as MR to their native community religious leaders.

Besides the above respondents, several people called and left messages as follows: "we left our retarded relatives in Bangladesh. Our hearts are with them. We will be grateful to you, if you could do something for them." In doing so, they wanted to relieve their guilt for leaving their MR relatives back home and to show that they feel for them and are still trying to help them.

Table 3: Respondents Participating in the Study

Category of Respondents	Respondents	Percentage
Total Respondent	34	100.00%
Respondents Refused:	5	14.71%
Respondents Joined	29	85.29%

Table 3 shows that of the 34 initial respondents. 5 (14.71%) refused to participate. Of the 5 who refused, 2 were only interested in joining the study if the study could find a cure for MR. One person said, "if your study can give me an answer to the cause of my daughter's problems, I shall join you." Another person said, "what new treatments will your research find for a cure to my child's problems?" One mother does not want any more help. She said, "the U.S. government is doing enough for my child."

The twelfth question was about the religious faith of participating families. It is important to consider their religious beliefs early in the chapter, in order to show how religious beliefs influenced participants' responses.

Table 4: Religion of Participating Respondents

Religion	Participants	Percentage
Islam (Muslim)	26	89.65%
Hindu	2	6.90%
Christian	1	3.45%
Total	29	100.00%

The responses given in Table 4 show that of the 29 families, 26 (89.65%) are Muslims, 2 (6.90%) are Hindus and only 1 (3.45%) family is Christian. Although, religious beliefs and cultural values affect the decisions of the families to seek help for certain diseases such as MR, with such a small sample of Hindu and Christian families as compared to Muslim families, the differences in impact of religious differences cannot be determined. Dessite their releigious differences, Bangladeshi people closely adhere to the same cultural values, social customs and superstitions which affect their decisions in seeking help for MR persons. Thus, their decisions do not differ significantly from each other.

The second question was about the gender of the family members, as shown in Table 5.

Table 5: Number of Each Gender in Participating Families

Gender	**Population**	**Percentage**
Female	68	53.54%
Male	59	46.46%
Total	127	100.00%

Table 5 shows that the total membership of the 29 families is 127 of whom 68 (53.54%) are females and 59 (46.46%) are males. Chapter 1 explained earlier that more male family members migrate to America than females. But in the families of the MR members, it appears that there are more female members than male members. To explain the reason for more female than male members in the family, one father volunteered, "I would not bring my son to America with such problems unless I could bring my wife. who could take care of him. Without her help, I could not survive. Women are especially needed for such family problems." This statement suggested that women (mainly mothers) do most of the caring for their MR children regardless of the sex of the MR children and that their greater presence in these immigrant families is directly related to MR child care needs.

The third question asked if the families have any members who could be considered MR. The responses are summarized in Table 6.

Table 6: Family Members vs. M.R. Population

Type of Members	No. of Members	Percentage
Total Family Members	127	100.00%
MR members	29	22.83%
Total Other Members	98	77.17%

Of the total family members, 29 (22.83%) were reported to be MR persons and 98 (77.17%) persons are normally functioning members. It can be mentioned here that those parents, who took the initiative to contact the researcher, said they wanted services for their MR children. In addition, they seemed interested in venting their pains of caring for their MR children. One mother said, "my daughter was performing normally for the first six months of her life. One day, she fell to the floor from bed and within a few weeks she began changing. Later, she grew up as an MR child." This mother indicated that she feels guilty for her daughter's present condition and that she will take all the pains of caring for her daughter for the rest of her life. In fact, most of the parents appeared to be guilt-ridden in one way or another for their MR children.

Table 7 shows that of the total MR persons identified through this study, 11 are mildly, 9 moderately and the other 9 are severely and profoundly retarded. Eight of them are up to 5 years old children, twelve are between 6 and 20 years old (school age) and the remaining 9 are 21 years and older. Two of the 11 mildly MR are children, 4 are of school age and 5 are adults. Two of the 9 moderately MR are children, 3 are of school age and four are adults. Finally, 4 of the 9 severely and profoundly MR are children; 5 are of school-age and none are adults.

Table 7: Age and Classification of M.R. Population

Classifications	**No. Of MR Persons by Age Groups**			
	Up to 5 Yrs	**6 - 20**	**21 - Above**	**Total**
Mild	2	4	5	11
Moderate	2	3	4	9
Severe/Profound	4	5	0	9
Total	8	12	9	29

Classification of the MR persons as reported by their respective parents/guardians is done in 3 groups: namely, mild (educable), moderate (trainable) and severe/profound (custodial) as shown in Table 7. They are grouped according to their social, intellectual, behavioral and daily living skills and functioning levels as described by their parents/guardians. They are also classified into three age-groups. The age-groups are determined according to their relevance for the utilization of the available services. The children up to 5 years old (non-school going) need different types of programs which might be home and nursery or day care-based. The public school system has special schools for the school-age MR persons. Adults, however, are not allowed in the public school system. The Office of Mental Retardation and Developmental Disabilities (OMRDD) of the State of New York provides funding to hundreds of not-for-profit agencies for running different types of day programs for the MR persons of this age-group.

The study of population suggests that more mildly and moderately retarded adults came to the US than children. No severely or profoundly retarded adults have come to the USA. Several parents said that they brought their younger MR children to the United States for treatment. They said that if their MR relatives would have been adults and profoundly or severely retarded, they would not have brought them here.

It is very difficult to control the behavior of the profoundly or severely MR adults. Support is needed from extended family members or domestic help in this new society. However, family members are often not available and domestic help is not affordable in America. Respondents also believe that once an MR person becomes an adult and continues to function as profoundly retarded, there is not much hope for any cure or improvement. On the other hand, they hope that younger MR children might have hopes of improvement if proper treatment is available. Therefore, more trainable and educable adults and more custodial young MR persons have immigrated to America with their families.

The fourth question involved the availability of extra help within the family to assist with the disabled individual. These responses are in Table 8. In this table, 17 (58.62%) families said that the mother of the retarded individual was helping their children with their needs. The other 12 (41.38%) families said that they did not have anyone within their family to help.

Table 8: Availability of an Extra Person in the Family

Availability	Number of Participants	Percentage
Available	17	58.62%
Not Available	12	41.38%
Total	29	100.00%

These findings support the patterns noted in Table 8 which revealed that there is a lack of availability of additional persons in the family to help the MR individual with his/her needs. Those who directly care for the MR persons often get "burned out" and need respite. At the same time, these families have great difficulty functioning with only one source of income. Consequently, female members need to work as well, to supplement the family's economic survival. In describing their financial and physical hardships, one mother said, "I am the only person to help my child with extra needs. I need my entire time and energy only for my child. My husband works day and night to earn money to keep us alive. I need time to rest for myself and to work to earn extra money to help my family survive. I cannot even do baby-sitting. No family brings babies to me because of my child's problems. I live in isolation from the rest of the society."

The fifth through eleventh questions are about the service needs and desires of the respondent families. The responses to these questions have been summarized according to the specific needs as expressed by the respondents. These responses are included in Table 9.

Table 9: The Service Needs of 29 Families

Services	# and % of Families Receiving		# and % of Families Needing/Wanting		# and % of Families Not Wanting	
Social Worker for Assessing Services	0.00	0.00%	29	100.00%		
Psycho-Social Evaluation	0.00	0.00%	29	100.00%		
Psychological Evaluation	0.00	0.00%	29	100.00%		
Psychiatric Evaluation	5	17.24%	24	82.74%		
Medicaid Card	7	24.14%	22	75.86%		
Medicare Card	0.00	0.00%	29	100.00%		
Skills Development Training for MR People	0.00	0.00%	18	62.07%	11	37.93%
Day Programs	4	13.79%	19	65.52%	6	20.69%
Group Homes	0.00	0.00%	4	13.79%	25	86.21%
Disability Benefits	2	6.90%	27	93.10%		
After School Attendant	0	0.00%	7	24.14%	22	75.86%
Full-Time Home Attendant	0	0.00%	10	34.48%	19	65.52%
In-Home Training and Tutor	0	0.00%	19	65.52%	10	34.48%
Respite Services	0	0.0%	17	58.62%	12	41.38%
Job Placement Service	0	0.00%	8	27.59%	21	71.41%
Interpreter Service*	0	0.00%	18	62.07%	11	37.93%
English Language Training*	0	0.00%	5	17.24%	24	82.76%
Free Transportation	4	13.79%	15	51.72%	10	34.48%

Services	# and % of Families Receiving		# and % of Families Needing/Wanting		# and % of Families Not Wanting	
Adaptive Equipment	2	6.90%	6	20.69%	21	71.41%
Speech Therapy	2	6.90%	14	48.28%	13	44.83%
Physical Therapy	0	0.00%	5	17.24%	24	82.76%
Occupational Therapy	0	0.00%	6	20.69%	23	79.31%
Long-Term Nursing Care	0	0.00%	5	17.24%	24	82.76%
Treatment for a "Full Cure"	0	0.00%	5	17.24%	24	82.76%
Medical Treatment	7	24.14%	22	75.86%		
Training for Families	0	0.00%	15	51.72%	14	48.28%
Better Special School*	2	6.90%	8	27.59%	19	65.52%
Separate Center for Bangladeshi People*	0	0.00%	12	41.38%	17	58.62%
Help with Immigration*	0	0.00%	5	17.24%	24	82.76

* These needs were not mentioned in the questionnaire, but were raised by respondents. spontaneously.

Table 9 is a summary of all assessed needs of those who participated in this study. In this table. column one is the name of the service, columns 2 & 3 are the number of families currently receiving some of these services, columns 4 & 5 are the number of families who need/want these services and columns 6 & 7 are the number of the families who do not want services. There are 29 different types of specific needs identified by interviewing the 29 families.

Regarding the service needs of professionals, this study found that all the participating families wanted help from qualified social workers to enable them to access services which they need to ease their survival. They need psycho-social, psychological, neurological and psychiatric evaluations including current functioning levels of their MR relatives. None of them have received psycho-social and psychological services. Only five (17.24%) of these families have received psychiatric evaluations, but only on a one-time basis. These families did not know whether psychiatric services will be provided again if needed. Another 24 (82.74%) families indicated need for psychiatric services, as well.

The question referring to the need for help from a qualified social worker in finding and accessing services was not, at first, understood. After giving respondents a brief idea about the roles of a social worker, the families realized that they needed a person like the social worker who can help access the services. They also need a friendly person like the social worker with whom they can talk and vent their pains and sufferings. One parent said, "we didn't have such professional social workers in Bangladesh. We now know we need a person who is familiar with our problems and can help us reach these available resources." Another parent expressed his frustration that he took his daughter for the required professional evaluations about four years ago for admission into a day program, but his daughter was put on a waiting list. He was waiting for years without hope. Through this researcher's intervention, his daughter was admitted into a day program within a few months, including all the required tests and evaluations done free of cost.

Regarding the need of Medicaid and Medicare cards, only 7 (24.14%) families said that they have received Medicaid cards and none received a Medicare card. Twenty-two people (75.86%) need Medicaid and 29 (100%) need Medicare cards. Only 4

(13.79%) families are currently receiving disability benefits from the Social Security Administration with the remaining 25 (86.21%) families needing disability benefits.

The responses to the questions on the need for Medicaid and Medicare cards as well as disability benefits were very enthusiastic. These services are supplied from the Department of Social Services and the Social Security Administration. Medicaid and Medicare pay for evaluations, medical treatment, prescriptive medications, transportation to special schools and other day programs, adaptive equipment, therapy, in-home training, respite, medical and nursing services, etc. Disability benefits are cash payments given to the care givers for taking care of the MR persons. These are very lucrative benefits for the parents, agencies and other service providers. But they are very hard to obtain and require the skills of a qualified social worker who knows the exact eligibility requirements and the bureaucratic make-up of the Departments. One father said in this regard, "I have been trying for the last two years to obtain Medicaid and Medicare cards. I did not succeed. My applications were returned repeatedly, citing different problems such as errors and incompleteness. I need help from someone who knows how to fill out applications without errors." Another parent said, "I do not know where to go and how to apply for these benefits for my child." Many parents do not even know about the existence of such Medicaid, Medicare and disability benefits that can help for treatment, professional services, schooling, transportation, medication, adaptive equipments, food, housing, clothing, recreation, training, home-based services, etc., of their MR children. The problem lies in their lack of appropriate knowledge about MR resources and skills in accessing these benefits. Naturally, this is especially hard for people who are new to this society and these systems like the Bangladeshis.

On the question of utilizing day programs, only 4 (13.79%) families said that their retarded members go to the day programs, which are the special schools for MR children. Two of these 4 families are not happy with their schools. The other 2 (6.90%) families expressed satisfaction with the services of the school. The remaining 19 (65.52%) families want day program services immediately. Only 6 (20.69%) families do not want day program services.

The response to the need for the day program services is also very great. As explained earlier, there are different types of day programs such as day habilitation, usually for high functioning adults of 21 years and older whose IQs are at the border level, i.e., 70 or just below 70, and who are ambulatory. The workshop is also a place for day habilitation for persons of a similar level. A day training program is usually for those adults who are moderately functioning. The day treatment program is generally for those adults who are very low functioning with IQs from 0-35. They may or may not be ambulatory. They may be wheelchair bound and may have multiple disabilities such as deafness, blindness, down syndrome, cerebral palsy, etc. (Fogelman, 1974; & AJP, 1972).

Most of the parents of MR children of all functioning levels expressed their desire to have their children admitted into these day programs, except those who are still infants and require care by mothers. One parent said, "we could get some time off from such a tiring job if our child is accepted in a day program." The urgent need of these services is reflected in a painful story told by one mother. She said, "I have three young daughters

(8, 5 & 2 years old). The older one is retarded. I do not have any rest, day or night. I need a school for my MR daughter then, I can get a little relief and pay attention to my other daughters. My husband is working two shifts, seven days a week, to earn enough to feed us. He doesn't have time to see the children. Sometimes, I get so frustrated that I will not find hope for our family. I feel we both are working like slaves and isolated from the rest of the community." Most of the parents think that the modern and scientific special education system in America can gradually bring real changes in the lives of their MR children.

On the question about the need of skills development training for the MR persons, it was found that none are currently receiving any skills development training. When asked, 18 (62.07%) families said they want this training. Skills development training could increase the independent living and vocational skills of the MR persons in the areas such as cooking, shopping, money concepts, making phone calls, travelling, recreation, laundry, household chores, simple assembly jobs, etc. One woman said that her sister can improve her skills if proper training is given. She is very dependent on them at home. She needs to be exposed to outside learning opportunities. One parent has expressed his frustration that his grown daughter continues to sit on the toilet until her mother or sister comes to clean her. It would be very helpful if she could be trained in toilet using skills. She does not want to learn from her mother.

On the issue of job placement service, none of the families have yet received any such service. Only 8 (27.59%) families expressed a need for job placement service for their MR relatives and 21 families (71.41%) did not. Despite their economic hardships, many of these families do not want their MR relatives to be wage earners. They think the retarded persons are either too young, or vulnerable, and mentally and physically incapable of doing any outside job. They are also fearful about allowing their MR relatives to work under bosses of other cultures, where they might be harrassed, abused and mistreated. They are fearful about their MR relatives travelling by public transportation where there are potential dangers such as getting lost, being mugged and girls being kidnapped and sexually assaulted. One person explained his fears, "I don't feel secure to let my sister travel by subway and buses in this city. If she is provided transportation both ways, she can go to an outside job or job training." But a few parents have shown their interest in job placement for their retarded persons. One parent said, "I don't mind if my son is given a job opportunity. I believe he can learn how to travel by public transportation if proper travel training is provided." But no parents of MR females would agree to job placement opportunities without free door to door transportation.

Regarding the opportunity for residential services, none of these families would want this option. After describing this kind of placement, only 4 (13.79%) families would even want to consider this alternative. Twenty five (86.21%) families were clearly opposed to residential programs. There are 5 different types of residential facilities for different functioning levels, such as Intermediate Care Facilities (ICF) for very low functioning persons; Community Residences (CR) and Individual Residential Alternatives (IRA) for high functioning persons; Supported Apartments (SA) for more high functioning persons; and Independent Living Apartments (ILA) for the borderline retarded persons. Bangladeshi families were unwilling to consider these programs. None are using this service. None of them feels comfortable in placing their MR relatives in the hands of an institution and its employees. In fact, they express very negative ideas about the group homes which are reflected in the statements of two parents who said, "I would never let my daughter stay in any group home," and "I don't trust the employees of the agencies who are operating the facilities." Parents of MR females are expecially sensitive about placing their daughters in such group homes. They believe that sexual abuse will take place. Another parent said. "regardless of any laws to protect the residents, there might be abuse of the MR persons by the employees, because the MR persons are the weakest group of people who cannot defend themselves." After explaining to them about the laws to prevent any sort of abuse in such facilities, only fathers of 2 MR males agreed that they would try this residential option if their sons were accepted.

On the question of in-home training and tutoring services, 19 (65.52%) families expressed interest, while 10 (34.48%) did not. Seventeen (58.62%) families have expressed a desire for respite services and 12 (41.38%) families did not. Regarding the need of after-school home attendant, only 7 (24.14%) families conveyed their desire for this service and only 10 (34.48%) families wanted full-time home attendants.

The responses to the questions regarding the needs of an after-school attendant, full-time home attendant, in-home training & tutor and respite services are mixed. While only a few indicated a desire for after school attendant, more asked for full-time home attendants and a majority have asked for in-home training & tutor and respite services. None of these families are currently receiving any of these services. There is a great need for these services, but a distrust about leaving their children alone. Certain parents get very emotional in explaining the severity of these needs. The mothers need time for themselves. They want help from a home attendant in their homes to relieve them of the burden of taking care of their children at least for a few hours a day. Some of them also need time to work and earn money for the survival of their families. Many need a different type of work in order to relieve their mental stress and physical toils. One mother said, "I have been taking care of my daughter for 3 decades. I need to keep my eyes on her every single moment, 24 hours a day without any help from anyone. Even in sleep, I hear her making sounds to call me for help. If someone can help her in the day time, I can at least sleep for a few hours." Another mother described how painful it is to care for her son who has difficult behavior problems. She said, while weeping, "I cannot count how many times my son attacked me with a baton, knife or other objects. I bled so many times because of his hits and bites. He tears my clothes, pulls my hair and tries to undress me. I am tired now. I need help, at least for a few hours a day."

A few religiously conservative males responded differently. They do not want outsiders to work in their homes even for their MR children. Instead, they want financial support. One father said, "I don't want my son to be taken care of by other people. My wife is the best person for that job. I don't want any outsider to know my family problems. I would prefer to receive financial support instead of any home-attendant." Another person said, "I know how the baby sitters abuse babies in this country. I don't trust outside employees. They will abuse my child." They don't trust people of other cultures to stay at their homes for many reasons, such as child abuse and exposing family problems and properties to the strangers, etc.

The responses to the questions about free transportation for day programs, medical treatment facilities and other professional services are very enthusiastic. Only 4 (13.79%) families are currently receiving free transportation paid by Medicaid. Three of them are receiving transportation to attend special schools and 1 for attending medical care and professional services. The remaining 25 (86.21%) families did express a desire for free transportation services, because adult male members of these families go to work and cannot help transport their MR relatives to attend any service. Women respondents expressed fear of riding buses or subways or taking car services with an MR person. The statement of one mother reflected such fear clearly. She said, "as a woman, I am scared to travel by public transportation and in car service. It is impossible to travel with my difficult child. We need free buses with specially trained staff." Many MR persons have behavior problems and many are wheel-chair bound, so they need escort services with more than one person, because a mother cannot help alone. They need to walk a few blocks both ways to avail public transportation and it is very difficult to walk a few blocks in hot, cold, snow and rain with an MR person. Besides, many families are functioning so marginally that they hardly can afford car service.

The need for adaptive equipment has been indicated by only 6 (20.69%) families and 2 (6.90%) families are currently receiving this equipment. The remaining 21 (71.41%) families did not. The needs for adaptive equipment, such as wheel chairs, hearing aids, walkers, specialized plates, cups, communication board, etc. as well as physical, occupational and speech therapies, are specialized needs and not every retarded person needs all of them. Only those who have deficiencies in one or more of these areas in addition to mental retardation, need these services. When discussing adaptive equipment, one mother said, "I need a wheelchair for my child. I cannot carry her by myself." Another person said that her child needs a hearing aid and another person's child needs a special communication board.

There is a great expressed need for speech therapy. At least 14 (48.28%) families indicated this need. 2 (6.90%) are currently receiving speech therapy and the remaining 13 (44.83%) are not. But few express need for physical therapy and occupational therapy. Only 5 (17.24%) families wanted physical therapy and 6 (20.69%) families wanted occupational therapy.

On the question of the possibility of treatment leading to a complete cure, the responses are understandable. Only 5 (17.24%) families have the expectation that their MR relatives will be completely cured. But 24 (82.76%) families did realize the impossibility of this dream, and did not expect such a miracle. Most people understood that MR is not a temporary disease but a permanent mental condition. Even though, a few parents and relatives believe that with the help of modern technology, training, treatment and medicines, their MR relatives can be cured in America. One young man asked, "why is there no treatment in the world's most developed country that could cure my niece? I brought her to America for better treatment and a cure."

Regarding the issue of long-term nursing care, only 5 (17.24%) families have expressed for this need. Only those who, in addition to MR, are suffering from different types of medical problems such as, medical frailty, inability to eat and move by self, chronic diseases like cancer, high blood pressure, cardiac problems, diabetes, etc., need long-term nursing care. In discussing this issue, one woman said that her child is medically frail and needs long-term specialized nursing care for the rest of his life. She has been carrying him from the bathroom to bedroom and every place else. She is tired and wonders how much longer she could stay by his side for 24 hours a day.

At least 7 (24.14%) families are currently receiving medical treatment free of cost (provided by Medicaid), and the other 22 (75.86%) families are looking for the same services. As MR people are more vulnerable than others to the environment, they get sick frequently. The majority of the respondents revealed that they are not receiving needed medical treatment because they do not have health insurance or Medicaid or Medicare cards which are the basic ways to pay for the treatment and medicines. Most families cannot pay from their own income. Medical treatment, lab tests, professional services and medicines are so expensive that these people cannot even think to pay for them. Without health coverage, only city hospitals can provide some basic treatment. However, their treatment is not appreciated by most of these families. In this regard, one mother explained how she and her child were ignored. She said, "I do not have money or Medicaid. My MR child was not accepted to any clinic. She was accepted at the city hospital, where I had to wait for hours to see a nurse and a doctor. Nobody could imagine how difficult it was to wait for hours in line with an MR child, where others were yelling at us every moment."

Regarding the need for training the family members who take care of their MR relatives at home, it has been discovered that none of the participating families have received any such training. But the responses are mixed. Fifteen (51.72%) families have shown their willingness for such training. The respondents are divided almost equally in expressing their opinions about whether they really need the training for their family care givers, who are primarily women. Some men felt that women, who are the primary care-givers to their MR relatives, do not want to expose themselves to outside trainers for learning additional skills. But the findings suggest that many women want to learn more about MR through training, and their husbands do not let them. As men are the dominating force in these families, women's voices are usually over ruled. The following statements show how much the men and women of a family are in conflict in a family over this issue. One mother said, "I need some type of training so that I can deal with the behaviors of my child in a better way." But her husband said, "my wife and I have been taking care of our child for years. We don't need to learn anything new. We need training and treatment for our child and we need financial help." Another man said, "I don't want my wife to go to training and expose our family problems to outside people." Although women bear the burdens of caring, men dictate the conditions and needs of the family. But after coming to this open society, the perspectives of both men and women are changing. They are encouraged to minimize their differences in order to survive in this open society. Therefore, a little more than half of the respondents agreed and felt the need that their women should avail the training opportunity if offered. The other reason behind this willingness to compromise on cultural values might be that in Bangladesh, there was help from the extended family members and maids to take care of the MR persons, so the mothers did not have to bear as much physical burden as they need to do in America, where the help from the extended family members or house-maids is neither available nor affordable.

A few additional needs were raised spontaneously by the respondents during the interview. After discussing all the written questions, respondents were asked if they had any other issues, needs or problems which were not covered by the written questions. Many of them have mentioned some special needs in addition to those written in the questionnaire. These needs were mainly, English language training, interpreter services between Bengali and English languages, help for changing the visa status from non-immigrant to immigrant and the need to create a service center for Bangladeshi MR people.

Regarding the question of the need for interpreter service and English language training. the responses are mixed. While only a 5 (17.24%) families have expressed their desire for English language training, the majority (18 families, 62.07%) of the respondents expressed the need of interpreter services in order to receive better services. Many of those who have asked for interpreter service did not feel the need for English language training. They think that if the job can be done through an interpreter they do not need to spend time attending English language training. They realized that they could earn more money if they can speak English fluently, but they believe that they will improve their English eventually. At this moment, they view their time as more valuably spent earning money to help their families survive. However, the needs of English training and interpreter services are echoed through the statements of a mother who said. "I have a very hard time in communicating about my child's problems. I need an interpreter to help me explain the problems of my child." She also said, "I would go to an English course if there is a free course and if I have someone to take care of my child for that time." But many respondents, especially the males, think differently. One father said, "I do not feel that English speaking is a great problem. We need the technical and scientific services for our MR children, but not English language training for our women."

Regarding the legal help for visa problems, only 5 (17.24%) families have indicated that because of the problems concerning their legal status, they cannot avail the services and properly take care of their MR relatives. Many Bangladeshi families are living in New York with non-immigrant visas. As they are not citizens or permanent residents (immigrants), they are not eligible for the available free services, such as medical treatment, professional services, school programs or any other support services. A number of families told their painful stories in this regard. One said, "we came here to find better treatment for our child, but we could not get her treatment. We don't have enough money to pay. On the other hand, my child cannot get Medicaid unless she gets her status changed to immigrant." Another person said, "public schools accept everyone regardless of their visa status. But the special schools are giving us a hard time with our retarded child. We need help solve these basic problems."

The issue of a separate center/school or program for Bangladeshi MR people was also raised by the respondents. On this issue, many families feel that they need such center. At least 12 (41.38%) families advocated such an idea because of the language, cultural and social problems and differences. The language, religion and socio-economic systems are very different of what they are getting here. Their MR children have also grown up in those systems. Therefore, they believe, a separate center for the Bangladeshi people will greatly benefit their MR relatives. But many families do not agree. Seventeen (58.62%) families did not feel the need for such a center or school for Bangladeshi MR persons. One parent said, "I don't feel any different about sending my child to a non-Bangladeshi center. He will rather learn and adjust himself better and more quickly with the American systems." Even though, many families, particularly the families with lower socio-economic and educational backgrounds and comparatively newer migrants, feel the need for such a separate center for the Bangladeshi MR persons to which they can have quick and easy access.

Conclusions

In summary, the aggregate needs and wants of the Bangladeshi families with MR members living in New York City are enormous and diversified. From the information collected from the families, this study is able to formulate a list of both diagnostic and prescriptive needs for both the MR persons and their family care givers, and to outline the sorts of services necessary to meet these needs. A service cannot be effective, until a person with needs is identified. The group whose services are even less developed is the mentally handicapped. This study makes estimates of the prevalence of MR in the NYC Bangladeshi population; it looks at the problems of the families of the MR persons; the education and care of retarded persons and then makes certain proposals and recommendations for the social, human and community organizations. This survey has tried to give a picture of aggregate needs which can be used by the Bangladeshi community leaders and other service providers in New York City for planning the overall allocation of resources.

The specific needs of the participating families for caring for their MR relatives have been assessed and established on the basis of their feelings on the problems, expressions of their needs and asking for the services to meet their or reduce their sufferings. The information collected was based entirely on responses to a questionnaire. Since only the respondents know the true situation, it seemed best to accept the statement of the respondents as being accurate. This study has observed that when a mother was weeping and expressing her need of a helping hand for a few hours a day, it would be very difficult to deny her need of a home attendant. As Thayer (1977) put it, respondents only request services for which they think it reasonable to request or hope. The questionnaire was intended to provide a "profile" of the families concerned as well as details about the reasons for acceptance of services.

The felt needs of respondents have been assessed thus far in the study. The criteria of felt-needs were followed to establish these needs. As reasonable demand retains the criteria of felt need, namely that need is perceived by the individual concerned, it also introduces some normative criteria. Thus, the need for these new forms of help has also been derived on the basis of the criteria of normative assessment. For example, this study revealed how badly mothers felt the need for free transportation for bringing their MR children to treatment centers.

These needs are felt-needs as they are especially felt by the real sufferers and are established by asking the participating families. As observed by Jonathan Bradshaw (1977), these needs are equated with want. When this study asked the families whether they would need the services of qualified social workers, some told painful stories of failing to meet their certain needs and how badly they needed the services of the qualified social workers. As Bradshaw said felt need is, by itself, an inadequate measure of "real need." because it is limited by the perceptions of the suffering people without knowing whether there is a service available, as well as reluctance in many situations to confess a loss of independence. On the other hand, it is thought to be inflated by those who ask for help without needing it. But in this study, when responding, the families were told about the existence of the services that they might need. At the same time, the respondent families showed little inclination to inflate their needs, because many of them were religiously conservative and reluctant to expose their families to outside services. Their life-long sufferings and painful experience show that they did not inflate their needs. Therefore, their needs are real-felt-needs.

Bradshaw said that a total need is the need that causes people to demand service. These families could not demand or express these needs unless they would have felt them. These needs are identified as felt-needs based on the prescriptions of the families themselves. Therefore, these reasonable demands have retained the criteria of the assessed felt-needs, namely that the needs have been perceived by the families concerned. But these needs are still unmet needs and thesee families have not demanded services.

These needs have also been established on the basis of the needs expressed by these families, because felt and expressed needs are closely related. Felt-need becomes expressed need when it turns into action. One does not express or demand a service unless one feels a need (Thayer, 1972). This study has revealed that when the families had the opportunities to tell their problems and needs, many were overwhelmed and excited to express their problems and urged to find services to meet their needs. These demands for services came directly from their inner feelings about their suffering and the need to address those problems. Thus, all expressed needs are felt-needs and felt-need subsumes expressed need. Felt-need is also the best guide to individual diagnostic need. An estimate of the degree of felt-need has been obtained through this study by asking the respondents about the problems that they are facing in their present conditions and whether they would like to move for some services to address those problems and to change their present conditions. These respondents' perceptions have appeared very useful as criteria for their diagnostic needs. They were also very helpful to identify the prescriptive needs of the MR persons and their families.

Those services that are most frequently requested are well-known forms of help and the needs of those services are mostly felt by most of the people concerned. On the basis of this criterion, the prioritization of the assessed and established needs has been done. The most popular and urgent needs have been given priority. The major thrust of these needs is the need to access the services available for these families. Most of the families do not know about the availability of the services and how to obtain them. All of them expressed their grief that they did not know where to turn to reach any service they need until they met this researcher to discuss their problems, sorrows, pains and sufferings.

The first step in helping these people is preferably to find an empathic professional with the knowledge to link them up to these services. This is an essential part of the professional services they need. Other needs for professional help include psychological and psychiatric services. These are the basic services needed to evaluate the individual's level of functioning so as to determine the person's eligibility to access the needed services. In addition, most of them need Medicaid and Medicare cards and almost everyone needs disability benefits and financial support. Free medical treatment is needed on a priority basis by these families. The need for the training of family care givers is also very great. The majority of the families expressed a desires for full-time and after school home attendant services, as well as in-home trainers and respite services. Of the social and educational programs, most of them need the programs for education, intellectual, social, behavioral and daily independent living skills development as well as recreational and vocational activities offered by special schools, day treatment programs, workshops, day training centers, day habilitation centers, etc. Free transportation for attending these facilities and other service providers is also a prioritized basic need for most of the participating families. Some specialized services such as speech therapy, physical therapy, occupational therapy, long-term nursing care, adaptive equipments, etc. are especially needed. Some of the families want job placement service. As most of them do not want residential placement, this is not a priority. These families also expressed needs which are typical in nature and are specifically needed for the

Bangladeshi people. These are mainly the interpreter service between English and Bengali languages at different treatment and service centers; English-language training; help with immigration and/or legal status issues; and a separate service center for only Bangladeshi retarded people.

As discussed earlier, because of the contrasts of values and attitudes of Bangladeshis in America, many families are fearful about the futures of their families and children in America. Many of them had culture and value shock which affected their attitudes. As the champion of both Islamic and Asian cultures and values, Bangladeshis are in the midst of conflicts between Islamic/Asian and Western individualistic cultures. As a result, many Bangladeshi families, including the families of MR relatives, are trying not to expose themselves to the rest of the society and are silently maintaining their survival.

It has also been noted in earlier discussion that in general Asian minority groups seldom use MR services. This study has documented this among the Bangladeshis. In addition to their religious beliefs, cultural values and the fear of humiliation and stigma, these families are ignorant, uninformed and incapable of seeking available MR services. As they are not aware of these services, service providers are also not aware of them and their needs. Therefore, there is a lack of an intermediary to make a link between these families and service providers.

There is a large and unmined field of study regarding the provision of support and services to the Bangladeshi community in New York City. There is a great need for the interested and qualified professionals to find these families, share their sufferings and link them with the available service providers. In the next chapter, attention is given to available services and service providers.

Chapter 4: Available Services for the Mentally Retarded

Types of Available Services

In order to discuss available MR services in America in general and in New York City in particular, some statistics of MR are necessary. Schalock (1983) has indicated that the estimated prevalence of developmental disabilities varies widely. For MR alone, estimates range from 1% to 3% of the general population (Blatt et al., 1977). For example, there are estimates that 1% of the total population needs special services due to MR, 1% due to behavioral disturbances, and another 1% due to sensory and/or physical disorders.

According to the United States Office of Technology Assessment (US-OTA, 1986), the estimated prevalence of psychiatric disorders among children is 17-22% with a diagnosable mental disorder, and 12% are clinically maladjusted. The OTA report stated that the most conservative estimate is that 7.5 million out of 63 million children are in need of mental health services; about 3 million are thought to present serious disturbance. The OTA estimated that of the above numbers, only 2 million children a year received mental health treatment: "The majority of children with mental health problems fail to receive appropriate treatment. Many of the 6 to 8 million children in our nation who are in need of mental health interventions receive no care; other children, perhaps 50% of those in need of treatment, receive care that is inappropriate for their situation." More recent statistics from OTA (1991) indicate that 12% to 15% of adolescents present emotional/behavioral problems at levels warranting intervention, but less than one-third of these youth actually receive mental health services (Flaherty, Weist and Warner, 1996). Extrapolating from these general trends, at this time, the available services are not adequate to meet the needs of the MR children and adolescents.

Nevertheless, Miller, O'Neal and Scott (1982) have observed current trends in the design of available MR services. They found that current programs for MR persons are based on normalization and integration principles that are generally translated into three major agency goals---that is, making the persons less dependent, more productive, and more integrated socially. Such deinstitutionalization and normalization principles have led to the planning of programs stressing independent living, vocational training and placement, and community integration. In this regard, Schalock (1983) has mentioned that the term "independent living" has emerged as possibly the most dynamic development in the field of mental retardation since the popularization of the normalization principle by Wolfensberger. To some, it is an emerging social or civil rights movement (DeJong, 1978; Roberts, 1977) that endeavors to counteract the devaluation experiences of disabled persons including being regarded as inferior, useless, burdensome and unesthetic." Stoddard, (1978) has referred independent living to the ability of the retarded persons to participate in society---to work, have a home, raise a family, and generally share in the joys and responsibilities of community life. Independent living means freedom from isolation or from the institution; it means the ability to choose where to live and how; it means the person's ability to carry out activities of daily living that non-disabled people often take for granted.

According to Jacobson (1996), there has been massive information generally available regarding the services for MR people in the past 25 years. Today, many fewer people with MR live in large, impersonal and depriving institutional settings, and most MR people who continue to reside in institutions have a rehabilitative focus with long term goals for living in community situations. A large number of formal institutional residents now live in a variety of small group living situations in communities. More individualized services are available to support more independent living. In addition, the capacities of sheltered work settings have increased dramatically. These settings provide day services, vocational training, supported employment and job placement services. In addition, families of MR people are able to obtain in-home trainers, and other needed support. Importantly, MR children are guaranteed free public education. Early child intervention services are also becoming increasingly available as well.

The U.S. Government has recognized the fact and urgency of the needs of MR people and has taken a number of legislative measures over the past two and half decades in order to offer funding for innovative programs, some of these measures are reflected in the Public Laws of the US Congress which are given in the Appendix D.

Schalock (1983) has observed that the Medicaid program has emerged as the principal source of federal support for MR services at the state and local levels. In order to receive this support, an MR person needs the following: a recent assessment of the person's present level of functioning, formation of an interdisciplinary team (I-Team), and development of an individual treatment plan. The I-Team requires the participation of the handicapped individual, the individual's parents or any representative, and a team of staff and professionals of the service providing agencies.

Contents of the plans include statement of needs, goals, objectives relative to goal attainment, services to be provided, duration of services, strategies for achieving objectives, responsible persons for implementing the plan, and evaluation procedures and plan review process (at least annually) to determine the individual's progress, to make modifications, and to evaluate appropriateness of placement in accordance with the individual's progress. The MR individual and his/her parents or any representative have the opportunity to review the plan and participate in its revision.

The I-Team works for a unified and integrated approach to diagnosis, evaluation, an individualized habilitation plan development and remediation based on the individual's needs. The habilitation plan implementation involves a face-to-face team meeting in which participants share and discuss all information and recommendations. The I-Team develops an active treatment plan as a part of the MR person's Individual Treatment Plan (ITP).

Shalock (1973) defines an active treatment model in which the MR person participates on a regular basis in accordance with an individual plan of care in professionally developed and supervised activities or therapy. An individual plan of care is written and set forth for measuring goals or behaviorally stated objectives. The overall objective of the plan is to attain or maintain the optimal physical, intellectual, social, or vocational functioning of which the MR individual is presently or potentially capable.

The I-Team is also responsible for recommending and approving any behavior modification plans and psychotropic medications in dealing with any maladaptive, destructive, aggressive or self-abusive behaviors of the MR person. Informed Consent form is required to be signed by the parents or legal guardians of the MR person for administering any psychotropic medications and implementing any behavior modification plans after they are prescribed by the psychiatrists and approved by the I-Team.

In addition, there is also a Human Rights Committee in each agency to over see the decisions of the I-Team, who finally approves, rejects or suggests any modifications of any I-Team decisions and psychiatrist's prescriptions in order to protect the MR person's human and civil rights. Each service agency has written policies and procedures to guide the operation of the I-Team, who works actively in all programs.

MR service agencies provide the following professional services on a regular basis as needed by an MR person: psychiatric, psychological, psycho-social, medical, speech, hearing, occupational and physical therapy, behavior modification, nutritional, neurological, technical and financial support, in-Home training, respite, outreach, job placement, free transportation, adaptive equipments and other needed services. Families of the MR persons are provided training, information and referral services (Pancsofar & Blackwell, 1985).

In addition, the I-Team attempts to develop the following major functional skills of the MR person: intellectual, independent living, social, recreation, vocational, and adaptive behavior skills. The I-Team also attempts to develop the following specific community living skills of the MR individuals: grooming, showering, toileting, personal hygiene care, dressing, eating, performing household chores, managing money, laundry, meal preparation, social integration, communication, recreation, community access, shopping, interpersonal relations, travelling, vocational, job seeking, on-the-job evaluation, on-the-job training, industrial practicum, etc. (Schalock, 1983 and Miller & Cates, 1982).

In order for an MR person to access these facilities and services, certain basic requirements need to be fulfilled. The person must provide current medical information, social and intellectual development history. and psychological, psychiatric and neurological reports. Additional information should reflect the intellectual maturity of the individual in relation to problem solving, communication, judgement and how it influences the daily progress of the person. Reports on adaptive behavior are also required. Information that gives prominence to special handling of the person when specific problems exist, including strategies that have worked in the past such as specific behavior modification techniques should also be included (Pancsofar & Blackwell, 1986).

In addition to the available services mentioned before, Drotar and Sturm (1996) have observed that "wraparound" services have become the treatment of choice for MR persons in many locations. Recent data suggest that 75%-90% of these MR people improve over time. Because wraparound services involve a process rather than a specific set of procedures, the services will vary from one location to another. The procedures, however, are based on a number of principles: child and family focus, core services team, unconditional care, individualized services plan, community based, culturally competent, interagency collaboration, and flexible funding. Thus, wraparound services exemplify a different philosophy and approach to serving MR children and their families.

Problems Faced by English-Speaking Americans

There are a number of major problems that the English-speaking Americans have faced over the decades for accessing and utilizing the available services needed for taking care of their retarded children or family members. Schalock (1983) has observed that the basic problem at the Federal, State and local levels is that those agencies primarily responsible for the mentally disabled do not have the funds needed to develop the adequate care systems nor the responsibility for the standard of care in communities. Therefore, they have approached deinstitutionalization without any central guidance, but by relying on many social, welfare, and other programs that affect such target groups as the poor, aged, children, or the disabled.

All too often, however, programs are hampered in accomplishing these goals because they lack a clear philosophy, focus, or program emphasis. As a result, clients and staff are stagnant, not because of lack of effort, but because of lack of direction. Hence, stress should be given to the importance of an organization's internalizing a philosophical position regarding its clientele before developing its programs.

According to Drotar and Sturm (1996), in the traditional service delivery system, parents are not equal partners in the decision-making process, professional services are not implemented and terminated by team consensus, agencies do not pool their resources together to provide whatever services are necessary to meet highly individualized needs, and most interagency decision makers and providers do not transcend failed placements unless they are legally mandated to do so.

English-speaking Americans find many problems in the vocational training programs. The handicapped clients lack movement from workshop into the competitive labor market. They have dual roles at the workshop; clients and employees. Federal wage and hour regulations are not maintained. The training and employment services suffer from poor coordination of service delivery and lack of accountability. The linkages of sheltered workshops with private business and industry are generally limited. Day habilitation programs generally reflect a welfare approach to services and have become indefinite placements for many handicapped persons. Although the number of handicapped people served in these programs has rapidly increased over the past few decades, many individuals still do not have access to community-based services.

In addition, fiscal contingencies created by current policies result in disincentives to local service providers, and state agencies. The uncoordinated funding sources and regulations by different agencies and levels of government have created duplication and confusion. Federal policy has had relatively little influence on the way in which states organize services for MR persons. Each state has evolved its own idiosyncratic organizational structure for furnishing such services (Molaison, at. el., 1995).

English-speaking Americans also have significant problems with accessing and utilizing services for MR people. There are philosophical differences between the providers and families. For instance, most of the work has been based on impressions, assumptions and clinical intuition; and the service providers concentrate their efforts on the material aspects of the problems i.e., relocation, employment, financial assistance and have paid mostly lip service to the idea of adjustment as a major problem. Providers lack coherent policy and services. There is also a lack of interagency cooperation. The attitudes of the general population towards the retarded are still not favorable. Their parents are also not given adequate information in a timely fashion (McKay, at. el., 1996).

In addition, there are many problems with protecting the rights of the English-speaking MR persons: the problem of initiating client-attorney contacts, the complexity of their potential cases, the lack of adequate resources for advocacy in ethically sensitive, time-consuming cases and the reluctance of some advocates to take on clients who are poor and sometimes difficult to serve.

Acosta (1980); Sue & Morishima (1982) have found that there is as well a lack of sensitivity of workers, which is a problem for engaging MR people in programs. As a result, MR adults are less likely to receive a full array of available services. They also receive differential treatment. There are tendencies among mental health clinicians to minimize or overlook psychopathological symptoms in MR persons as well as to make differential treatment recommendations (Dorn & Prout, 1993).

English-speaking Americans also face the problems that the service providers do not explore methods of increasing family involvement in the programs. Providers have failed to integrate their programs into local communities. Communities are not informed or consulted for initiating any programs. Community input or resources are not effectively integrated to conceive, plan and implement the programs (Flaherty, M.D., et al., 1996).

English-speaking Americans are also facing problems in accessing services for their MR persons in managed care systems provided by the Health Management Organizations (HMOs). In these HMOs, the well-being of the MR persons is adversely affected because the primary care providers act as 'gatekeepers' in HMOs when they coordinate consumer use of services. Because of their attempts at promoting efficiency in medical care, access to specialists under the gatekeeping system is rationed and enough time is not be allowed to examine people with MR. MR people need more time for examination because of the problems of direct communication between patients and physicians. As a result, there is a possibility of misdiagnosis. In addition, primary care physicians in HMOs also lack appropriate knowledge about MR problems (Birenbaum, 1995).

While addressing the American Association on Mental Deficiency, Carl Haywood (1981) referred to the vulnerability of MR persons, because this vulnerability has manifested in factors such as accumulative mental age deficit, society's reliance on institutionalization, restrictive ordinances, frequent exploitation, and active attempts to exclude MR persons from a variety of social systems and institutions. English-speaking Americans face these problems everyday in accessing and utilizing the services for their MR relatives.

Service Delivery Systems

According to Haywood (1981), a reasonable goal for a service delivery system is a balance between maximum social participation and minimum social vulnerability. This requires the dual process of changing the environment to accommodate the needs of MR persons and increasing MR persons' behavioral skills for coping with environmental demands.

Magrab and Elder (1970) defined a delivery system as a general strategy for the mobilization and organization of all relevant resources to provide for the prevention, intervention, and rehabilitation of human problems. The current human service delivery system is composed of several separate systems, each the result of a categorical response to service needs. None of these single subsystems of education, health, rehabilitation, welfare, and housing satisfies the above definition of system, since none alone can solve the multiple problems of the MR persons. Cooperation, coordination, and collaboration among these subsystems are, therefore, necessary to achieve this. Another requirement of an effective service delivery model is to incorporate the mechanisms for controlling the nature of programmatic interventions that intend to change clients' behaviors (Johnston & Shook, 1995).

Each MR person, who is already enrolled or admitted for services by an agency, is assigned an advocate or an advocacy committee. The client advocacy committee is composed of individuals chosen to serve as client advocates, which has earned an important place in programming service delivery systems. There is such a committee in each state's region and institution. It meets monthly to discuss the issues that involve client rights and review any programming activities of interest. A Consumer Advisory Board (CAB) also works on behalf of New York State for preventing any abuse and mistreatment of the MR persons and assuring quality care as well as upholding human and civil rights (Dorn & Prout, 1995).

There is an ongoing system of monitoring program activities as another component in the service delivery systems. This monitoring system has the responsibility of monitoring all programs operated by the service organizations. There are additional components of a state's monitoring system that are required by federal and state regulations, which are Quality Assurance, Professional Utilization Review and Independent Utilization Review. The state-wide regulations have been documented in a widely distributed manual. The central office of OMRDD (Office of Mental Retardation and Developmental Disabilities), of New York State, manages the delivery of all programming services for MR people. Its responsibilities are implicit in developing and maintaining its state-wide functions in the areas of policy, regulation, legislation, budget, and oversight. Because of its broad mandate, legal authority, and budgetary resources, this office takes a strong leadership role in order for all the components to develop and work in the integrated manner (Shook & Johnston, 1993).

The trend of deinstitutionalization of the MR people has led to an increased reliance on community health care systems to meet their complex needs. MR individuals have unique health care needs and pose a significant challenge to the health care delivery systems. In order to adequately care for these individuals, the health care delivery systems provide a range of services; a primary care provider with specific knowledge and expertise is assigned to meet the unique medical and social needs of the MR persons; mental health, dental, behavioral and rehabilitative services are given; and health care coordination services which include assembling past medical records, ordering initial laboratory work, arranging for medical screening, tests and immunizations, as well as referring and accompanying clients to specialists at the hospital's clinics are also provided. These health care delivery systems integrate the health care of MR persons with residential, behavioral, educational and occupational activities of other service providers. These systems provide services for health promotion and, disease prevention programs as well as provide support for research activities as a vital link in the provision of high quality clinical care. These delivery systems serve as a training resource for direct care workers, health care professionals and families of MR persons (Criscione, at el., 1994).

Gaps in Delivery Systems

Although the field of mental retardation in the United States long ago abandoned a custodial model of care in favor of a treatment-oriented or educational approach, professionals are still struggling with the transition. The treatment or educational model that has slowly emerged as the standard for intervention services has become increasingly well-defined, but state-of-the art care is infrequently achieved. Despite sincere efforts to offer truly effective programming, facility staff often manage to accomplish little more than the bureaucratic facade mandated by federal and state requirements. Thus the gaps in delivery of services are also noticed in poor academic achievement, lack of motivation and poor discipline of the staff, heavy caseload, heavy paper work, and clerical work for counsellors, performing disciplinary functions, lack of time, and lack of resources (Gary, at. el., 1982).

Fletcher & Poindexter (1996) have observed that many MR persons have been or are being deinstitutionalized, often without adequate community supports. This group comprises a complex population whose needs are often poorly identified, and who are often referred from one agency to another in frequently futile efforts to obtain adequate MR services. Grimes and Stanley (1990) have found that families have great concerns about the quality and availability of community services and staff stability. Family members are not convinced that their relatives are capable of attaining a higher developmental level and remain opposed to future relocations to less restrictive community residences. There are also gaps noticed between the deinstitutionalization and the availability of appropriate educational components when persons are moved from the institutions to communities. Salisbury (1990) observed that respite systems are not as responsible as necessary, as a result, many mothers who used respite services left the program for more informal support. Mothers have relied on their families and friends more frequently than they might have otherwise. Alternatively, mothers who did not use respite services might have used other formal or informal resources that might have lessened the need for respite care. But the disturbing fact remains that 70% of the needs of the mothers seeking respite service were not met by a program specifically designed to do so.

In explaining the gaps in the delivery systems, Schwartz (1992) has painted a dark picture of the failure of delivery systems to protect the well-being of people with MR. He traced these failures to remnants of paternalistic thinking, misconceptualizations about the meaning of community, and overregulation of programs designed to help people in need.

The quantity and quality of training for independent community living currently offered by community-based programs is frequently less than adequate. The training program is typically carried out in bits and pieces. The mixed message approach leads to confusion as to what is expected on the part of the clients. The burden of training for independent living is usually assumed by the residential staff after the day program is complete -- a staff that is often the least paid. trained, or respected in the agency hierarchy. The picture is further complicated by the notion that continuing the training after 8 hours in the adult center is considered by some to be over-programming for those 'lucky' clients who happen to be living in the group homes (Miller, at, el., 1982).

Partly to address problems related to limited access to services for most MR children. these services have been placed in schools. But due to the increasing costs of special education services and budget reductions in recent years, the special education programs have been looking for ways to reduce the number of MR clients. Limited program evaluation, a major deficiency in special school programs, is often poorly documented because of the public demand for quick remedies. As a result, these programs consume the time and energy of school staff without producing convincing results. A decrease has been seen in referrals for special education services after outside clinical therapists are placed in schools, but ironically, the special schools are suffering from a multiplicity of programs that overlap, but are not coordinated with each other. The result is unnecessary duplication of services in some areas, but gaps in others. Both overlaps and gaps in MR services are attributable to deficiencies in planning as well as inadequate funding for program administration and evaluation (Flaherty, 1996).

Additional Problems to be Faced by Bangladeshi People

Bangladeshi families with MR members in New York City face all the problems that the English-speaking Americans face in accessing and utilizing available services for their MR relatives. In addition, they also face all those problems which the new non-English-speaking immigrants and financially poor and culturally conservative communities face every day in this city in accessing and utilizing needed services for their MR relatives.

Although, providing adequate mental health services to those in need has been a national priority for the last twenty years in the US, social services continue to be under-utilized by vulnerable populations, like minority children (Hu, et al., 1991; Wallen, 1992). Clearly, children are the most vulnerable to these serious social problems, yet if they are from a minority low-income family, they are even more vulnerable (Cheung, 1989).

Bangladeshi families, like other minority communities, suffer as well the full impact of a culture of poverty to a much higher extent than the general population, high unemployment leading to family disruption, devastation by MR problems, almost no services are available to them, social workers seem not to be comfortable working in their minority communities or with minority persons, the social worker cannot make a true connection between the individual, the family and the community for their minority clients, and discover that the social worker does not think about or utilize non-traditional community resources (Miller and Cates, 1982).

Traditional community approaches to problem resolution, such as talking to elders, folk healers, and clergy are not integrated with direct practice and community education. Service planning is not sensitive to linguistic barriers, social factors and cultural misunderstanding.

To avoid these problems, the utilization of expanded parent education is critical. Family life education programs can be used successfully with low income families as well as middle class ones. Such education programs can emphasize the history and culture of the immigrant groups as the knowledge base for American service providers, educators, and community members in providing services (Gary, at. el., 1982).

The Asian groups, including Bangladeshis, do not seek help for MR problems. This attitude is derived from their cultural perception of MR problems as they often associate MR with shame, guilt, and punishment. This perception prevents Asians from expressing freely their emotional anguish. An Asian seeks professional help for MR problems only when it is emergency. The culture also teaches them to endure suffering, to accept and to believe in faith, and to trust authority (Mai, 1981).

As a result, Asians tend to rely on emergency services. To some extent, barriers to utilization and underutilization of MR services by lower income minority clients have been increased by the stigma associated with counselling services, lack of information regarding available services, inaccessible locations, unresponsive service providers and reliance on alternative methods of help. In addition, family attitudes about professionals, as opposed to more informal sources of help, have been identified as critical to the engagement of minority families (Wallen, 1992; Flashkerud, 1986).

Children of Bangladesh-born mothers, like any other foreign-born mothers, are less likely to have received school services related to MR issues as compared to children of American-born mothers. Religious beliefs and cultural practices prevent Bangladeshi mothers from seeking help for their MR children. Language barriers also prevent Bangladeshi-born mothers from enhancing the probability of effective communication with English speaking professionals and teachers (Martin, et. al., 1996).

For several decades, various researchers have found that Asian-Americans receive unequal and poor mental health services because the services are not accessible to them. Advocacy for making service available and accessible to Asian American-communities is generally absent. Browne and Broderick (1994) indicated that Asian-Americans do not receive health and welfare benefits comparable to their needs, even though they appear to have faced more problems for their MR relatives than their English-speaking counterparts. They listed a number of reasons for this apparent under-use of services. Among those identified are financial and language problems, a distrust of government programs, a belief that services based on a Western model of wellness are not relevant for their MR relatives and the perception that staff are not culturally sensitive. Furthermore, professionals consider the Asian communities, including Bangladeshis, to be the model minority with no problems, so the professionals do not take their problems seriously. Fong and Mokuau (1994) have acknowledged that Asian Americans and Pacific Islanders are more group-oriented than self-oriented. Therefore, professionals who serve them should use direct practice techniques that involve the individual in combination with the family, group, or community.

In order to facilitate achieving the objectives of this study, information about a private and a state agency specific MR services is provided below:

Private Agency - Association for Children with Retarded Mental Development (ACRMD), Inc.

This agency has been and is currently engaged in providing services to MR people in New York City. The Association for Children with Retarded Mental Development, known by its acronym, ACRMD, has been chartered as a not-for-profit Membership Corporation since 1951.

Current Mission of the Agency

ACRMD is committed to the principle that all MR persons are able to become contributing members of their families and communities and thereby achieve a sense of self-worth and self-actualization. It is ACRMD's aim to provide MR persons with the special assistance and support necessary to achieve a level of functional behavior and cognitive skills, which enable them to maintain themselves in their community in the most integrated and independent manner possible. A list of the ACRMD provided services are given in Appendix E.

In response to a question about the criteria for recruiting mentally retarded people for these services, the researcher learned that the agency serves MR people 18 years of age and older, some of whom they reach through the media, especially radio advertisements. The agency works with developmentally disabled individuals, both ambulatory and non-ambulatory with multiple disabilities, as well as with dual diagnosis mental health disorders.

A State Agency

This researcher has also interviewed a representative of a state agency which serves MR persons and developmentally disabled population in New York State. This agency is under the auspices of New York State's OMRDD (Office of Mental Retardation - Developmental Disabilities) and is responsible for the institutionalized individuals as well as those in the community, in foster care or living at home. They have legal services from State Mental Health services whose representative vigorously sees that the clients' rights are preserved. These agencies work together in placing institutionalized individuals into family care, in group home settings. Services offered by this agency include granting authorization to foster care homes and overseeing placement of individuals from the institution into group homes.

Agencies in New York City

There are several not-for-profit agencies, including hospitals and clinics in the New York Metropolitan Area, which provide services to meet the specific needs of highly specific family situations. Some of them operate within a specified catchment area; others have broader bases, including the State Office of Mental Retardation and the New York City Departments of Mental Health and Mental Retardation, and Alcoholism Services, as well as Human Services. Conserquently, a skilled social worker can match family needs with available services. These agencies are listed in a comprehensive volume called the Source Book of Social and Health Services in the Greater New York Area, published by Oryx Press, Phoenix, Arizona. A list of the services provided by these agencies is given in Appendix F.

The Source Book contains specific information on government and private agencies currently engaged in providing support and services to the MR people in New York City. A list of 50 agencies, along with specific descriptions of their activities and their telephone numbers, has been developed for use by the families, service providers and agencies. The list is given in Appendix G.

Chapter 5: Community Activities and Recommendations

Community Activities of Bangladeshis in New York City

As discussed earlier there are about 54,000 Bangladeshi people presently living in New York City. Though this is a relatively small community as compared to other Asian communities, it is a sizeable, growing and active community. Most Bangladeshis in New York and other parts of America are Muslims. There are also Bangladeshi Hindus, Christians and Buddhists in New York, but their numbers are very limited. Despite religious differences, Bangladeshis in New York are closely linked through political, cultural and social organizations.

As new immigrants from the Third World, most Bangladeshis in America are comparatively poor. Many of them do not have high levels of education or fluency in English, nor skills in modern technology. As a result, they cannot find jobs quickly and easily. Many of these low- skilled low-educated Bangladeshis finally end up in the low paying jobs, such as security, retail, waiting-tables, cooking, delivery, flyer distribution, cleaning, etc. Many earn as little as $25 a day. Many drive cabs. Cab drivers earn more money than many other job-holders. Cab driving has become a relatively high-earning profession among the Bangladeshi immigrants.

There is a small but growing Bangladeshi business community in New York. There are about 3 dozen Bangladeshi grocery and halal meat stores, 18 Bangladeshi restaurants, 12 travel agencies, 6 driving schools, 6 Bangladeshi book stores, a few dozen small supermarkets, clothes and fabric stores, export imports, courier and cargo services. Many other businesses are booming in New York under the ownership of the Bangladeshi New Yorkers. Many of these businesses are doing well, but some of them are struggling for survival.

Of course, the richest Bangladeshi community in New York consists of professional people such as physicians, dentists, pharmacists, engineers, lawyers, and accountants. Initially, they had to go through a hard time studying for, qualifying for and obtaining their professional licenses. But once they got over all these hurdles, they actually succeeded in realizing the American dream of material success. The majority of Bangladeshi immigrants during the 1970's and 1980's were professionals and they are now living with their entire families and leading financially comfortable lives.

Bangladeshi people in America and in New York City are organization-minded. Accordingly, they are very active in forming, organizing, running and maintaining different types of organizations. In addition to their every day work, they spend a lot of time, energy and money on organizing and for volunteering in such organizations. These organizations are mainly of the following types:

Cultural/Entertainment: A number of organizations have already been founded in this area. These organizations occasionally offer Bangladeshi music such as songs, dances, dramas, theaters, etc. Some of them run schools for teaching Bangladeshi music such as songs, dances, musical instruments, etc., as well as Bengali language and literacy. Bangladesh Institute of Performing Arts (BIPA) and Saderang School of Music, Doel

Cultural Association are a few of the organizations that play leading roles in this area. There are also a number of other such cultural organizations which are currently serving Bangladeshi people in New York. A number of these are producing stage-based drama and theater productions on a regular basis. Drama Circle, Bangladesh Theater of America and Bangladesh Theater of New York are highly significant in this area. Bangladesh Theater of America is staging theatricals on Broadway. Many commercial entrtainment organizations are also bringing famous Bangladeshi singers to the United States and organizing their live concerts to New York several times a year. In addition, many social and political organizations organize cultural shows as well as exhibitions of Bangladeshi food, handicrafts, cloth, books, etc., in observance of special days, such as independence day, victory day, Bengali new year's day, birthdays of famous Bangladeshi personalities and other politically and culturally important days. Many not-for-profit organizations organize fund-raising shows of concerts, songs and dramas for some specific charitable organizations as well as for helping suffering people in Bangladesh who are victims of natural calamities such as floods, cyclones, etc.

Literary Organizations: There are a few cultural organizations which are actively organizing literary forums where participants read and discuss their own writings. Several Poetry Forums are also functioning. A number of literary magazines are brought out every year. Moreover, both new and experienced writers in New York are now publishing their books of poems and stories and novels as well.

Social Organizations: Bangladesh people in New York are involved as well in different types of social organizations. These are mainly:

Professional-Based Organizations: Some of these organizations are: Bangladesh Medical Associations of North America, Bangladesh Dental Association, Bangladesh Pharmacist Association, Bangladesh Agricultural Engineering Association, Bangladeshi Yellow Cab Drivers Association of New York, Bangladesh Journalists and Writers Association, etc.

Area-Based Organizations: There are a number of Area-Based Organizations in New York. These are formed on the basis of the geographically and administratively divided areas of Bangladesh. There is at least one organization formed for each of the 60 districts of Bangladesh, such as Habiganj District Association and Sunamganj Association. There are also organizations for many of the Sub-Districts, such as Sandip Association and Bianibazar Association. There are also organizations formed for the former 21 greater districts, such as Greater Sylhet Association, Greater Chittagang Association, Greater Comilla Association and Greater Noakhali Association.

Charitable/Non-Government Organizations: There are two types of Charitable/Non-Government Organizations. One is non-religious and the other one is religious. Some Islamic religious-based organizations raise funds to support religious organizations in Bangladesh as well as for religious education in America. The Bangladesh Muslim Center is one of these organizations. The non-religious charity organizations are mainly involved in raising funds and providing support of non-religious-based development, education and relief programs in Bangladesh as well as for English language, technical education, job search and shelter arrangement for new and poor Bangladeshi immigrants in America. Bangladesh Sangsad is one of these organizations.

Other Social organizations: There are many social organizations formed by the people of Bangladesh in New York and a few of those are: Bangladesh Society of New York, Bangladesh Society of America, Bangladesh League of America, Bangladesh Association of New York, Bangladesh-America Friendship Association, Bangladesh-America Assistance Society, and many more.

Religious-Based Organizations: Many traditional Bangladeshi people are actively engaged in religious activities. There are about ten Bangladeshi mosques currently functioning in the Greater New York area. Each mosque also runs a weekend school for children for teaching the Holy Qur-An, prayer rituals and Islamic ideals. There are also 2 Puja Samities presently functioning actively for the Bangladeshi Hindu people. There is also one Bangladeshi Christian and one Bangladeshi Buddhist organization now functioning in New York City.

Political Organizations: There are a number of political organizations currently functioning actively in New York. Most of these political organizations are the American and New York branches or chapters of the main political organizations or parties of Bangladesh. Almost all the major political parties of Bangladesh have their organized branches/chapters in New York. These branches are very active and hold meetings, discussions, forums, press conferences, etc., almost every week. Some of these political parties are the Bangladesh Awami league, Bangladesh Nationalist Party (BNP), Jatiya Party, Jatiya Samajtantric Dal, etc. The Hindu-Christian-Buddhist Unity Association is also a religious-based political activist party which is working for protecting the rights of the religious minorities in Bangladesh. This organization's purpose is to stop discrimination and oppression against the religious minorities in Bangladesh.

American Political-Based Organizations: There is also a Bangladesh Republican Party and a Bangladesh Democratic Party formed by the Bangladeshi people in New York who are closely working with the American Republican and Democratic Parties.

Semi-Political Organizations: There are many Semi-Political Organizations actively functioning in New York. These are not branches of political parties but are affiliated with the ideals of the specific political parties. Some of these organizations are: Bangladesh Mukti Jodha Sangsad, Ghatok-Dalal Nirmul Committee, etc.

Memorial Organizations: There are many organizations formed to commemorate special political and cultural personalities such as Bango Bandhu Cultural Association, Col. Taher Smriti Sangsad, Shahid Zia Smriti Sangsad, Rebel Poet Kazi Nazrul Islam Smriti Sangsad, Poet Tagore Sangsad, etc.

Issue-Based Organizations: Some organizations are formed in response to national problems and issues in Bangladesh such as Organization for Establishing Democracy in Bangladesh, International Farrakka Committee, etc.

Because of the values and attitudes of Bangladeshis, many families are fearful about their future in America. Consequently, many conservative families are seeking refuge in their religious and cultural organizations. On the other hand, many newcomers are mainly concerned about jobs, schools and the struggle for survival in this new society. The tension between old ways of coping with adversity and finding ways to cope with the new context in which they find themselves is a serious problem for many Bangladeshi immigrants.

Recommendations

This tension is particularly poignant in planning services for Bangladeshi MR persons and their families. As described above, there are already a few hundred Bangladeshi organizations established and actively functioning in New York. Some of these organizations are reminiscent of the political clubs of New York once described by Dr. Roy V. Peel (1935) in his book, "The Political Clubs of New York City."

Peel defines a club as a form of voluntary organization clearly distinguished from other institutions, such as the church, the state and the family. They all exist for any number of reasons---social, political, literary, artistic, etc. However, political clubs are unique in one respect---their dominant motive is to achieve a political purpose. Similarly, a few of the Bangladeshi organizations in New York are established with the political motive of creating influence and power for the Bangladeshi community in North America.

Political clubs have both a program of action and the goal of advancing the political fortunes of certain individuals. The number, the distribution, the motives, the interests, the objectives, the activities and the form which characterize political clubs of a community depend on the environment, the tradition and the leadership within the community (Peel, 1935).

The Bangladeshi community in New York in 1996 is similar in organization to earlier immigrant communities. Most Bangladeshi organizations are not specifically politically oriented but are mostly involved in organizing meetings, press conferences and discussion forums where they can attract the Bangladeshi news media. This public attention can be used to influence people. Publishing public statements with pictures in the native news media is one result of their activities.

Peel (1935) mentioned that political clubs may and do pursue their objectives within the club walls or outside them; that is, their activities may take place inside the club house, on the street, in hired halls or in parks. These activities may involve only the members and their friends and relatives. Similarly, most Bangladeshi organizations are "folder-based," i.e., all of their activities "exist" within manila folders. They do not have offices, places to sit or hold meetings nor addresses other than the homes of their leaders. They hold meetings in restaurants or in rented places, in parks and community centers. Nonetheless, they are the ganglia of political organizations in the Bangladeshi community.

What Bangladeshi community leaders are doing now was suggested by Peel's work 61 years ago. He described the leaders of the clubs as gratified by the sense of power they experience; by the prestige they acquire; by the companionship of subordinates; by the betterment of their personal fortunes; by opportunities for retreat from the cares of the worldly city, for recreation, for intellectual discussion and for rest. Similarly, Bangladeshi leaders in New York are often engaged in infighting and ultimately breaking the organizations into factions and leading the factions into separate organizations. The followers of these leaders are also gratified by aiding the leaders in breaking from the main organization and creating new ones where they also get shares of leadership positions.

This survey of political organizations in the metropolitan area, has disclosed an extensive proliferation of Bangladeshi organizations like the political clubs of New York in the 1930s that are meeting a variety of social and political needs of their members. It has been seen that the Bangladeshi organizations, like the older political clubs, engage in a wide range of activities. At the same time, they ignore many problems which are pertinent to the needs of the community.

While many of these Bangladeshi organizations are not-for-profit and social and human service-oriented, none of them is devoted to providing services to MR people and their families. Selecting one of these organizations, which could incorporate the activities of providing services to the MR people and their families, has been discussed in the community. But there are a number of potential problems identified in this proposal.

Selecting any particular organization from many of similar category is very difficult. Existing organizations have their self-defined missions, objectives, and program activities publicly declared and established. It is very difficult for them to change and or add any new ideas. Such change requires the approval of the Board, general members and change of constitution. Most organizations do not want to go through these hurdles. Besides, providing services to the MR people and their families, is such a big job and one that is foreign to the mission of so many existing organizations that it would probably be extremely difficult to render these services as a part of any such organization. Unless there is a leader who would have a MR family member, it is difficult to imagine the development of such an organizational change. Besides, many parents of the MR people think that the leaders of the existing organizations do not have a special interest in the MR people, otherwise, they would have included the MR people as their target group from the beginning of establishing their organizations. Therefore, a separate organization with the missions, objectives, specialties and expertise to provide necessary services to the MR people and their families needs to be established with the involvement of the parents and family members of the MR people.

In order to provide MR services, a new organization is probably needed. Such an organization needs professional expertise and personal experience with the MR field. The organizations of the Bangladeshi community have to be supplemented by a functional organization, whereby those needy MR people and their families could be consolidated across the Greater New York area into the structure of an effective functional social service organization. If the families with MR members are not organized, they will stay unserved and will continue to suffer from the problems of mental retardation. The Bangladeshi community has no such organization because there is no single Bangladeshi leader in New York who understands the needs and interests of the MR people.

Establishing a new organization and obtaining funds for a minority ethnic group in any country is as hard as climbing the Himalayas. It is even harder if it is for any new minority ethnic group unfamiliar with the American culture.

In this regard, the experiences of founding The Arab-American Family Support Center, Inc. in Brooklyn, can be cited. Emira Habibi Brown, a Palestinian woman, founded this organization in 1993. Prior to organizing this new organization, she worked in another American organization for a long time. While working as a clinical social worker in Brooklyn, she came to learn about the problems that Arab families are facing.

Because of male domination, religious conservativism, language problems and cultural mores, poor Arab women, especially those who have come from the Palestine, Lebanon, Jordan, Syria, Egypt, Yemen and other poor Arab countries, cannot go outside the home for jobs, education or medical help for themselves or their children without male accompaniment. As their men are busy day and night earning a living, women sit at home with their children. They cannot go out even at the time when they and their children are sick until their men find time to take them out. As a result, they suffer a great deal from medical, social and family problems including family violence and child abuse.

Ms. Habibi Brown realized that these Arab women and children need support and services more ungently than the women and children of any other ethnic community. Although there are services available in the larger society, these Arab women cannot seek these services and nobody from the larger society is going to reach out to them with the services. Thus the women and children of the poor Arab families are completely isolated from the rest of the American society and even from the rest of the Arab community.

The problems encountered in founding the Arab-American Family Support Center were enormous and can be described in 3 stages: Initiating, Developing and Implementing.

It took about one and half years to form this organization. Ms. Habibi Brown worked day and night alone and completely on a voluntary basis. She had to go door to door to the Arab families living in Brooklyn in order to identify and organize those Arab families who need support services. At the initial stage, people could not believe her that as an Arab woman, she could establish an organization and obtain funds in America. But the major problem was with the male leaders of the Arab community in Brooklyn. The leaders, who did not spend any time and money on this organization, were fighting for offices on the Board of Directors and were imposing their own views and priorities in setting the operational guidelines of the organization.

The next step was to incorporate the organization as a not-for-profit agency with New York State. This can be a time consuming and expensive process. Fortunately, a law office worked pro bono and helped obtain the incorporation from NYS and tax exemption status from the IRS.

After obtaining incorporation and tax exemption, Ms. Habibi Brown went to City Hall with a proposal for funding programs of her new organization in early 1993. Her proposal received a positive review at the initial stage. But the decision was postponed for other reasons. At the end of 1993, the City Administration was changed and her proposal was delayed again. Her proposal was finally approved and funds were made available in June, 1994.

Apparently, some strings were attached to the approval. Because, she had a new organization which did not have any experience of implementing social programs and handling public funds, for accountability purposes City Hall asked Ms. Habibi Brown to find an existing organization and subcontract with it. Thus funds were channeled through an intermediate organization to which 5% of the total funds are allocated as an administrative charge.

The agency had no office at the beginning and used a room of another agency until October of 1994. As soon as programs were started, however, the agency was overwhelmed with the response of the Arab families. Arab women, children and even men flooded the Arab-American Family Support Center. But the center did not have counsellors and money to handle such demands. All the counselors are required to be bilingual (Arab-English-speaking) and most of them are Arab-women (an interview with Ms. Brown, H. Emira, 1996).

Given these experiences in establishing Arab-American Family Support Center, it no doubt would be difficult to organize and receive funds for a new organization to be established to specifically serve the Bangladeshi MR persons and their families in New York. Yet using an existing organization whose special interest is not to serve the MR people, would be even more difficult. The problems of families with MR members are too severe to be handled by an old-style American-type Bangladeshi political club. Although, creating a new organization is difficult, it is possible, as the above example shows. Therefore, creating a new organization is probably the most feasible way to serve needy Bangladeshi MR people and their families in order to provide the necessary services.

Although, Bangladeshis are the fastest growing ethnic community in New York, they remain underserved in the field of human services. They especially do not come out to seek help and use MRservices, even though their needs are urgent and enormous. Developing any organization that seeks to serve them will have to prioritize its services.

The needs survey described earlier in this study suggests a set of priorities. The primary need is access. Many families need interpreter service, English language training, help with immigration issues, etc. These families are uninformed and incapable of seeking help on their own. They are not aware of available services, and service providers are not aware of them and their needs. Therefore, there is a great need for an intermediary organization to link these needy people with available services.

An empathic, skilled professional is needed with the knowledge to link them with services. They require help in accessing educational, psychological and psychiatric services, Medicaid, Medicare and disability benefits. There is also a need for training of family care givers and full and part-time home attendant services, in-home trainers and respite services.

Once these needs are met MR peresons require behavioral and daily independent living skills development as well as recreational and vocational activities. Specialized services such as therapy, nursing care, adaptive equipments, job placement, etc. are especially needed for many families. This research is intended to encourage Bangladeshi community leaders to take the initiative to achieve the objective of creating a new organization to better serve the Bangladeshi MR people and their families in New York.

Appendix A

Copy of Advertisement and Flyer

নিউইয়র্ক শহরে বসবাসরত বাংলাদেশী পরিবারের জন্য
একজন বাংলাদেশী বিনামূল্যে সহায়তা প্রদানে আগ্রহী

আমি একজন বাংলাদেশী অভিবাসী। আমি মানসিক প্রতিবন্ধী ও তাদের পরিবারের প্রতি সহায়তা প্রদানে আগ্রহী। একজন অভিবাসী হিসেবে আমি জানি যে এই অজানা দেশে আমরা কেমন সমস্যার সম্মুখীন হই, বিশেষ করে, যখন কোনো ব্যক্তির প্রয়োজন অস্বাভাবিক হয়। আমার বিশ্বাস, আমরা একে অপরকে সাহায্য করতে পারি। যেমন আমি আপনার পরিবার ও মানসিক প্রতিবন্ধী সদস্যদের জন্য সার্ভিস পাওয়ার তথ্যাদি প্রদান ও সার্ভিস খুঁজে বের করায় সহায়তা করতে পারি আর আপনি আপনাদের সমস্যা ও প্রয়োজন সম্পর্কে আমাকে জানাতে পারেন। যা নিয়ে আমি গবেষণা করছি। আপনি ও আপনার পরিবারের পরিচিতিসহ সকল তথ্যাদি কড়াকড়িভাবে গোপন রাখা হবে। আপনার অংশগ্রহণ স্বেচ্ছামূলক হবে। আপনি যে কোনো সময় কোনো কারণ ছাড়াই বা বিনা নোটিশে আপনার অংশগ্রহণ বন্ধ করতে পারেন।

বিস্তারিত তথ্যের জন্য দয়া করে নিম্নে বর্ণিত ঠিকানা, টেলিফোন বা ফ্যাক্সে আমার সাথে যোগাযোগ করুন:

A Bangladeshi Wishes to Provide Free Services to Bangladeshi Families Living in New York City

I am a Bangladeshi immigrant, interested in serving the mentally retarded people and their families. As a recent immigrant, I know about the problems we meet in a strange country, particularly when the needs of an individual are special. I believe we can help each other. I can provide information and help in finding services for your family and the retarded member (s), and you can supply information on your needs and problems, which I am studying. All information will be strictly private, including who you and your family are. Your participation is voluntary. You can stop at any time without showing any reason or giving any notice.

For Further Information, please contact:

এম এম আলী
৪১-১৫, ৭১ স্ট্রীট
উডসাইড, নিউইয়র্ক ১১৩৭৭
ফোন: ৭১৮-৪৫৭-৮২৮৫
ফ্যাক্স: ৭১৮-৪৫৭-৮৩০৪

M.M. Ali
41-15, 71st Street
Woodside, N.Y 11377
Phone: 718-457-8285
Fax: 718-457-8304

Appendix B

Questionnaire on Needs Assessment of Bangladeshi Families with Mentally Retarded Relatives Living in New York City

1. How did you learn of this research project?

2. How many family members (male and female) do you have?

3. Is there anyone in your family who would be considered mentally retarded? If yes, how many people?

4. Do you have anyone living with you who helps this family member with extra needs?

5. Are you receiving any professional services such as medical, psychiatric, psychological, nursing, social work, etc.?

6. Is the individual with special needs receiving any skills training (daily living, vocational skills, etc.)?

7. Is this individual attending any special education school, day treatment, training program or workshop?

8. Is this individual residing in a group home?

9. Do your family members need training in the care of your mentally retarded member at your home?

10. Do you need any of the following specific services for this individual: Medicaid, Medicare, social Security disability (SSD) payments, habilitation, day treatment, job placement, group home, in-home care, attendant's training, respite care, workshop, transport services, etc.?

11. Do you have any other need(s) that are not mentioned above? If yes, please explain.

12. Could you please tell me what your religion is?

Appendix C

Statement of Information for the Participants

The researcher wants to conduct research among the Bangladeshi families of this neighborhood. With your participation and help this research project can be made successful. This study has been devoted to identifying the families who have mentally retarded members in their families. The researcher will help these suffering families identify their needs for the care of their retarded relatives and he will search for the services currently available in New York City from different sources.

The researcher will also request that you talk to him about a series of questions. If you voluntarily agree to participate in the research project and give your informed consent, then the researcher will schedule a talk concerning the survey for obtaining information from you about certain issues which are important to you and your family.

Here is a copy of the statement of your voluntary informed consent to participate in this research project. You can take this statement home and read it by yourself. You can also talk to your family members, relatives, and friends or any other counsel and get advice about making your decision to join or not to join this research project. You are free to make your decision without any obligation or risks. Please contact the researcher at (718) 457-8304 or (718) 457-8285 (41-15 71st Street, Woodside, N.Y. 11377). The researcher will arrange a time for you to meet him.

If you decide to participate in the research, you will be welcomed into the project. If you decide not to join, your decision will be respected and you will not be asked any more questions about the research project. Your participation will be voluntary and self-motivated. You will however, be asked to sign a written consent before you participate in the research project. Again, no solicitation or intimidation will be used in any way under any circumstances. You will be accorded your full right to refuse to sign the consent. Your consent will be completely voluntary and non-binding and without any obligation or risks.

During the interviews, you will have the right and opportunity to refuse to answer any question or give any information and you can freely express your feelings, reservations, and objections to any question. You are free to exercise your rights and options and are able to withdraw or discontinue your participation from the research at any time without giving any reason or prior notice. You will not be asked any questions for your sudden withdrawal or discontinuation. You can even discontinue your participation just before the research report is finalized.

While you are involved in the research, your information will be kept confidential at all times and will not be shared with anyone. All research documents and records such as the questionnaire sheets, interview recording sheets, any other types of documents recording any conversations and meetings between you and the researcher will be kept confidential. The information to be gathered through this research will strictly be confidential and used only for this study. No information will be shared and/or made public. Thus your individual privacy and the confidentiality of your information will be protected and ensured. But without mentioning any name or any other identifiable characteristics, the general information and the result of this study will be circulated to leaders of the Bangladeshi community and to service providing agencies for educational purposes and to arrange for needed and available services for subjects.

Only after you give your voluntary, non-binding and no obligation informed consent, will the researcher begin questioning you to collect information. If you do not understand a question or any part of the question, please tell the researcher immediately. The questions will be repeated again and explained to you. If you do not want to answer any question or any part of a question, please say so and you will not be asked that question again. If you think that any question is difficult or too sensitive for you, you need not be asked that question again. Please feel free to tell your feelings about any question. The researcher will be glad to avoid those sensitive questions. You can be assured that this research in no way will embarrass you or hurt your feelings. The question will be stopped as soon as your negative feelings or reservations are understood or conveyed.

You and other persons involved in this research will be treated fairly and equally and with great respect and dignity regardless of your origin, your color, your religion, your education and your socio-economic condition. Your civil rights will be protected and maintained in a relationship of mutual trust, privacy, and confidentiality. The research will be based on helping you understand and use your mutual relationship, in furtherance of your legitimate desires and interests and to achieve your self-fulfillment and maximum potential.

Appendix D

Public Laws of the U.S. Congress Which Incorporated Measures for Rehabilitating Mentally Retarded People

Public Law (PL) 95-602 has incorporated the special needs of the MR people into four priority services. Alternative community living arrangements have been made for maintaining suitable residential arrangements in the community; child development services have been included for the prevention, identification, and alleviation of MR people; non-vocational social-development services have been proposed for improving the skills of MR people so that they can perform daily living and work activities; and case management services have been offered for MR people to gaining access to needed social, medical, educational, and other services.

The previous Act PL. 94-103 set the priority for its national program goals which included: deinstitutionalization of MR people for improving quality of life through community living with programs for care and habilitation; early screening, diagnosis, and evaluation of MR infants and preschool children; and adult programs for counseling, program coordination, follow-along services, protective services, and personal advocacy services.

In addition, the Social Security Administration also provides funding for rehabilitative services under the Titles II and XVI of the Social Security Act (PL. 94-566). The Office of Human Development Service provides supports for training and employment services utilizing Title XX of the Social Security Act. The Health Care Financing Administration provides funding for habilitation services through Title XIX (Medicaid) of the Social Security Act (PL. 92-223). The Public Health Service provides funding for training and employment services through the Mental Health System Act. The Employment and Training Administration (US Department of Labor) supports through the Comprehensive Employment and Training Act. The Rehabilitation Services Administration (US Department of Education) provides funding allocated under the Rehabilitation Act of 1973. The Office of Special Education (US Department of Education) provides funding for education and training under the Education for All Handicapped Children Act of 1975. The Office of Vocational and Adult Education (US

Department of Education) provides funding for training handicapped children and adults through the Vocational Education Act and the Adult Education Act.

Appendix E

Some ACRMD-Provided Services

Day Training and Vocational Rehabilitation - Provide diagnostic vocational evaluation, personal adjustment training, vocational training, and job preparation through actual paid work experience, employment counseling, and job placement and follow-along services.

Sheltered Employment - Includes job development and job matching, ongoing supervision and training of the worker on the job site, intensive job coaching, interventions designed to maintain daily living skills and other functions necessary for employment.

Supported Work Placement and Follow-Along - travel training, assistance to the employer in orienting, training and supervising the worker, family supports and evening recreation.

Employment Placement - Includes job development and job matching as well as intensive job coaching interventions designed to maintain daily living skills.

Community Residences - Structured and supervised community living services for developmentally disabled men and women.

Intermediate Care Facilities - Comprehensive professional residential services including care for adults with multiple disabilities.

Supportive Apartments - Supportive living in neighborhood settings designed to foster community inclusion for developmentally disabled people capable of living with minimal supervision and supports.

Independent Living Apartments - For developmentally disabled individuals capable of independent living and securing employment.

Day Treatment Services -An array of services individually tailored to consumers' needs, which will integrate them into the community. Ongoing diagnostic and therapeutic services including instruction in self care, nutrition, as well as independent living and recreation. Medical, nursing, psychological, social work, speech, physical therapy, and occupational therapy services are also available.

Mental Health Services - Day treatment services for dual -diagnosed people encompassing psychiatric and individualized therapeutic daily activities, i.e., clinic treatment including psychiatry, individual, group and family therapy and recreation therapy.

Family Support - Training and support for developmentally disabled adults with their families.

Home and Community Based Services - Case Management, Residential Habilitation, Environmental Modification, and Adaptive Technologies.

Senior Citizens Services - Services and programs specifically designed for aging developmentally disabled people.

Clinic Treatment Services - Psychological counseling, social work services, rehabilitation counseling, occupational therapy and speech therapy.

Staff Training Services - Training that recognizes that care provided must meet the unique social, psychological and physical needs of the consumer.

Information and Referral Services - Provides the consumer and his/her family with information about obtaining services specifically designed to meet their needs, both within and outside of the agency.

Appendix F

Following is a list of the specific services that most of the agencies in Greater New York area are currently providing. Each of these services are given a number for identification.

No. **Services**

1. Day Program
    - 1.1. Day Treatment Center (21 years and older)
    - 1.2. Workshop (21 years and older)
    - 1.3. Special School (up to 20 years)

2. Residential Services
    - 2.1. Intensive Care Facility (ICF) for Adult Low Functioning
    - 2.2. Community Residences (CR) and Individual Residential Alternative (IRA) for Adult High Functioning
    - 2.3. Independent Living and Supported Apartments for Adult Borderline Persons.
    - 2.4 Residences for the Children
    - 2.5. Residences for the Adolescents

3. Professional Services
    - 3.1. Psycho-Social
    - 3.2. Psychological
    - 3.3. Psychiatric
    - 3.4. General and Specialized Medical
    - 3.5. Speech, Audio and Hearing

    3.6. Physical Therapy
    3.7. Occupational Therapy
    3.8. Recreational Therapy
    3.9 Neurological Services

4. In-Home Training, Respite and Outreach Services
5. Job Placement Services for Adult High Functioning
6. Disability Benefits
7. Medicaid
8. Medicare
9. Transport and Adaptive Equipments
10. Family Training and Support Services
11. Information and Referral Services
12. Financial Supports

Appendix G

Fifty Agencies and Services They Provide

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
1. Ass'n for Children with Retarded Mental Development (ACR MD), Inc. (212) 741-0100	◆	◆		◆	◆	◆				◆	◆
2. Ass'n for the Help of Retarded Children (AHRC), Inc. (212) 780-2500	◆	◆		◆	◆	◆				◆	◆
3. Association for Children with Learning Disabilities (ACLD), Inc. (516) 334-4210	◆	◆		◆	◆	◆				◆	◆
4. Aid to the Developmentally Low Disabled (ADD), Inc. (516) 727-6220	◆	◆		◆	◆	◆				◆	◆
5. Ass'n. for Advancement of Blind and Retarded (ABBR), Inc. (718) 479-8241	◆	◆		◆	◆	◆				◆	◆

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
6. Builders for Family and Youth Diocese of Bklyn.(718) 596-5500	◆	◆		◆	◆	◆				◆	◆
7. Catholic Charities (516) 768-5213	◆	◆		◆	◆	◆				◆	◆
8. Catholic Guardian Society (212) 371-1000	◆	◆		◆	◆	◆				◆	◆
9. Contemporary Guidance Service (212) 239-4810	◆	◆		◆	◆	◆					◆
10. Community Living Alternatives (CLA) Inc. (718) 981-44671	◆	◆		◆	◆						◆
11. Community Mainstreaming Associates (CMA) Inc. (516) 462-5810	◆	◆		◆							◆
12. Epilepsy Foundation of Nassau County (516) 794-5500	◆	◆		◆	◆	◆					◆
13. Family Residence and Essential Enterprises (516) 756-9800	◆	◆	◆	◆	◆	◆				◆	◆

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
14. Independent Group Home Living Program (516) 878-8900				◆		◆					◆
15. Jewish Community Services (516) 485-5710	◆	◆		◆	◆	◆				◆	◆
16. Little Flower Children's Center (LFCC) (516) 929-4020		◆	◆	◆		◆				◆	◆
17. Little Village House (516) 365-4480		◆	◆	◆		◆				◆	◆
18. Maryhaven Ctr. of Hope (MCH), Inc. (516) 474-4100	◆	◆		◆	◆	◆				◆	◆
19. Mini-Travelers (Camelot) (516) 331-6300			◆	◆		◆				◆	◆
20. Young Adult Institute (212) 563-7474	◆	◆	◆	◆	◆	◆				◆	◆
21. Inst. for Basic Research in Developmental Disabilities of NY State (718) 698-3803										◆	◆

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
22. State of NY, Off. of Mental Retardation and Developmental Disabilities (OMRDD) (212) 587-4540							◆			◆	◆
23. NYC Off. of Mental Retardation and Developmental Disabililities (OMRDD)							◆			◆	◆
24. Boro Developmental Disabillities Service Office (BDDSO) of Manhattan (212) 741-3866				◆	◆	◆	◆			◆	◆
25. Boro Developmental Disabillities Service Office (BDDSO) of Brooklyn (718) 834-6600				◆	◆	◆	◆			◆	◆
26. United Cebral Palsy (UCP) of New York City, Inc. (212) 677-7400	◆	◆	◆	◆	◆	◆				◆	◆

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
27. United Cebral Palsy (UCP) of New York State, Inc. (212) 947-5770	◆	◆	◆	◆	◆	◆				◆	◆
28. Jewish Board of Family and Children's Services (JBFCS), Inc. (212) 582-9100	◆	◆	◆	◆	◆	◆				◆	◆
29. Ctr. for Urban Community Services (CUCS), Inc. (212) 801-3300	◆	◆		◆	◆	◆				◆	◆
30. Beacon of Hope House (212) 801-3300	◆	◆		◆	◆	◆				◆	◆
31. Federation Employment and Guidance Service (FEGS), Inc. (212) 742-7110	◆	◆	◆	◆	◆	◆				◆	◆
32. Early Childhood Detection Centers of Manhattan, Queens, Brooklyn, Bronx, S.I., (212) 472-6535 (718) 640-6412 (718) 579-5778		◆	◆	◆	◆	◆				◆	◆

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
33. Services for the Underserved	◆	◆		◆	◆	◆				◆	◆
34. Creative Arts Rehab. Center (212) 246-3113	◆	◆	◆								◆
35. Board of Education, City of New York (718) 935-2000			◆			◆				◆	◆
36. Community School Bd., City of New York (718) 257-7500			◆			◆				◆	◆
37. Coney Isl. Hospital (718) 615-4000						◆				◆	◆
38. Jewish Guild For The Bline, Inc. (212) 769-6200	◆	◆	◆	◆	◆	◆				◆	◆
39. Interfaith Medical Ctr. (718) 935-7000						◆				◆	◆
40. Mt. Sinai Hospital (212) 241-6500						◆				◆	◆
41. Children's Day Treatment Ctr. and School, Inc. (516) 929-4020		◆	◆	◆		◆				◆	◆

Agency Name	Workshop	Day Treatment	Special School	Residential Services	Job Placement	Home Services	Disability Benefits	Medicaid	Medicare	Professional Services	Info./Referral Services
42. Social Security Insurance (SSI)							◆	◆	◆		◆
43. Social Security Admin.							◆	◆	◆		◆
44. Adult Retarded Center (718) 253-9090	◆	◆		◆	◆	◆					◆
45. Graham Windham Child Care (212) 889-5600	◆	◆		◆	◆	◆				◆	◆
46. BIAS EZRA (718) 851-6300	◆	◆		◆	◆	◆				◆	◆
47. Bedford Stuyvesant Community Mental Health Ctr., Inc. (718) 636-4360	◆	◆	◆	◆	◆	◆				◆	◆
48. Herbert G. Birch Community Services (718) 528-5754	◆	◆	◆	◆	◆	◆				◆	◆
49. Brownsville-Ocean Hill Community Mental Health Ctr. (718) 467-6441	◆	◆		◆	◆	◆				◆	◆
50. Lexington Children's Center (212) 876-1899		◆	◆	◆	◆	◆				◆	◆

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