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La Fundación Puertorriqueña Síndrome Down

**THE DOWN SYNDROME POPULATION OF PUERTO
RICO: DETERMINING THE NUMBER AND ASSESSING
THE SERVICES**

May 9, 2000

This project report is submitted in partial fulfillment of the degree requirements of Worcester Polytechnic Institute. The views and opinions expressed herein are those of the authors and do not necessarily reflect the positions or opinions of La Fundación Puertorriqueña Síndrome Down or Worcester Polytechnic Institute.

This report is the product of an education program, and is intended to serve as partial documentation for the evaluation of academic achievement. The report should not be construed as a working document by the reader.

Abstract

Carmen Avilés-Ortiz, the Executive Director of la Fundación Puertorriqueña Síndrome Down, commissioned us to determine the size of the Down Syndrome population on the island of Puerto Rico. This was done using previously conducted population studies and population data from the Department of Health. She also asked us to determine the needs of Down Syndrome individuals, and to analyze the adequacy of the current facilities in Puerto Rico. The necessary information for this task was gathered using questionnaires and interviews. This data was then analyzed using various statistical methods. The results will be used to acquire funding for the Foundation, as well as to expand and improve other facilities needed by Down Syndrome persons and their families across the island.

Authorship Page

This statement is to confirm that all members of this Interactive Qualifying Project group contributed equally to all aspects of this report. The chapters entitled Introduction, Methodology, Data and Results, Analysis of Results, and Conclusions and Recommendations were written collectively while at the Project Center in San Juan, Puerto Rico. The Literature Review was compiled from research conducted by all project members. Alyssa Brokaw wrote the sections concerning data collection and the case study performed in Worcester, Massachusetts. Diane Kavanagh was responsible for the background information on Down Syndrome and the analysis of one population study. Tracy Patturelli authored the sections dealing with statistics, culture in Puerto Rico, and the analysis of the other population study.

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Executive Summary

La Fundación Puertorriqueña Síndrome Down is a nonprofit organization located in San Juan, Puerto Rico. The Foundation, established in 1991, focuses its care on Down Syndrome children ages birth to five through inclusion daycare, various therapies, preschool, and family orientation and support groups. The Foundation receives the majority of its funding from governmental organizations, private contributors, industries, and other non-profit organizations. To improve care for the Down Syndrome individuals on the island, the Foundation continuously needs additional funding to expand their services.

Carmen Avilés-Ortiz, the Executive Director of la Fundación Puertorriqueña Síndrome Down, has commissioned us to determine the number of Down Syndrome individuals on the island, in order to help the Foundation advocate for additional funding. She also asked us to evaluate the needs of Down individuals and their satisfaction with services currently available. Our objective was to determine which services were lacking, in hopes of filling this gap with the help of further funding.

When accomplishing these objectives, we focused on all Down Syndrome individuals, placing a strong emphasis on those Down children ages birth to three. The ages from birth to three were considered separately due to the importance placed on early intervention services. Down Syndrome children who do not receive care during this critical time period have extreme difficulty developing to their full potential.

To determine the Down Syndrome population in Puerto Rico, we used previously conducted population studies, birth numbers from the Department of Health and life

expectancy data. From the population studies, we acquired a mean Down Syndrome birth prevalence rate of 13.2 per 10,000 live births with a range of 11.5 to 16.9. Using this data, we were able to approximate the total Down Syndrome population as well as the birth to three year population. These mean estimations were found to be 2607 and 239, respectively.

In order to evaluate the adequacy of the current services in Puerto Rico, a survey of Down Syndrome families and their health care providers was conducted.

Questionnaires were sent to all individuals on the Foundation's mailing list, as well as to health care providers at each of the seven pediatric clinics island wide. The responses received from those on the Foundation's mailing list were used to assess the current services for Down individuals, in addition to providing contact information to update the Foundation's database. These responses were analyzed according to three distinct age groups based on the care given to each. These age groups were as follows: birth to three years, three to twenty-one years, and twenty-one years and older. Expert knowledge regarding availability of services and proper care of Down individuals was gathered from the responses from the health care providers, as well as through interviews with other professionals.

In analyzing the responses from the questionnaires, we focused on the availability and the usage of services. We were able to draw conclusions, distinct for each age group, based on an analysis of our results. For Down Syndrome children ages birth to three years, it was found that all of the services needed for development are available through the pediatric clinics, though many are understaffed. However, some parental lack of knowledge about services does exist, because communication between the pediatric

clinics and Down Syndrome families is inadequate. This was confirmed by the responses we received from the health care providers and through the interviews we conducted. It was also found through our analysis that the respondents from this age group were relatively satisfied with the services available to them, although this satisfaction did not match their immense need for care. Individuals from the three to twenty-one years age group felt less satisfied with services, as compared to the birth to three years age group. The principal need of these Down Syndrome individuals was for more therapeutic services through the school. The responses from those twenty-one years and older illustrated the greatest dissatisfaction with services specific to Down Syndrome. From our analysis, the main problem for this age group was the lack of vocational and social training programs.

Based on our conclusions we were able to make recommendations for each of the three age groups. From our approximation of the Down Syndrome population, it was apparent that there are many Down individuals who are not in contact with the Foundation. Using our approximation of 2607 Down individuals in Puerto Rico, la Fundación Puertorriqueña Síndrome Down will be able to justify their need for more funding, allowing them to reach these individuals. Based on our assessment of services and resources permitting, the Foundation will be able to expand the current services according to the needs of each age group. To fill the current gap in services we suggest after-school tutoring and recreational programs, increasing the current workforce, and implementing vocational and social programs. All three age groups could benefit from improved communication about the services actually available. Better communication

could be facilitated through more comprehensive advertising, such as television, radio, newspaper, the Internet and local schools.

Introduction

Down Syndrome is a common genetic disorder that causes physical and mental disabilities. Those affected by Down Syndrome have varying levels of ability ranging from the need for constant surveillance to being relatively self-reliant. In order to care properly for these unique individuals, it is necessary to be aware of their needs. The most advantageous way to accommodate the needs of all Down individuals is to determine their population size and to provide appropriate services locally. Once services are provided for a Down person and family, it is crucial to evaluate their satisfaction with these services.

La Fundación Puertorriqueña Síndrome Down^{*} has commissioned us to accomplish two objectives relating to the Down Syndrome population in Puerto Rico. These objectives are as follows:

- To determine the approximate number of Down Syndrome cases in Puerto Rico.
- To assess the needs of the Down population and their satisfaction with the current services, while updating the Foundation's preexisting database.

To accomplish the task of determining the approximate number of Down Syndrome cases on the island, we used relevant data from previously conducted population studies, birth numbers from the Department of Health, and life expectancy data. Some simple calculations and extrapolations yielded a total Down Syndrome population estimate for the island, as well as a birth to three year approximation. These

^{*} This report was prepared by members of the Worcester Polytechnic Institute Puerto Rico Project Center. The relationship of the Center to la Fundación Puertorriqueña Síndrome Down and the relevance of the topic to la Fundación Puertorriqueña Síndrome Down are presented in Appendix A.

numbers helped us to gauge the scope of Down Syndrome care needed on the island, as well as to make the Foundation aware of the number of Down Syndrome individuals with whom they are not currently in contact.

In order to determine if the needs of the Down individuals are being met by the current facilities, we distributed questionnaires to the families of Down Syndrome individuals on the Foundation's mailing list and also to health care providers associated with the seven pediatric clinics across the island. The pertinent data is presented in our report in the form of graphs and tables illustrating the services and the satisfaction thereof. Some of the data from the questionnaires sent to those on the Foundation's mailing list will be used to update the Foundation's database. We also conducted interviews with professionals at two local pediatric clinics and with professionals involved with the Foundation in order to understand the procedures that govern the seven pediatric clinics and to ascertain the services offered. These expert opinions furnished a framework by which to interpret the responses received.

Our findings are useful to la Fundación Puertorriqueña Síndrome Down for the acquisition of funding and the expansion of facilities. The families of Down individuals will also benefit from our findings. An updated mailing list will facilitate communication and allow families to become more involved in the Down community. Suggestions we collect from the families will also be taken into consideration by the Foundation in order to help tailor programs to meet the families' needs. Families will be able to contact each other for emotional support and aid in treating those affected. Other researchers and agencies will be able to use our methodology, data and recommendations to conduct similar investigations and to develop a strategy to maximize care for the Down Syndrome

population. It is hoped that all those involved will learn more about the services available to them, and will have an active role in the improvement of Down Syndrome care.

The Interactive Qualifying Project (IQP) is a requirement for all undergraduates at Worcester Polytechnic Institute. The IQP examines the impact of technology upon society by using qualitative and quantitative social science techniques to investigate a social problem. Through this project students will learn to consider how technological advancements affect society and also how cultural mindsets affect scientific thinking. This project will connect technology to society by using scientific systematic reasoning to assess the population and needs of Down Syndrome individuals. It will also propose ways to bring all that technology and science have to offer to the families of Down Syndrome people. Ultimately, we hope to help children and families link to a network of sympathetic caretakers and individuals.

Literature Review

The purpose of our project is to estimate the Puerto Rican Down Syndrome population, to research their needs and measure their satisfaction with the services provided specifically for the Down Syndrome population, and to update the Foundation's database. In order to evaluate the needs of the community we have researched the special needs of Down Syndrome individuals and have incorporated this information in our project. Complex medical terms are defined in the glossary at the end of the paper. A Down Syndrome Facility case study performed in Worcester, Massachusetts is also included. Two studies estimating the Down Syndrome birth prevalence rate will help in approximating the Down population in Puerto Rico.

The mindset of a community towards an illness affects the perceived needs for services. Due to this influence, understanding the culture is paramount. Thus, information is included concerning Latin American family structure and medical treatments.

Valid data must be collected about the population via standard research methodologies. For this reason we have researched several accepted practices. The sections dealing with statistical analysis explains proper handling of data.

General Information and Background of Down Syndrome

According to Smith (1995), Down Syndrome, affecting 1 in 800 to 1 in 1000 newborns, is a genetic condition caused by extra genetic material from the 21st chromosome. Babies are normally born with two copies of chromosome 21 but people with Down Syndrome are born with three copies of this chromosome. Smith states that it

is the multiple copies of chromosome 21 that cause the defining characteristics of Down Syndrome.

Hassold (1999:25) remarks that Down Syndrome is the most common form of mental retardation, causing mild to severe mental deficiency. Down individuals who have only mild mental deficiency function much like individuals who do not have any type of mental retardation. However, Down individuals develop more slowly.

In addition to mental retardation, there are a variety of physical traits that are typically linked to Down Syndrome. Batshaw (1997:315) lists traits that affect all areas of the body, ranging from hypotonia or reduced muscle tone (See Glossary) to short stature. He also lists some other physical traits common to Down Syndrome such as flat facial profile, upwardly slanting eyes, small ears, small nose with low nasal bridge, and a single palmar crease.

Causes and Types

Kliewer (1998:83-84) explains that the cause of Down Syndrome is that the 21st chromosome does not separate as it should during meiosis (See Glossary), although it is unknown why this occurs. Cell division occurs during meiosis in which each parent cell undergoes a two-step process that results in four sex cells being formed. During normal meiosis, the chromosomes of each cell split in half leaving each new cell with 23 chromosomes. However, during meiosis - from which Down Syndrome cells are produced - Chromosome number 21 does not separate completely, leaving one of the four sex cells with an incorrect number of chromosomes. Kliewer remarks that there are three main ways in which Chromosome 21 can produce a cell resulting in a Down Syndrome child. These result in three different types of disability.

The first and most common type of Down Syndrome is known as non-disjunction. Non-disjunction affects roughly 95 percent of all people with Down Syndrome (Smith, 1995). Kliever (1998:87) tells us that in the non-disjunction form of Down Syndrome, Chromosome 21 does not split in half, leaving two copies to join the copy of Chromosome 21 from the other parent cell. He goes on to explain that this defect causes three copies of chromosome 21 to remain in all the cells of the body, thus producing the complications of Down Syndrome.

The second type of Down Syndrome described by Smith (1995), which occurs only three to four percent of the time, is translocation. In this particular type, only a portion of Chromosome 21 fixes itself on to another chromosome. Kliever (1998:89) adds that in addition to a normal Chromosome 21 pair, there is another portion of Chromosome 21 that attaches to either Chromosome 14 or 22. This attached matter is the cause of the problems related to Down Syndrome even though there are still 46 chromosomes in each cell.

The third and most uncommon type of Down Syndrome is called mosaicism. Mosaicism, which Kliever (1998:91) says takes place after fertilization, occurs in one to two percent of the Down cases, and in this case, the person affected with Down Syndrome has an extra 21st chromosome in only some of the cells but not all of them. The other cells simply contain the usual pair of the 21st chromosomes.

Life Span

According to Gundersen (1995, 63-64), the life span of Down Syndrome individuals has increased greatly with the advent of modern medicine and continues to increase as medical improvements are made. Due to incurable heart conditions, the life

expectancy of a Down Syndrome individual in the early 1930's was nine years. Lott and McCoy (1992, xi) now estimate an average life span of fifty-five for individuals with Down Syndrome. As technology becomes more sophisticated the average life span is expected to continue increasing.

Prenatal Diagnosis

In the past, there was only one way to determine if the baby in a mother's womb would be a Down Syndrome baby. This was deduced by amniocentesis (See Glossary), which can result in miscarriage. However, Smith (1995) states that in recent years, doctors have begun to recommend a different type of screening test for all pregnancies.

There are two types of tests used for prenatal diagnosis, according to Smith (1995). These types are diagnostic and screening. Diagnostic tests sample fetal cells and give a definitive diagnosis whereas screening tests are noninvasive to the womb and find most of the fetuses with Down Syndrome.

Diagnostic tests include amniocentesis and chorionic villus sampling (CVS) (See Glossary). With amniocentesis a needle is passed into the mother's womb, using ultrasound, to sample fetal cells in the amniotic fluid (See Glossary). The cells are then sent for chromosome analysis. CVS samples cells as well, but these are cells from the chorionic villi (See Glossary), located on the surface of the chorion (See Glossary). Smith (1995) explains that both procedures are relatively safe but still have a small risk of miscarriage.

Screening tests include maternal alpha-fetoprotein and the triple test. The maternal alpha-fetoprotein test checks the level of alpha-fetoprotein (See Glossary). According to Smith (1995), if the level of protein is low, there is a good chance that the

baby in the womb will be born with Down Syndrome. Batshaw (1997:364) explains that the triple test measures three components of the mother's blood and uses these measurements to determine if the baby will be a Down baby. Batshaw notes that if tests point to Down Syndrome, doctors recommend a follow-up amniocentesis.

Related Health Conditions

In addition to the levels of mental retardation associated with Down Syndrome, there are also a number of related health conditions. Most of these health conditions are quite serious and can cause permanent damage if not monitored. For this reason, according to Batshaw (1997:372) early intervention programs are best if started as soon as the disability is detected.

Congenital heart disease.

Pueschel (1997:51) states that the most significant health condition associated with Down Syndrome is congenital heart disease, which occurs in 40 to 60 percent of all children with Down Syndrome. Batshaw (1997:364) goes on to explain that ventricular septal defects, complete atrioventricular septal defects and an endocardial cushion defect (See Glossary for descriptions) are among the most common lesions. The major complication of congenital heart disease is a condition known as pulmonary vascular obstructive disease. He states that this condition can lead to congestive heart failure and must, therefore, be identified at an early age. For this reason, Cohen (1996:9) strongly recommends that all infants with Down Syndrome have an evaluation by a pediatric cardiologist before they reach three months of age. Batshaw (1997:364) believes that this

examination should include an echocardiogram, which has been proven to detect two thirds of all congenital heart disease.

Sensory impairment.

Batshaw (1997:364-365) reports that studies have shown that more than 60 percent of children with Down Syndrome suffer from vision problems, most of which require treatment or therapy or both. Cohen (1996:11) remarks that one specific problem for an infant with Down Syndrome is a congenital cataract, which can lead to loss of vision if not treated. He believes that in order to determine such a problem, visual examinations should start at six to twelve months of age and continue once every one to two years. Some other common vision problems, most of which are frequent and are detected in a routine eye examination, are refractive errors, tear duct obstruction, blepharitis and conjunctivitis (See Glossary for definitions), according to Batshaw (1997:364-365).

Many Down Syndrome children also suffer from hearing loss. Hearing loss affects roughly two thirds of the children with Down Syndrome (Batshaw, 1997:365). This hearing loss can range throughout the ear causing such problems as conductive loss, which is related to middle ear effusions, or sensorineural hearing impairment (See Glossary), or both (Cohen, 1996:9). Conductive hearing loss results from a combination of impacted cerumen (See Glossary) in the ear canal, abnormalities in the tympanic membrane and middle ear disease (Pueschel, 1997:50). This can lead to recurrent ear infections as well as sleep apnea (See Glossary) (Batshaw, 1997:365). Cohen (1996:9) suggests that all Down Syndrome children have an objective measure of hearing

performed before six months of age to detect, and possibly treat, these hearing problems. Because many Down Syndrome children have small ear canals, it may be necessary to visit an Ear, Nose, and Throat physician instead of a pediatrician in order to obtain an accurate examination.

Atlantoaxial instability (AAI).

Another medical condition related to Down Syndrome is a ligament-skeletal disorder. Atlantoaxial instability is a term used to describe increased mobility of the cervical spine at the level of the first and second vertebrae. This condition affects roughly 14 percent of the people with Down Syndrome, only 10 percent of whom have symptoms, according to Cohen (1996:9-10). Pueschel (1997:53) relates that these symptoms are due to the compression of the spinal cord and can include neck pain, unusual posturing of the head and neck, loss of upper body strength, abnormal neurological reflexes and change in bowel and bladder functioning. Cohen (1996:11) believes that to determine the extent of these spinal problems, screenings must be performed in the neutral, fixed, and extended positions.

Thyroid disorders.

Thyroid disorders are another health condition related to Down Syndrome. These disorders affect people of all ages and may be subtle in individuals with Down Syndrome (Cohen, 1996:11). This subtlety is because people with Down Syndrome exhibit many of the same physical characteristics as people with thyroid disorders (Pueschel, 1997:52). Thyroid disease is seen about twenty-eight times more frequently in people with Down Syndrome than in those without Down Syndrome (Cohen, 1996:12). The most common

thyroid disorder in Down individuals is hypothyroidism (See Glossary), which is most prevalent in Down adolescents (Pueschel, 1997:52). This disease is a problem because people with Down Syndrome do not have usual thyroid levels that are necessary for normal growth. For this reason, Batshaw (1997:372) says following growth and height charts as well as monitoring the weight of those with Down Syndrome is necessary.

Neurodevelopmental issues.

Along with the various health conditions mentioned above, there are also many neurological problems that are associated with Down Syndrome. People with Down Syndrome, Cohen notes (1996:13), experience seizure disorders more frequently than do the general population. Pueschel (1997:368) states that seizures affect roughly six percent of those with Down Syndrome and there appears to be a connection between age and the frequency of the seizures. Seizures also appear to be most frequent under the age of three and after the age of thirteen. Moreover, he continues, 62 percent of seizures are related to congenital heart disease.

Attention Deficit Hyperactivity Disorder (ADHD), another neurodevelopmental disorder, occurs as much in individuals with Down Syndrome as it does in individuals with other mental retardation. According to Hassold (1999:48), six to ten percent of Down Syndrome individuals are diagnosed with ADHD, which is roughly two to three times as prevalent as in the general population. However, ADHD is often unnoticed in children with Down Syndrome. Many people simply link the child's inability to be attentive for a long period of time with the mental problems inherent to Down Syndrome itself.

Schooling of Children with Down Syndrome

Historically, people with disabilities have been discriminated against and have been excluded from traditional schooling. Kliever (1998:39-41) remarks that it was only recently, in the late twentieth century, that educators, doctors and parents began to realize the importance of traditional schooling for Down Syndrome children. This realization was further supported by the federal Education for All Handicapped Children Act of 1975 mandating that all disabled children be given the same opportunities for schooling as those who are without disabilities. Following the passing of this act, children with Down Syndrome were allowed to attend traditional schools. These schools, however, says Pueschel (1997:145-146), were greatly segregated and the disabled students had little to no contact with the children who were not disabled. As time passed, and the push toward integrating disabled students with non-disabled students grew, many schools and school systems adopted the inclusive education principle, integrating students of all abilities in the same classroom.

Along with this inclusive education system, came the tendency not to put Down Syndrome children into institutions. It is possible that most children with Down Syndrome were placed directly into institutions in order to lessen the burden and pain on the child's family. Today, however, it is only those children who are severely disabled who are placed in a home for the mentally disabled. Lane (1985:359) observes that children with Down Syndrome profit and grow from family relationships and from interacting with their peers.

Development of Children with Down Syndrome

Due to the mental disabilities of Down Syndrome children along with the various other physical and neurological disabilities, the developmental process in these children is considerable slower than that of children without disabilities. According to Lane (1985:350), studies show that early intervention and family support improve development.

Motor Skill Development

According to Gunderson (1995:122), motor skill development can be broken down into two main groups: namely, gross and fine motor development. Gross motor skill development is the development of large muscle groups such as legs, arms, and abdomen. These groups are vital for movement. Fine motor skill development takes place through the use of ones hands and fingers and aid in controlled movements. Lane (1985:188) states that the development of motor skills, gross and fine, in Down children is slow because they have poor muscle tone. In order to aid in the development of motor skills physical therapy is sometimes necessary, according to Burack (1998:640).

Children with Down Syndrome who participate in physical therapy early in their lives tend to gain skills and the use of muscle groups at an earlier age than those who begin at a later age. He stresses that it is also important that these children have support from their families to develop their motor skills. If children with Down Syndrome receive the correct form of therapy and a good amount of support, he tells us, they can possibly learn to do most things that normal children can do, only at a slower rate.

Cognitive Development

Cognitive development deals with an individual's ability to reason and solve problems. One way to measure cognitive development is to measure his or her Intelligence Quotient (IQ). The American Association on Mental Retardation (AAMR, 1996) defines mental retardation based on IQ, as an IQ below 70 to 75. This low IQ along with significant limitations in two or more adaptive skill areas defines mental retardation in a person in which the condition has been present since childhood. The AAMR (1996) further classifies this mental retardation by dividing the IQ level in to four categories: mild (IQ 55-69), moderate (IQ 40-54), severe (IQ 25-39) and profound (IQ under 25). Approximately 87 percent of people who are mentally retarded will be mild cases and will only be a little slower than the average person. The remaining 13 percent will have serious limitations. The AAMR also remarks that with early intervention, these limitations can be reduced. Kallin (1996) also comments that the IQ of Down Syndrome individuals typically varies between 20 and 80, most being below 50. Therefore, most Down individuals have moderate to severe limitations.

According to Gunderson (1995:139-140), cognitive development includes the capability to comprehend object performance, which describes how objects do not vanish when they are out of view. He states that it also includes the ability to understand cause and effect situations. When children with Down Syndrome are young, their ability to reason is relatively good. However, this ability to reason decreases as the children get older (Pueschel, 1997:91). Sinex (1982:89) comments that the exact reason for this decrease in IQ is unknown but could possibly be linked to Alzheimer's Disease. He believes this is true because degenerative brain lesions, similar to those found in

Alzheimer's patients, have been identified in the Down Syndrome population. It is thought that these lesions are the cause for the degenerative IQ.

Speech and Language Development

The development of speech and language in children with Down Syndrome is also slowed because of the effects of the disease. Cohen (1996:14) believes that children with Down Syndrome can understand the spoken language better than they can express themselves. To develop better language skills, Down Syndrome children must develop comprehension and production skills. Comprehension refers to the use of language to understand the thoughts and ideas of others, and production refers to the use of language to express one's thoughts and feelings (Hassold, 1999:146).

Hassold (1997:147) states that in addition to the limitations due to cognitive development, the facial and oral deformities of Down Syndrome also contribute to the difficulties experienced in language development. Down individuals usually have an enlarged tongue making it a challenge to form words correctly.

Children without disabilities may also experience problems dealing with speech and language. The problems for Down Syndrome children, however, are more pronounced according to Hassold (1999:147). Some specific problems experienced by Down children, he informs us, are in the areas of vocabulary, sequencing of words and sounds, and fluency.

Social and Self-Help Development

Social and self-help developments are crucial to interacting with others as well as being independent. Social development is characterized by one's ability to interact and relate with others. Down Syndrome persons tend to react slightly differently to situations

than do people without disabilities. This difference is in the level of reaction. Studies show that reactions in Down people are less pronounced (Lane, 1985:292). According to Lane (1985:292), for instance, a Down individual might smile when another child would laugh. Down children are also less apt to cry when their parents leave them. Lane says this reaction is attributed to the fact that Down Syndrome children have a slow processing ability. Simplistic games elicit laughing and smiling more than social games do in Down children.

Self-help development is important to all Down Syndrome individuals, especially in those who have a mild case of the syndrome. If Down individuals do not develop the skills necessary to function day to day independently, they will always be dependent on others.

Reading Skills Development

The development of reading skills also causes some difficulty for a child with Down Syndrome. In the past, it was believed that children with Down Syndrome were unable to read, and if they did their comprehension level would be quite low. However, if given the chance, Pueschel (1997:94) says that approximately 50 percent of Down cases can achieve a useful degree of literacy. This degree of literacy can be reached when teaching is begun at a young age, but training during adolescence has also proven to be beneficial, he says (1997:94). Recently, Hassold (1999:155) emphasized that individuals with Down Syndrome are expected to learn to read and to use this ability as a tool to enable them to function independently in day-to-day life.

Necessary Services

Due to all of the health conditions related to Down Syndrome there are various services that are necessary to give the individuals the care they need and deserve. Cohen (1996:9-14) lists these services. They include:

- The usual immunizations and well child care
- Yearly screenings for hypothyroidism
- The use of Down Syndrome specific growth charts for height and weight
- Evaluations by a pediatric cardiologist including an echocardiogram
- Hearing examinations
- An examination by an Ear, Nose and Throat Physician, if necessary
- Surgery to correct any related health conditions, if possible
- Eye examinations, every one to two years
- Screening for Atlantoaxial Instability with lateral cervical radiographs
- Physical therapy to increase muscle development

Latin American Culture and Its Views Toward Down Syndrome

When dealing with physiological health or mental health issues, the cultural and social influences on the person affected tend to play a big part in the treatment of that person. As early as 1982, Becerra (1982:17) stressed that the issue of cultural and social relevance was not a new one, especially when it comes to health care. Becerra implies that in order to have success in the treatment of individuals from Latin American cultures, an understanding of that culture is extremely important. During the past three

decades, says Pueschel (1987:273-274), the approach towards Down Syndrome treatment has evolved from promoting institutionalization to promoting integration within society. However, the close knit family networks of Latin America have always supported and cared for their own and tend not to broadcast the occurrence of health issues, such as Down Syndrome, outside the family. He concluded that because of this privacy issue, some Down Syndrome individuals may not receive all of the health and educational care that they need.

It must be kept in mind that Becerra's book is almost twenty years old, and could express some views about Puerto Rico that have since changed.

Latin American Culture Groups

It appears that the close-knit family networks of Puerto Rico are subdivisions of a more powerful culture group. Young (1966:493-494) describes a culture group as a union of people who have common heritages, beliefs, social styles, and living environments. Young also asserts that the individuals constituting a culture group follow their own ideas and beliefs. He says, being in a culture group brings people of similar values together, and allows these people to follow what they each believe. He believes that any large city or area can contain a large number of culture groups, especially in America where immigration is constantly occurring.

In Puerto Rico, however, the island is comprised mainly of one culture group. This is because most Puerto Ricans share a common heritage, belief, social style, and living environment. Morris' (1995:75-81) study revealed, among other things, that Puerto Ricans felt Puerto Rico was in a category all by itself. She posits that there are no people in the world that have as strong a cultural bond as those of Latin America. Being

a Latin American island, Puerto Rico demonstrates this bond. Some of the respondents in Morris' study stated that moving to mainland America would hamper their Puerto Rican culture and beliefs. Rodriguez (1991:448) also expresses the idea that Puerto Ricans have continuously shown unease in abandoning their culture, language, and identity. This unease illustrates the strong cultural bond shared by most Puerto Ricans, accompanied by a fear of losing such a bond.

Latin American Family Networks

Young (1966:498-499) explains that culture groups lead to family organization and affection. From what has been discussed, one can see that the link between culture groups and family networks is evident in Puerto Rico. As discussed by Becerra (1982:22-25), Hispanics place a high value on family. The family is considered to be all those involved in the life of a Latin American person, such as relatives, friends, co-workers, clergy, and so on. In Puerto Rico this network is due in part to the development characteristics of cities and towns. Since most of the population is centered on the coast, a large number of relatives are located near each other, and in most cases in the same community (Becerra, 1982:47). Why would any Puerto Rican family feel that they needed more care for their Down Syndrome child, when they have such a strong network of help and support? A study conducted by Pescosolido, Wright, Alegria, and Vera (1998:1069), has concluded that the presence of social and family networks generally decreases the use of formal services.

Becerra (1982:50-51), in discussing the role of physicians in Latin America, says that a number of physicians see this devotion to family networks as a problem. While physicians feel that family support is an intricate part of treatment for the ill, they also

believe that formal medical care is a must. One hypothesis is that in Puerto Rico, it is likely that those close to someone who is affected by Down Syndrome will not know exactly what kind of medical or educational care is necessary for the individual. This could be because either they feel as though their family is doing enough, or they are afraid to publicly disclose the problem. This type of conduct illustrated in Puerto Rico supports Pescosolido's belief that family networks decrease the use of formal medical and educational care.

Latin American Views on Illness

Becerra (1982:20) states that in general, Latin American people are considered to be easy going and patient. He believes that Puerto Ricans in particular have a hard time expressing to their physicians feelings of depression or uncontrollable anger. Instead, they report the physical symptoms of such illnesses and believe that they have no relation to emotional or mental health issues. In the past, there have been rare cases in which mental illness has been viewed as a "dreaded affliction," and "the person is perceived to be under a "hex" and as being of weak character and pitied for his or her affliction" (Becerra, 1982:50). This is an example of why a Puerto Rican family might keep a case of mental illness to themselves, while still caring for the affected. Down Syndrome can encompass physical, intellectual, genealogical, and social impedance. If the mental illness is severe, a Puerto Rican family might have some of the feelings discussed above. Pescosolido (1998:1058) states that these feelings can lead to the distrust of the world outside of family and friends, therefore, encouraging the use of social and family networks to care for the disabled person.

The Benefits of Family Networks and Culture Groups

As was discussed earlier, strong family networks in Latin America may make it hard for a person with Down Syndrome to receive all necessary care. However, family networks and culture groups have their benefits. An explanation of these benefits will help the reader better understand what a Puerto Rican family may be experiencing when a close relative has Down Syndrome.

One benefit attributed to the organization of Latin American cultures is reliability. Becerra (1982:41-43) refers to this reliability as an always-present support system. The presence of such familial and cultural support assures a Puerto Rican that there is always someone to turn to in time of need. Becerra believes that these support systems can provide assistance, comfort, advice, and conversation thus lessening the stress placed upon a Latin American individual.

The lessening of a person's stress can be extremely beneficial to one's mental health. Saunders and Madsen (in Vega, 1991:367) state that family togetherness and traditional values are believed to lower the incidents of mental health problems among Latin Americans. Vega (1991:367-368) states that past studies have revealed a low rate of admittance into state institutions among Latin Americans. However, he also implies that the low rate could have been caused by either a lack of need for this type of care, due to lower stress levels, or to the unwillingness of Latin Americans to acknowledge such problems. When discussing the benefits of Latin American family networks and culture groups, one would like to believe that the first theory applies. Vega explains that moreover, additional past studies have found a lower rate of depression on

the island of Puerto Rico, possibly further proving the benefits of the Latin American culture.

As can be seen, the benefits of such a close-knit culture can be immense. A strong support system and strong family ties can be beneficial to anyone in a crisis. However, these benefits must always be considered with the needs of a person requiring specific medical care (Becerra, 1982:50-51).

Seven Hills Case Study

Seven Hills Foundation is a Down Syndrome non-profit organization whose main focus is to integrate Down Individuals into the community. In order to achieve this inclusion goal they have created many programs to develop skills among the participants. We conducted a case study on this organization to learn about the programs necessary for a Down individual to reach their potential. The following data has been compiled from Annual Reports, brochures, and a personal interview with Jeff Imbody (2000), an inclusion specialist with Seven Hills.

In 1952, a group of parents banded together to form what is now known as Seven Hills Foundation. Today this organization supports over 2000 individuals and families and is involved in over eighty program sites across Massachusetts. The 1999 motto for the Seven Hills Foundation was empowerment, the working definition being "to enable". The underlying belief is that all individuals can and should be integrated into society. It is upon this principle that the programs stemming from Seven Hills have been designed.

This goal of integration initiated Seven Hills Occupational and Rehabilitation Services. Career Source is the program responsible for employment. For this program,

individuals start in a sheltered workshop, which is a twelve-week program that teaches the participants skills and socially acceptable behaviors. This program is committed to moving people from the sheltered workshops to gainful employment, such as microfilming, secretarial work, and food service. Over the past year, about ten individuals per month have been placed in gainful employment.

Seven Hills runs several other programs to assist Down Syndrome individuals and their families. Seven Hills Family Services is a Medicaid-approved adult program, whose goal is to provide community living situations and respite to the families of Down individuals. Family Services has thus far placed 150 individuals in specialized home-care placements. Those who live at home can take advantage of the respite services, designed to aid the families and provide individual attention and companionship for a person. Sibling support groups are also accessible. For those children who take part in public schooling, extra-curricular activities are advocated, such as integrated sports and social activities. For those who have difficulty integrating into society, Seven Hills offers Dayhabilitation, which is a day program of arts and crafts created for those who cannot work in the community.

Design for the New Millennium 1998-2000, a strategic two-year plan, sets forth the goals and objectives for Seven Hills. In order to meet these goals, Seven Hills has branched out and obtained a number of affiliates. The newest affiliate is Seaside Education Associates that performs rehabilitation consulting. This company alters homes to meet the needs of disabled individuals and offers transition counseling and suggestions. New England residential Services together with Seven Hills Community Services purchase and maintain individual and group residences. The Worcester Area

Arc runs self-advocacy groups, and is involved in legislation promoting Down Syndrome interests.

Funding is derived mainly from the Department of Mental Retardation; government contracts and private contracts are also a major source of funding. More detailed account summary is outlined in the 1999 Annual Report: Empowerment.

Population Studies

Below are two studies that were conducted to determine the number of Down Syndrome cases per live births. Both studies contain trends pertaining to the percent of Down Syndrome cases observed in the Latino population. This data will be useful to establish an approximate number of Down cases on the island of Puerto Rico.

Down Syndrome Prevalence at Birth - United States 1983-1990

The United States Center for Disease Control analyzed data from seventeen states. Birth surveillance programs were used to determine the occurrences of Down syndrome in these states from 1983 through 1990. The report describes the methodology for collecting and analyzing the data, along with the results obtained and trends observed.

Flood (1994: 617-618) explains that two types of surveillance programs were used to gather the data on Down Syndrome cases. For ten states, cases were identified using reports such as birth certificates and medical records. This form of data collection is considered passive case ascertainment, where researchers gather information through documents and other studies, rather than personal observation. In the other seven states, the data was gathered using active case ascertainment, in which experienced personnel

record what they observe. Trained staff conducted the surveillance program directly in hospitals.

Flood (1994:619) believes that it must be noted that not all seventeen states had data available for the entire length of the study. In fact, only five of the seventeen states provided data for all eight years. Also, since the data is only from seventeen states, it may not be representative of all fifty states. However, the data represented 25 percent of the total births in all regions of the United States.

Once this data was gathered and organized, it then was analyzed using various statistical methods. Flood (1994:617) explains that data was categorized by race including white, black, and Hispanic. However, the numbers for other racial groups were too small for valid statistical analysis. Data for each race was then subdivided based on five-year maternal age groups. All data was then analyzed using linear regression, and chronological trends were discovered.

Flood (1994:618) states that it was found that for the three racial groups the occurrences of Down syndrome cases increased with an increase in maternal age. The prevalence rates for blacks and whites throughout the study were similar for maternal age groups greater than or equal to age thirty-five. However, in the case of Hispanics, the Down Syndrome birth rates for this age group were significantly higher. There was also a significant decline in the number of Down cases from 1983 through 1990, where the maternal age was greater than thirty-five years. The prevalence rate for Down cases was 36.6 in 1983 and only 25.9 in 1990. Flood cites an increase in the use of prenatal screening since 1972 as a possible reason for this decline.

Flood (1994:618-619) attributes the higher percent of Down cases among Hispanics to two factors. The first is that Hispanic mothers aged greater than thirty-five take less advantage of prenatal screenings. Flood refers to a study done on a Hispanic population in Los Angeles where only 12 percent of Hispanic mothers took advantage of prenatal services. The second reason for the higher level of in Down cases could be due to Hispanic women having children at a later age than other ethnic groups.

Flood (1994:618-619) states that another significant finding was the amount of Down Syndrome cases per 10,000 live births. Using the passive form of surveillance, it was determined that there were 8.7 Down cases per 10,000 births, as compared to the active surveillance rate of 10.5. Only active surveillance will be looked at when determining the number of Down Syndrome individuals in Puerto Rico.

Birth Prevalence of Down Syndrome in a Predominantly Latino Population

According to Wilson (1992:285), a study was conducted at the Los Angeles County-University of Southern California Medical Center (LAC-USC) dealing with the birth prevalence of Down Syndrome in a predominantly Latino population. This study was useful in order to determine the prevalence of Down Syndrome so that proper medical and health services could be provided when necessary. The Genetics Division personnel made this investigation possible due to the efficient clinical monitoring of phenotypically abnormal infants. Wilson continues to discuss another factor that contributed to the success of the study. This second factor was the number of live births delivered, representing roughly 10 percent of all births in Los Angeles, at the Women's Hospital at LAC-USC.

Wilson (1992:286) remarks that to carry out this study, demographic and clinical information on Down Syndrome individuals was collected beginning in 1966. This information was maintained in computer-files and did not include a distinct code for ethnicity until 1974, when the study began. In order to be sure the clinical information was correct, the diagnoses for Down persons were verified by crosschecking data in genetics patients' charts and Medical Center charts.

Wilson (1992:286) states that the following statistical methods were used to obtain the final results. The number of live births for the Latino subpopulation was obtained by applying its percentage for births delivered to the total number of live births at the Medical Center. This percentage was found to be 87 percent and this data was then compared to the non-Latino population. The annual birth prevalence rate was then determined using age-specific birth prevalence rates. Finally, the number of Down cases was found based on the standard rates divided by the total live births.

The results, as stated by Wilson (1992:286), show that 1.65 to 1.75 out of 1000 live Latino births resulted in a Down Syndrome case from 1974 through 1988. The range of cases is due to many variables two of which are the use of prenatal diagnosis and maternal age. Wilson (1992:287) comments that this statistic is higher than that of non-Latino cases, which was determined to be one out of every one thousand live births. However, he does not state whether this value is statistically significantly higher. This increased rate was seen in Latino women of all age groups except that of twenty-five to twenty-nine year-old mothers.

Based on the results of the study in Los Angeles it is apparent that maternal-age greatly affects the rate of Down cases. Wilson (1992:289) notes that 41 percent of Down

Syndrome babies were born to Latino women over thirty-four. This corresponds to the fact that over the course of the 15-year study, the rate of Down Syndrome babies born to thirty to thirty-four year old women increased slightly.

Database at la Fundación Puertorriqueña Síndrome Down

In order to more effectively communicate with the parents of Down Syndrome children, a database was developed in 1997 to compile contact information and accurate statistics concerning the Puerto Rican Down Syndrome population. The database contains information dealing with age, residence, family, schooling and medical care. This information needs to be continuously updated to keep the Down population informed of the services available to them. This database is also helpful to la Fundación Puertorriqueña Síndrome Down because it allows them to keep track of the Down population on the island.

Data Collection

One of the goals of our project is to evaluate the satisfaction with the Down Syndrome Services available on the island of Puerto Rico. Fowler (1988:19) states that in order to measure the satisfaction on the island, those surveyed must represent the entire population so that the data can be extrapolated. Because random sampling will be impossible for this study, due to sample size constraints, purposive and snowball sampling will be used.

Sample Selection

As maintained by Fowler (1988:19), in order to ensure that the participants accurately reflect the total population, one must carefully select the sample frame. The sample frame is the pool of possible participants from whom responses will be used as data.

Fowler (1988:19) believes the easiest way to gather data is to collect it from willing participants. However, this is a self-selecting process, as only those who possess a certain level of initiative and availability will most likely participate. In order to compensate for this, the sample pool must be deliberately chosen by a sampling scheme. Fowler examines four schemes: probability, which can be broken down into area and total population, systematic, stratification, and multistage sampling.

Fowler (1988:22-26) furnishes short explanations of different types of sampling that ensure that the sample frame represents the total population being considered. Probability sampling, or simple random sampling, involves a computer generated random list of the number of participants one is looking to consider. Systematic sampling takes into consideration characteristics of the sample pool to ensure that one characteristic is not represented more often than it should be. Stratification arranges people in clusters to more accurately reflect the total population. For example, if one were performing a survey at a college where the known gender ratio is 1:1, it would be desirable to separate the sample pool into male and female and randomly select an equal number from each. Multistage sampling links population members to some kind of useful grouping; this could include schools, towns, or housing units. In this way, one could select 3 percent from each town on an island.

The sampling methods described above are the only ways to generate numbers that are representative of the entire population. However, these methods necessitate large sample pools and a foreknowledge of the constituency of which one is sampling. If one does not have a list of all those in the population that constitute the group, these methods cannot be used. Also, these methods are not able to generate hypotheses about cause and effect relationships.

According to Jupp and Sapsford (1996:79-103), purposive sampling is used when the researcher wants to determine cause and effect relationships. People are selected who possess a characteristic that one is studying. For example, if one were studying whether those in the city used Down Syndrome facilities more than those in the country, members of the metropolitan area and members of rural areas would be included in the study, and their responses would be compared. Purposive sampling does not attempt to estimate numerical proportions of types of people; random sampling is the only appropriate method to generate results that can be extrapolated to the general population. The intent of purposive sampling is to cover a full range of replies that are then used to develop and test hypotheses.

Fink (1995:19) maintains that snowball sampling is the best method to reach people that are difficult to find. If there is not a membership list of the people needed for the survey, then the researcher must start with a small number who possess the criteria for inclusion in the study. The researcher must then rely on these few to identify others who are part of the group being studied. This method cannot be expected to yield representative samples, but will provide information about populations otherwise difficult to reach.

Sample Size

In regards to the actual number of participants needed to provide accurate data for statistics, Dilman (1994:55) provides a table of required participants, displayed in Appendix B. The sample number needed is very large if one wants to extrapolate the data to the general population.

However, according to Jupp and Sapsford (1996:79), if one is performing snowball or purposive sampling, the sample pool must be large enough to generate a gamut of responses. In this case, the sample number should be considered on a case-to-case basis weighing the different goals of the project.

Sampling Error

Fowler (1988:19) writes that the prominent source of sampling error is created by the exclusion of pertinent people. Viswesvaran (1993:551-552) defines nonresponse as the condition in which researchers are unable to collect data from all units in the original subsample. For this reason, nonresponse can be a major source of error if one is not confident that the respondents and the nonrespondents share similar views of the subject material.

Determination of Survey Type

The instruments used to collect data must be relevant to the information needed and consider the proper sample frame. Each instrument has strengths and weaknesses and must be chosen based on its provision of the most important data. Our group will utilize questionnaires and interviews.

Questionnaires

Eaden (1999:398) writes that one advantage of written questionnaires is that the interviewer does not introduce bias, generated from intonation and phraseology. Fowler (1966:71) illustrates that another advantage is that there is less self-consciousness involved with a questionnaire. Questionnaires generate data in a format that is simple for the researcher to tally and to analyze statistically. One disadvantage expressed by Berg (1998:71) is that unclear questions will lead to guessing and thus will not accurately measure the response to that question.

Constructing Questions

Constructing valid interview questions is critical in order to ensure that the data produced will be useful. Berg (1998:71) outlines criteria that should be used in evaluating the questions:

- Are the questions comprehensive enough to test the research?
- Are the responses elicited applicable to the research?
- Is the language clear and non-offensive?
- Are any of the questions double-barreled, address two issues?
- Does the interview motivate the sample frame to participate?

Questionnaires and interviews require similar considerations. Since the interviewer will not be present to clarify in the case of a questionnaire, Young (1966:193-196) advises that clarity is of the utmost importance. According to Young, people will usually give an answer even if they are unsure of a question. Therefore, the researcher must ensure beforehand that the vocabulary and syntax is clear and straightforward. It is also paramount that controversial questions are divided into different aspects. Since there

is no interviewer to probe for more elaborate responses, subdivided questions will yield more data.

Conducting Interviews

Young (1966:190) discusses some benefits to different types of questions. Interviews, which involve more open-ended questions than other forms, allow for preliminary exploration. Fowler (1988:70) states that one can discover factors of which one was unaware. Interviews also incorporate visual clues and subject observation.

There are many aspects of interviewing that must be considered before one embarks on such an endeavor. Berg (1998:87) delineates what he believes to be the basic rules of interviewing. These rules are establishing rapport, maintaining purpose, listening intently, dressing appropriately, interviewing in a comfortable place, requesting more detail, and being respectful and appreciative.

The mere presence of interviewers and their demeanor can affect the outcome of a survey. Fowler (1988:13-14) suggests limiting unstructured talking and following a scripted introduction as a way to maintain consistency. Also the wording of a question must stay consistent throughout each and every interview.

Informant Methodology

According to Hughes and Preski (1996:82-85), key informant methodology consists of a small number of informants who are qualified to comment on social relationships. Characteristics of a key informant that might bring about bias should be considered prior to the selection of study participants. Key informant methodology is only effective when the collected data reflects a consensus or agreement.

Nonresponse

Viswesvaran (1993:551-552) describes nonresponse as the condition in which researchers are unable to collect data from all units in the original subsample. In order for the inferences derived from the sample frame to extend to the population of interest, the data provided by the respondents must generalize to the sample frame. For this reason, nonresponse can be a major source of error if one cannot be confident of the similarity of respondents and nonrespondents.

There are several techniques advised by Fowler (1988:139) to reduce nonresponse. One suggestion is to send an advance letter to define the purpose of the project and the necessity of the sample frames involvement. An interviewer should allow a flexible schedule and perform the interview in a non-threatening situation and manner and should listen attentively and display interest and sympathy. As a general rule, one should not do anything that will cause an inaccurate or deceitful response.

Berg (1998:85) states that if the candidate appears apprehensive about participation due to lack of knowledge, the researcher should emphasize that opinion, and not factual knowledge, is being measured.

Confidentiality

According to Fowler (1988:136), one reason for nonresponse may be fear of exposure to peers or superiors. To overcome this obstacle one must be able to assure their sources that all identities will remain concealed. As a responsible researcher one must strive to protect the identities of one's informants.

Standard procedures suggested by Fowler (1988:138) to reduce the risk of breach of confidentiality are as follows:

- All people with access to the raw data must be committed to confidence.
- Separate identifiers from survey responses-by assigning an ID number to each respondent and storing the ID key in a separate area from the research being shared.
- Anyone in a position to identify respondents by their answers cannot see the data in a form that would allow them to do so.
- Avoid making links that can be used for identification.
- Once data is analyzed destroy the ID key or commit to secure storage.

Rights of Respondents

According to Fowler (1988:136-137), it is the ethical responsibility of the researcher to ensure that respondents are provided with information about the use and confidentiality of their data.

- They should be informed of the name of the interviewer and the organization.
- The sponsorship should be revealed
- The purpose of the project should be outlined. Is the purpose to gather data for knowledge or future action? What topics will the questions include?
- Respondents must be assured of confidentiality. If there are any risks of exposure, participants have the right to know. It might be a good idea to delineate practices that maintain confidentiality.
- Possible respondents must be assured that cooperation is voluntary and that any questions that pose a threat to them may be skipped.

The Process of Statistical Analysis

Young (1966:81) outlines five factors that must be examined before proper analysis of data can be made. One factor is the presence of certain characteristics that

would make one more likely to respond. The media being used is another feature of which to be mindful. Are there limitations imposed by the media chosen, and does it bar some from participation? The third factor is being cognizant of social pressures to determine why one might respond a certain way. Does one fear exposure? The pattern of varying views is the fourth factor that must be analyzed to evaluate if there is a certain variable, which leads to one opinion. With that knowledge results can be characterized. The last factor recognized by Young is the social processes, which resonate certain mindsets. The cultural norm will dictate the assumptions used to arrive at certain answers.

Cronbach and Glaser (in Viswesvaran, 1993:551) discuss that a framework must be developed that best explicates the given body of information, so that the data can be correctly analyzed. By using a statistical form of analysis, more precise and objective results can be achieved.

Understanding the Tools of Statistical Analysis

Young (1966:277) lists some criteria that are almost always used in statistical classification: geographical, chronological or temporal, qualitative or attributive, and quantitative. Once all the data is classified, it is then sorted and tabulated according to the analyst's needs. Statistical tables are used to simplify and organize all related information. Young (1966:283) explains that some advantages to statistical tables are the conservation of space, the reduction of descriptions, and reduction of errors in analyzing. General-purpose and special-purpose are two types of tables that can be used.

Frequency distribution is another common way to ease the analysis of statistical data. Frequency distribution takes a variable and plots it versus the frequency of that

variable based on intervals. Young (1966:281) lists three things that must be determined in order to construct a frequency distribution: the number of intervals to be used, the size of the intervals, and the designation of the intervals. Along with determining the size of the interval, Young explains that upper and lower limits and a midpoint need to be developed for each interval. Once this is done, the next step is to count the number of occurrences that fall between each interval. The data is now ready to be plotted in a frequency histogram, a frequency polygon, or a smoothed frequency curve

Understanding the Processes of Statistical Analysis

In general, Young (1966:285-299) believes that all statistical analysis can be done using either statistical tables or frequency distributions or both. He states that once a researcher has created either of these tools for analysis, he or she can use various mathematical operations and procedures to determine the information needed.

Young (1966:285-299) states that there are three basic averages that can be calculated using data that is in frequency distribution form: mean, median, and mode. These items are important to any type of process dealing with statistical analysis. Another important factor in the analysis of data is the standard deviation. The standard deviation deals with variability, which is how much the data varies above and below the mean or median.

The mean or arithmetic mean of a set of data can be seen in numerous examples describing statistical analysis. This mean is easily calculated following the procedures outlined in any book explaining statistics. Young (1966:290-292) defines the mean to be a measure of the average value for a set of data, for example calculating your grade in a class based on the grades of three equally weighted exams.

Young (1966:293) explains that the median is considered a measure of the center of a set of data. For instance, if grades are arranged in order of magnitude, the median is the value where there are as many items above it as are below it.

In a set of data, Young (1966:296-298) states that the mode is the value that occurs most frequently. When looking at a frequency distribution, the mode is the point on the horizontal axis where the frequency is the greatest. For example, in the following data set: 60, 70, 70, 80, 90, 70, 60, 100, the mode is 70 because it appears the most number of times.

The standard deviation, as stated before, measures variability within data. In calculating the standard deviation, the mean is always used as a value in the equation. Young (1966:302-304) believes that the value for standard deviation can be used in many ways. For example, it can be used along with the bell-curve to calculate the grades of students who are taking the same class.

The use of these concepts can become very intricate with detail. The preceding discussion gives only a brief description of the process of statistical analysis. Although Young's book is over thirty years old, the statistical methods used to analyze data have changed little, if any. In any case, Young (1966:306) says that a statistical analysis based on this process would be beneficial to anyone looking to draw conclusions from an immense amount of data.

Methodology

One of the tasks given to us by our liaison, Dr. Carmen Avilés-Ortiz, was to generate an approximate number of Down Syndrome individuals on the island of Puerto Rico. We were also commissioned to evaluate the medical, therapeutic, and educational needs of a Down person, in addition to gathering information to update the Foundation's database. After the needs of Down individuals were determined, the adequacy and resources of the current facilities were analyzed based on these needs. The latter objectives were accomplished through questionnaires and interviews.

Determining the Number of Down Syndrome Cases

It was found that the United States' governmental agencies do not keep records concerning the Down Syndrome population, distinct from the mental retardation population. Therefore, we proposed the use of previously established population studies, the average life span of a Down individual, and the number of live births per year to determine the number of Down cases on the island. The population studies were gathered from the Center of Disease Control and the Los Angeles County University of Southern California Medical Center. In addition to estimating the total Down population, we approximated the number of Down individuals from birth to age three. The focus on birth to age three is due to the strong emphasis that is placed on the use of early intervention services.

Services Evaluation and Database Information

The evaluation of the services available in Puerto Rico was accomplished through questionnaires distributed to those on the Foundation's mailing list and to the seven pediatric clinics to be completed by health care providers. Information to update the Foundation's database was also gathered from the questionnaire sent to those on the Foundation's mailing list. To obtain further information, interviews were also conducted with the administrators from two local pediatric clinics and two experts involved with the Foundation. Lastly, we compared the services available in Puerto Rico with those deemed necessary by health care providers and experts from the seven pediatric clinics.

Necessary Data

In order to evaluate the current services and to gather information to update the Foundation's database, it was first necessary to develop a mailing list for our questionnaire. We had originally planned to send our questionnaires to those on the Foundation's mailing list, health care providers involved with the seven pediatric clinics, and those who are affiliated with the Parent Training and Information Project in Puerto Rico. However, it was brought to our attention that the Parent Training and Information Project no longer distributes mailing lists to the public. Therefore, we concentrated on those individuals already on the mailing list along with the health care providers. We also contacted the administrators at each of the seven pediatric clinics to find out what services they offer, as well as to set up the interviews with the two local clinics.

From the questionnaires sent to those on the Foundation's mailing list, we acquired information regarding their use of available services and their need for and

satisfaction with these services, as well as updated information for the database. The questionnaires sent to and the interviews conducted with the health care providers presented us with expert opinions concerning services necessary for a Down individual and also the availability of these services.

Design of questionnaire.

As suggested by Dilman (1994:141-144), the cover letter sent with our questionnaires stated who is conducting the survey, the purpose of the questionnaire, why it is important to participate, and the confidentiality of the responses. Our contact information was also provided for any questions or comments that arose.

The first sections of the questionnaire sent to those on the Foundation's mailing list contained information that was used to update the database. We obtained family, medical, and educational information from these sections. The next section asked the respondent to indicate which services are available to them and which of these services they use. The final portion of the questionnaire dealt with the evaluation of services island wide using ordinal questions, which required the respondents to rate an attribute on a scale ranging from zero to five. In this case zero through five were given the following designations respectively: not applicable, strongly disagree, disagree, neutral, agree, strongly agree. Ordinal questions produce quantitative data that can be analyzed using statistical methods. Need and satisfaction were determined from these ordinal responses. Figure 1, which follows, presents the most important portions of the questionnaire that were used in our analysis.

The questionnaire sent to the health care providers contained a similar set of questions to evaluate their satisfaction with the care their patients' are receiving. We also asked them what services are available at their pediatric clinic and what services they provide to Down individuals. Figure 2 contains those questions that were used in our analysis.

Complete copies of these questionnaires, including the cover letters, can be found in both English and Spanish in Appendix C.

Figure 1: Portion of Questionnaire Sent to Those on the Foundation's Mailing List

Medical Information

Indicate the services that are available in your city or town.

<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> Physical therapy	<input type="checkbox"/> Nutrition
<input type="checkbox"/> Social Work	<input type="checkbox"/> Transportation	<input type="checkbox"/> Ophthalmologist
<input type="checkbox"/> Dental	<input type="checkbox"/> Home care	<input type="checkbox"/> Cardiologist
<input type="checkbox"/> Audiologist	<input type="checkbox"/> Neurologist	<input type="checkbox"/> Others _____

Indicate which of these services you use for your child.

<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> Physical therapy	<input type="checkbox"/> Nutrition
<input type="checkbox"/> Social Work	<input type="checkbox"/> Transportation	<input type="checkbox"/> Ophthalmologist
<input type="checkbox"/> Dental	<input type="checkbox"/> Home care	<input type="checkbox"/> Cardiologist
<input type="checkbox"/> Audiologist	<input type="checkbox"/> Neurologist	<input type="checkbox"/> Others (Indicate)

If there is other information that you consider important, write it below.

Evaluation of the Services

Please, respond to the questions by circling the number that indicates how you feel about the following statements.

0 = Not applicable

1 = Strongly disagree

2 = Disagree

3 = Neutral

4 = Agree

5 = Strongly agree

1. My child needs educational services specific to his/her Down Syndrome condition.

0 1 2 3 4 5

2. I am satisfied with the educational services that my child receives.

0 1 2 3 4 5

3. My child needs medical services specific to his/her Down Syndrome condition.

0 1 2 3 4 5

4. I am satisfied with the medical services that my child receives.

0 1 2 3 4 5

5. My child needs therapeutic services specific to his/her Down Syndrome condition.

0 1 2 3 4 5

6. I am satisfied with the therapeutic services that my child receives.

0 1 2 3 4 5

Figure 2: Portion of the Questionnaire Sent to the Health Care Providers

Service Evaluation

If you provide a Down Syndrome service and/or provide treatment for a condition related to Down Syndrome, indicate it below.

<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> Physical therapy	<input type="checkbox"/> Nutrition
<input type="checkbox"/> Social Work	<input type="checkbox"/> Transportation	<input type="checkbox"/> Ophthalmologist
<input type="checkbox"/> Dental	<input type="checkbox"/> Home care	<input type="checkbox"/> Cardiologist
<input type="checkbox"/> Audiologist	<input type="checkbox"/> Neurologist	<input type="checkbox"/> Others (Indicate)

Please, respond to the following statements by circling the number that indicates how you feel about them.

0 = Not applicable

1 = Strongly disagree

2 = Disagree

3 = Neutral

4 = Agree

5 = Strongly agree

1. You feel that the educational needs of your patients are being satisfied.

0 1 2 3 4 5

2. You feel that the medical needs of your patients are being satisfied.

0 1 2 3 4 5

3. You feel that the therapeutic needs of your patients are being satisfied.

0 1 2 3 4 5

Indicate the services that are available for Down Syndrome patients in your city or town, different from the ones you offer.

<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> Physical therapy	<input type="checkbox"/> Nutrition
<input type="checkbox"/> Social Work	<input type="checkbox"/> Transportation	<input type="checkbox"/> Ophthalmologist
<input type="checkbox"/> Dental	<input type="checkbox"/> Home care	<input type="checkbox"/> Cardiologist
<input type="checkbox"/> Audiologist	<input type="checkbox"/> Neurologist	<input type="checkbox"/> Others (Indicate)

Pretest.

Dilman (1994:120-121) stresses that it is important to pretest a questionnaire before sending it out. A pretest screens out unclear and complicated questions, and ensures that the surveyor and participant interpret the questions and responses in the same manner. In order to determine if our questionnaire for those on the Foundation's mailing list was adequate, it was distributed to two of the parents involved with the Foundation. The responses were processed and the appropriate changes were made. The vice-president of the Board of Directors at the Foundation reviewed the questionnaire sent to the clinics and gave her suggestions for possible changes.

Mailing.

Our initial mailing consisted of our cover letter, questionnaire and return envelope, detailed above. These were sent bulk rate to all those on the Foundation's mailing list. The administrator at each of the seven pediatric clinics received an instructional cover letter, along with fifteen cover letters, questionnaires and return envelopes to be distributed to the health care providers. All return envelopes contained a first class stamp to ensure that we received the responses quickly. A reminder letter was sent one week later to those on the mailing list. We also placed follow-up telephone calls to the administrators at the clinics.

Interviews.

We interviewed administrators at the two local pediatric clinics in Bayamón and in San Juan. Our interview format included questions concerning the Down Syndrome

children receiving care at the clinic, in addition to questions dealing with the services they offer. We also interviewed doctors and experts involved with the Foundation. These expert opinions helped us with our analysis of the questionnaires, as well as with making conclusions and recommendations for our project.

Processing the Data

Due to time constraints, we allowed a three-week window from the time the questionnaires were sent to the time they were returned. All responses received after this three-week period were not included in our analysis. When responses to the questionnaires were received, we divided the data into four categories by age. These categories were determined based on the care commonly given to certain Down Syndrome age groups. We analyzed the ordinal responses along with the responses concerning services currently available and used across the island. Upon discovering that our response rate was rather low, we called a random sample of the nonrespondents to see if they would answer a few questions over the telephone. A Spanish speaking volunteer helped us to perform these calls, which were used to see if our respondents were representative of the whole Down Syndrome population. In the time available, we began to update the database. The remaining information was left to the Foundation to be entered at their convenience.

Problems Encountered with Survey Methodology

Survey methodologies are neither flawless nor without complication. Young (1966:81) outlines several factors that must be examined before proper analysis of data can be made. One factor is the presence of certain characteristics that would make one more likely to respond, or lead one to maintain a certain opinion. The media being used

is another feature of which to be mindful. Being cognizant of social pressures to determine why one might respond a certain way, such as fear of exposure, is also important. The cultural norms must also be considered since they will influence the assumptions used to arrive at certain answers.

One problem we encountered was our lack of ability to generate a random sample. Producing a statistically valid sample pool would involve stratification sampling, which would require a complete list of all Down cases on the island. Considering the large number of participants necessary for this endeavor and also the large response rate needed, stratification sampling could not be performed. For this reason, our research most likely yielded suggestions and recommendations, rather than data capable of representing the entire Puerto Rican Down Syndrome population. To compensate for this problem, we attempted to gather as much information as possible concerning our respondents and nonrespondents.

Another obstacle to overcome was nonresponse. Estimates will be biased if respondents and nonrespondents assert different opinions. An increased chance of being a respondent is caused by such factors as one's willingness to divulge information, being in a position of authority, or interest in a subject matter. Fowler (1988:19-22) states that nonresponse can cause important constituents to be overlooked. To minimize this as much as possible, we contacted some of the nonrespondents via telephone. The reminder letters sent to the mailing list sample pool and follow-up telephone calls made to the seven pediatric clinics also helped to decrease our nonresponse rate.

Because we received only 202 responses from the 842 questionnaires sent out to those on the Foundation's mailing list, we could not be sure from our results if the

respondents were representative of the total Down Syndrome population in Puerto Rico. In order to compensate for this nonresponse rate, telephone calls were placed to a random sample of the nonrespondents. The nonrespondents were asked to provide an answer to the six ordinal questions as well as to the questions dealing with availability and usage of services. Of the forty-eight telephone calls placed to the nonrespondents, there were six calls where the correct party was reached, and all six of those people were able to take the time to answer our questions. From the six telephone responses received, it was observed that the original respondents closely represented the thoughts of the whole sample pool.

We also attempted to gather as much information as possible concerning the 202 respondents. From our observations, it appeared as though the respondents were evenly distributed geographically across the island of Puerto Rico. We had also planned to go through the files at the Foundation to see whether or not those who responded were directly involved with the Foundation. However, this task proved to be unachievable due to the large amount of work involved and to the lack of time available. Even though there was also nonresponse with the health care providers, we can safely assume that all responding health care providers are cognizant of the services available.

Finally, we needed to overcome the obstacle of cultural difference. Certain phrases that are interpreted to mean one thing in our culture may convey a different notion in Puerto Rico. To compensate for this, we pretested both questionnaires; in addition to having them edited by Spanish speaking individuals.

Data and Results

The information that follows includes all data gathered from our investigation dealing with the Down Syndrome population on the island of Puerto Rico. Tables and graphs are used to depict trends in data, as well as for organizational purposes. All results below will be further analyzed in the chapter entitled Analysis of Results.

Estimated Number of Down Syndrome Cases

The vast majority of the funding for la Fundación Puertorriqueña Síndrome Down is acquired from the federal Department of Health. For this reason, we have determined an estimate of the number of Down Syndrome cases on the island. The Foundation will be able to use this approximation to justify the need for more funding.

Current Down Syndrome Population-Total

The two population studies that were examined in the Literature Review were “Down Syndrome Prevalence at Birth-United States 1983-1990” and “Birth Prevalence of Down Syndrome in a Predominantly Latino Population,” conducted from 1974 through 1988. Both of these studies evaluated the number of Down Syndrome cases per live births for an area of the United States. The study conducted from 1983 through 1990 encompassed seventeen states and three ethnic groups, whereas the latter study based its findings on a predominantly Latino population at the Los Angeles County-University of Southern California Medical Center (LAC-USC). Two problems we discovered with these studies were that they offered varying birth prevalence rates and that it was unclear if the trends for prenatal care and maternal age were statistically significant or if they were mere fluctuations that occurred during the time of the studies. If these trends do

indeed exist, it is uncertain if they apply to Puerto Rico. A detailed description of both studies is provided in the Literature Review.

To obtain an accurate Down Syndrome birth prevalence rate we looked only at figures obtained from active surveillance of the Hispanic population. The states that used active surveillance on the Hispanic population from the seventeen-year study were California, Arizona, and Washington. The Los Angeles study was done using only active surveillance. The birth prevalence rate from the Los Angeles study was averaged with that of California, since they both surveyed the same region of the country. The Los Angeles/California number was then averaged with the rate from Arizona and Washington to obtain a birth prevalence rate of 13.2 per 10,000 live births. Due to the various birth prevalence rates presented in the population studies, we used a range of 11.5 to 16.9 per 10,000 live births to calculate an upper and lower bound. This range was obtained from the low and high birth prevalence rates determined by active surveillance on the Hispanic population.

Life span of a Down person has increased greatly over the past century due to medical advances, and is currently fifty-five years. Because of this increasing life span, adjustments to our estimation were made. We were only able to find the life span and survival rate of Down individuals for a limited number of years. Therefore we had to extrapolate this data to the present. Nadel (1995:239) provided us with a table containing the survival rates used to perform this extrapolation, which can be seen in Appendix D2. Using this data, we predicted that Down individuals born before the year 1961 are most likely not alive today. For this reason, the number of live births per year up to 1996 was obtained from the Statistics Division of the Puerto Rican Department of Health, which

can be seen in Appendix D1. This information was extrapolated to the year 2000, as seen in Appendix D4, and the birth numbers from May 1st, 1961 to April 30th, 2000 were utilized. Due to time constraints, our study would only include one half of the month of May. For this reason we decided to end our estimate on April 30th.

Using the previously conducted population studies, life span adjustments, and the birth statistics from the Statistics Division of the Department of Health, a total number for the Down Syndrome population was determined. A spreadsheet of these calculations can be seen in Appendix D3. It was estimated that a range of 2250 to 3307 Down Syndrome individuals are currently living in Puerto Rico. Using a mean birth prevalence rate of 13.2 per ten thousand live births calculated from the population studies, the most likely number of Down Syndrome individuals was estimated to be 2607.

Current Down Syndrome Population-Birth To Three Years

As stated in our methodology, we also determined an approximation of the Down population, from birth to three years old. This was done because the literature researched placed strong emphasis on early intervention. Both the Foundation and the pediatric clinics care for these young children and are particularly concerned with reaching this age bracket. From our extrapolation we found a 97 to 100 percent survival rate of Down Syndrome individuals from the years 1997 to 2000. We used this information along with the mean birth prevalence rate of 13.2 per 10,000 live births to estimate that 239 individuals from infant to age three have Down Syndrome. With the birth prevalence range of 11.5 to 16.9 per 10,000 live births, the lower and upper bounds are 206 and 303, respectively.

Service Evaluation

In order to provide the necessary care to Down Syndrome individuals, it is important to build and expand programs across the island with their needs and desires in mind. Knowing the needs of Down Syndrome individuals, we developed questionnaires to assess their satisfaction with the current services in Puerto Rico and also to gather suggestions for the expansion of services. To help in obtaining more accurate data, information was also gathered from health care providers at the seven pediatric clinics island wide, in addition to experts and professionals involved with the Foundation.

Ordinal Responses

As was mentioned in the Methodology, ordinal questions were used in both the questionnaires sent to those on the Foundation's mailing list and the questionnaires sent to the health care providers. In regards to the former questionnaire, ordinal questions were used to allow the respondent to rate the perceived need for and satisfaction with educational, medical and therapeutic services. The latter questionnaire contained ordinal questions to measure the satisfaction of the patient through the eyes of the health care provider.

To organize the ordinal responses, we entered them into a spreadsheet, categorized by question number and age category of Down individual. These age categories included: birth to three years, three to five years, five to twenty-one years, and twenty-one years and older. We then calculated the mean and the standard deviation for each question in order to determine if the results were statistically significant. The standard deviation was then applied to the Student t-Table to obtain the probability of

where the true mean lies. A copy of the Student t-Table can be seen in Appendix E. The responses pertaining to the services currently available and used by Down individuals were tallied in a spreadsheet according to the age categories listed above. The results from this information allowed us to make recommendations and suggestions for services to meet the needs of a Down person.

Age categories.

As aforementioned, ordinal questions were used to assess the need for and the satisfaction with the services currently available. The 202 responses were divided by age groups and a separate analysis was performed on each group. The first age group, birth to three years, receives its early intervention care from the Department of Health. The second age group, three to twenty-one years, is school-aged children including those who attend preschool. Age groups three to five and five to twenty-one were combined because they all receive care under the Department of Education. The final age category was twenty-one and older, who are responsible for finding their own care. Using the responses from the six ordinal questions discussed above, six frequency histograms for each age group were created.

Questions one and two from the questionnaires sent to those on the Foundation's mailing list asked for a rating from zero to five, or not applicable to strongly agree, pertaining to the following statements, respectively:

- My child needs educational services specific to his/her Down Syndrome condition.
- I am satisfied with the educational services that my child receives.

These two questions assessed the individuals' need for educational services, along with their satisfaction with the education received.

The medical services for Down Syndrome individuals were explored in questions three and four, as follows:

- My child needs medical services specific to his/her Down Syndrome condition.
- I am satisfied with the medical services that my child receives.

Again, the purpose of these two questions was to evaluate the need for and the satisfaction with medical services being received.

The final two questions pertained to the therapeutic services on the island of Puerto Rico. Question five asked to what degree therapeutic services were needed, whereas question six requested the level of satisfaction with the current therapy received by the Down individual. The exact wording of these questions was as follows:

- My child needs therapeutic services specific to his/her Down Syndrome condition.
- I am satisfied with the therapeutic services that my child receives.

The histograms for the ordinal responses from the birth to age three category can be seen in Figures 3 to 8 below.

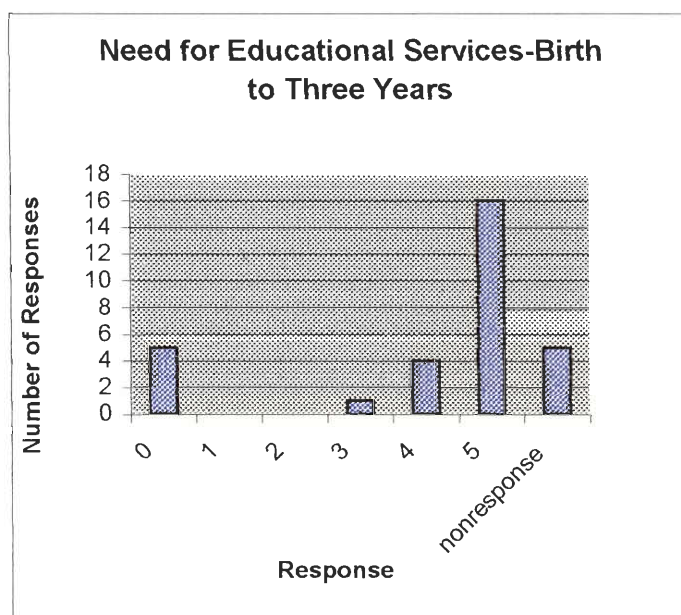
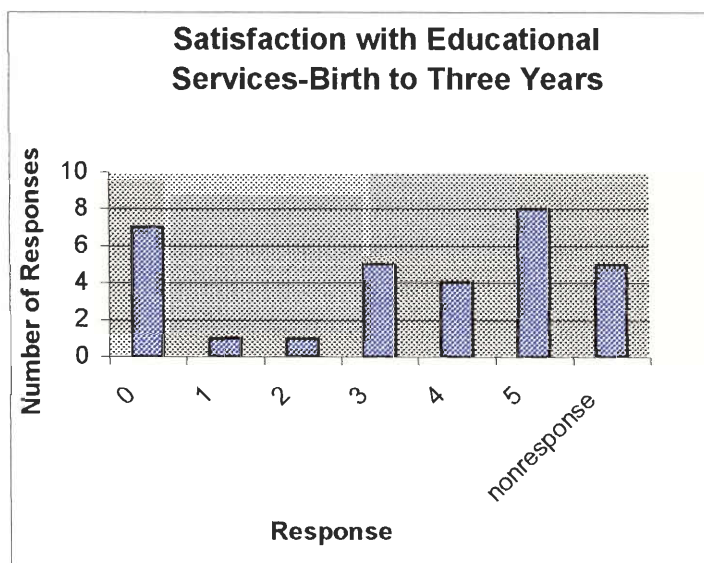
Figure 3: Frequency Histogram for Question 1-Birth to Three Years**Figure 4: Frequency Histogram for Question 2-Birth to Three Years**

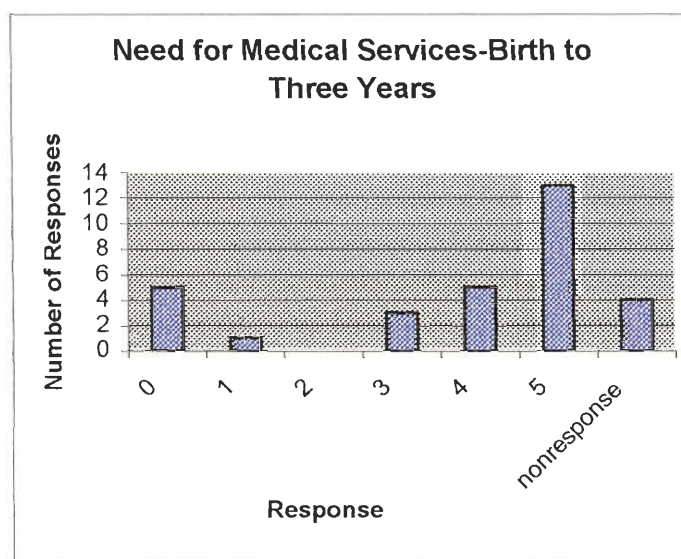
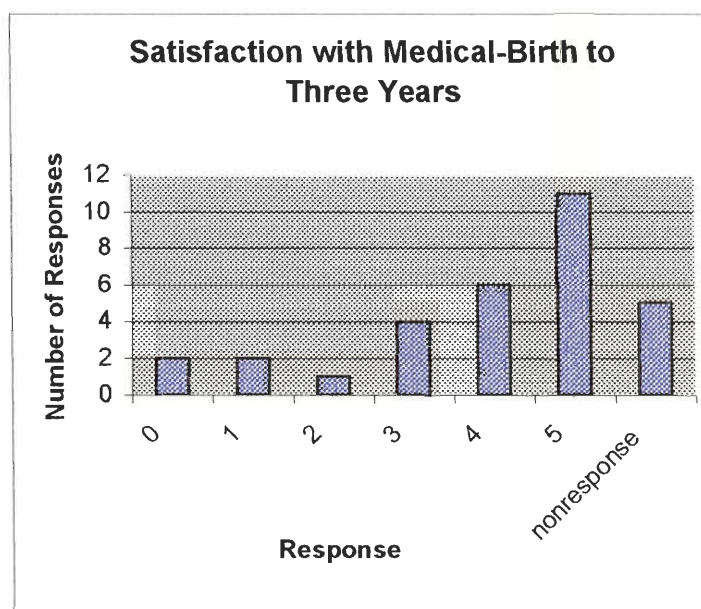
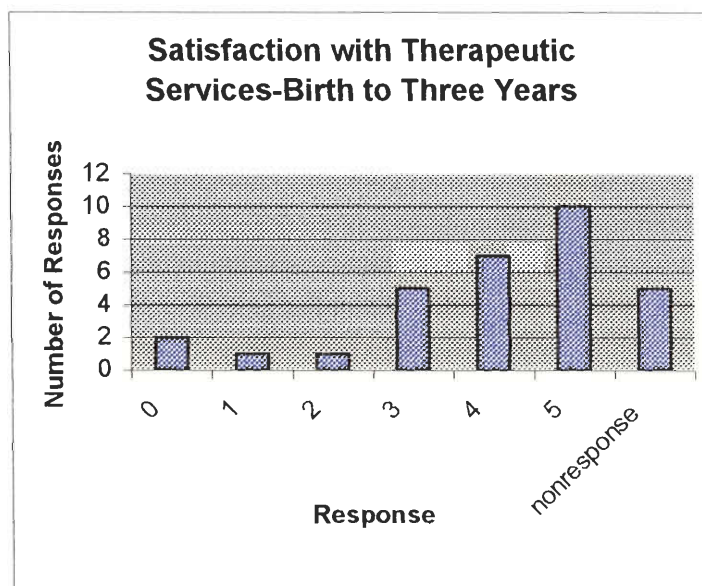
Figure 5: Frequency Histogram for Question 3-Birth to Three Years**Figure 6: Frequency Histogram for Question 4-Birth to Three Years**

Figure 7: Frequency Histogram for Question 5-Birth to Three Years**Figure 8: Frequency Histogram for Question 6-Birth to Three Years**

The following six histograms, Figures 9 to 14, were constructed from the responses to the ordinal questions from the three to twenty-one age category.

Figure 9: Frequency Histogram to Question 1-Three to Twenty-One Years

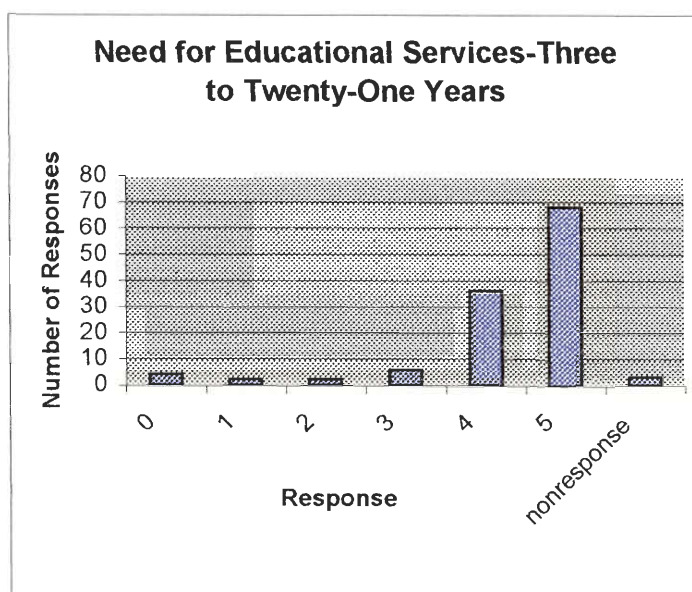


Figure 10: Frequency Histogram to Question 2-Three to Twenty-One Years

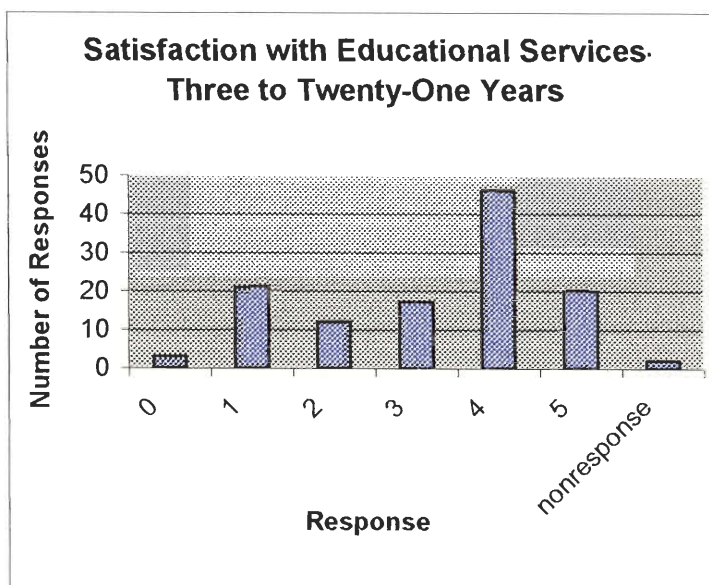


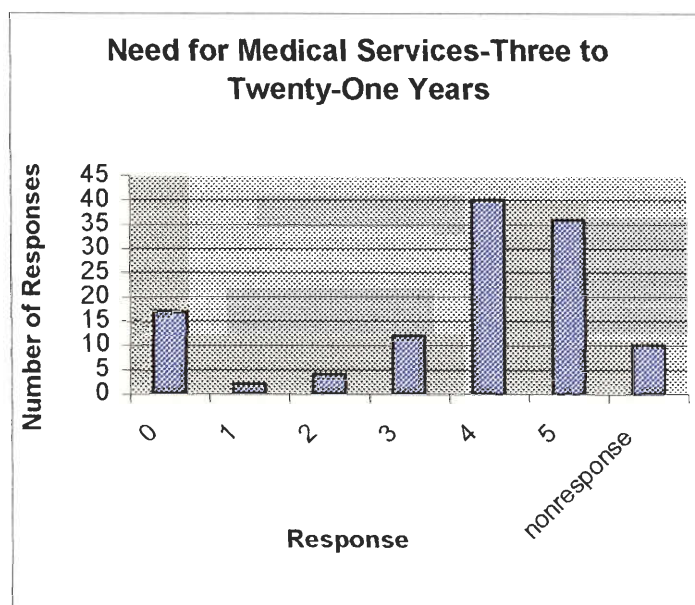
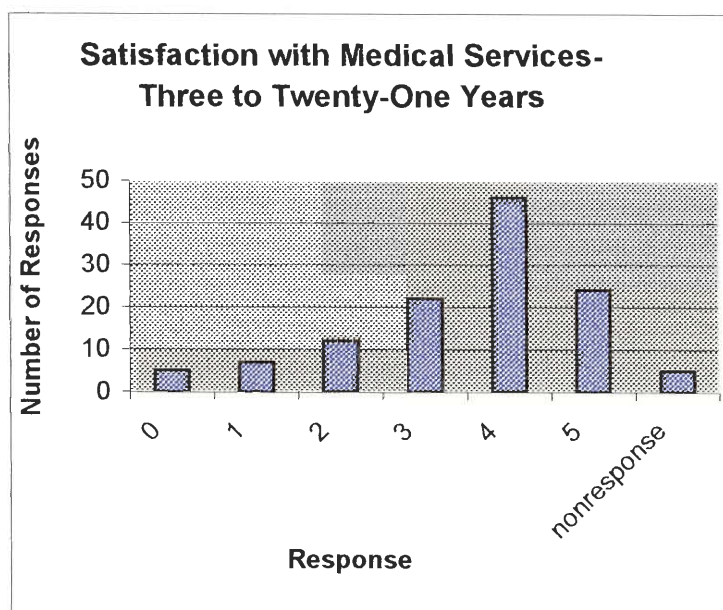
Figure 11: Frequency Histogram to Question 3-Three to Twenty-One Years**Figure 12: Frequency Histogram to Question 4-Three to Twenty-One Years**

Figure 13: Frequency Histogram to Question 5-Three to Twenty-One Years

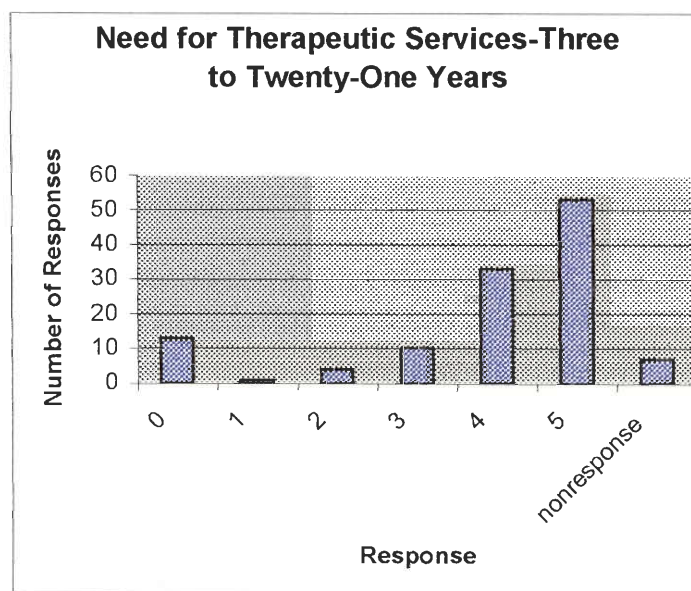
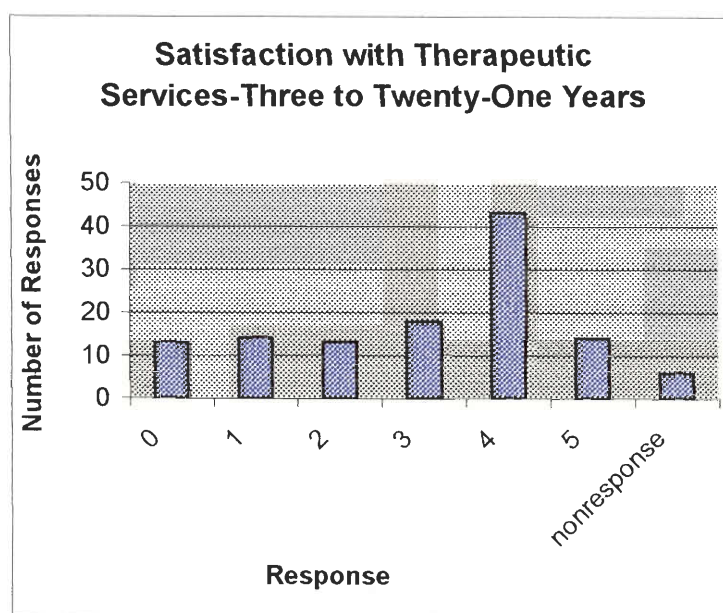


Figure 14: Frequency Histogram to Question 6-Three to Twenty-One Years



Figures 15 to 20 illustrate the responses from the twenty-one years and older group.

Figure 15: Frequency Histogram to Question 1-Twenty-One Years and Older

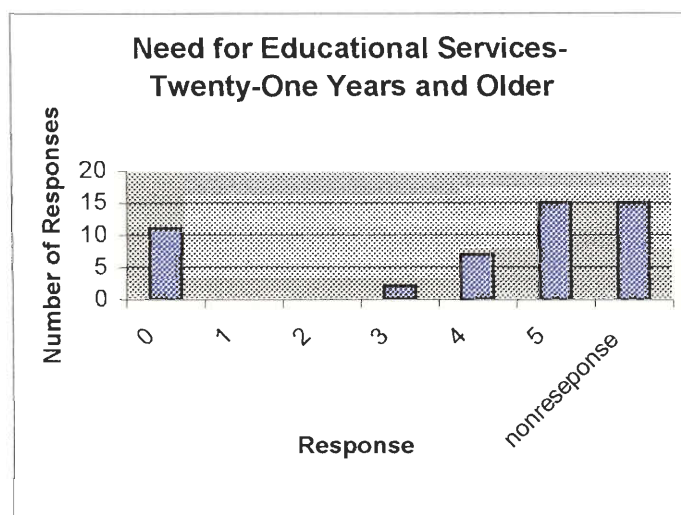


Figure 16: Frequency Histogram to Question 2-Twenty-One Years and Older

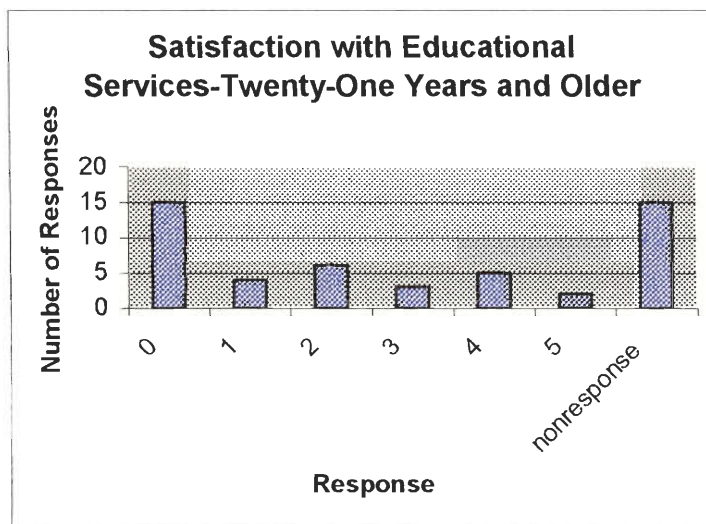


Figure 17: Frequency Histogram to Question 3-Twenty-One Years and Older

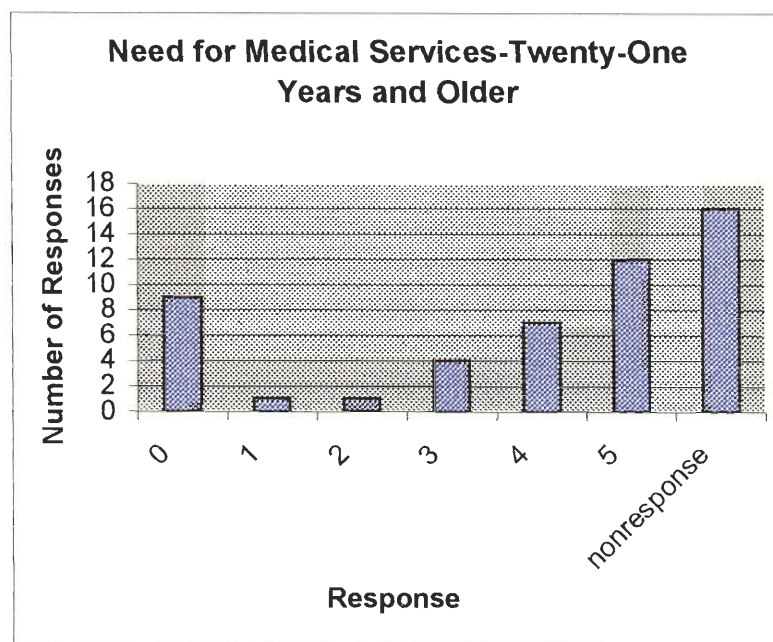


Figure 18: Frequency Histogram to Question 4-Twenty-One Years and Older

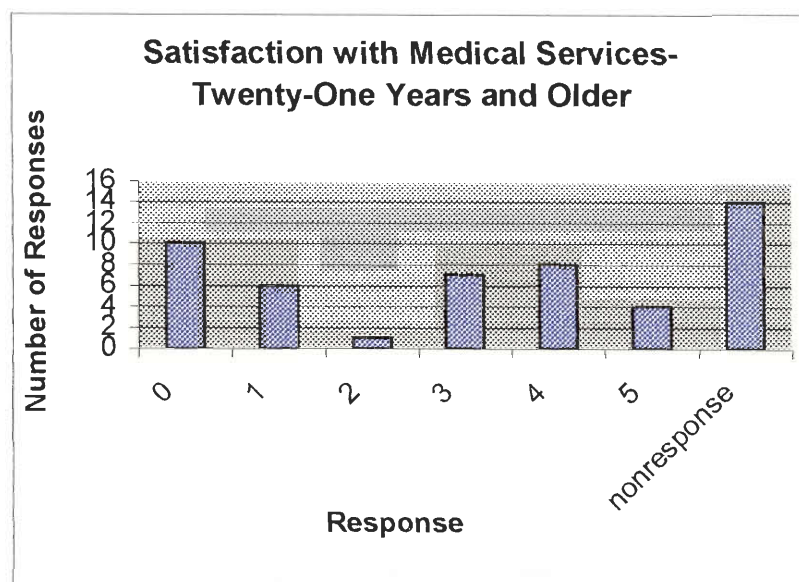


Figure 19: Frequency Histogram to Question 5-Twenty-One Years and Older

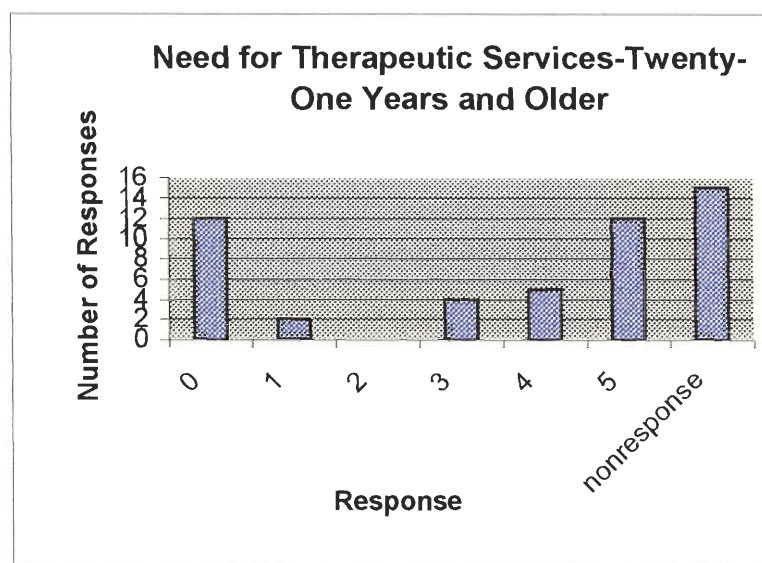
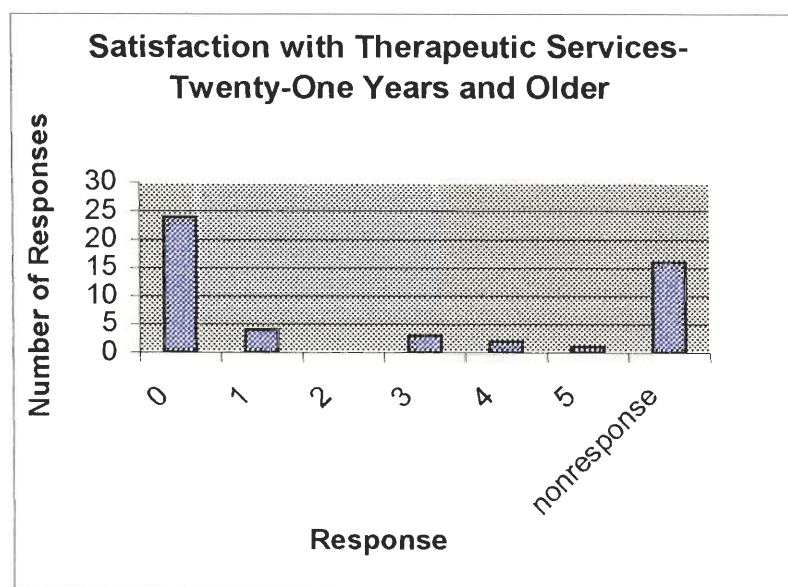


Figure 20: Frequency Histogram to Question 6-Twenty-One Years and Older



Health care providers.

A total of thirty questionnaires were returned from the health care providers at the seven pediatric clinics. These health care providers were asked to express their satisfaction with the care their patients are currently receiving, based on the same rating of zero to five. Ordinal questions one, two and three dealt with educational, medical and therapeutic services, respectively, and can be seen below:

- You feel that the educational needs of your patients are being satisfied.
- You feel that the medical needs of your patients are being satisfied.
- You feel that the therapeutic needs of your patients are being satisfied.

The results can be seen graphically in Figures 21, 22 and 23.

Figure 21: Frequency Histogram for Question 1-Health Care Providers

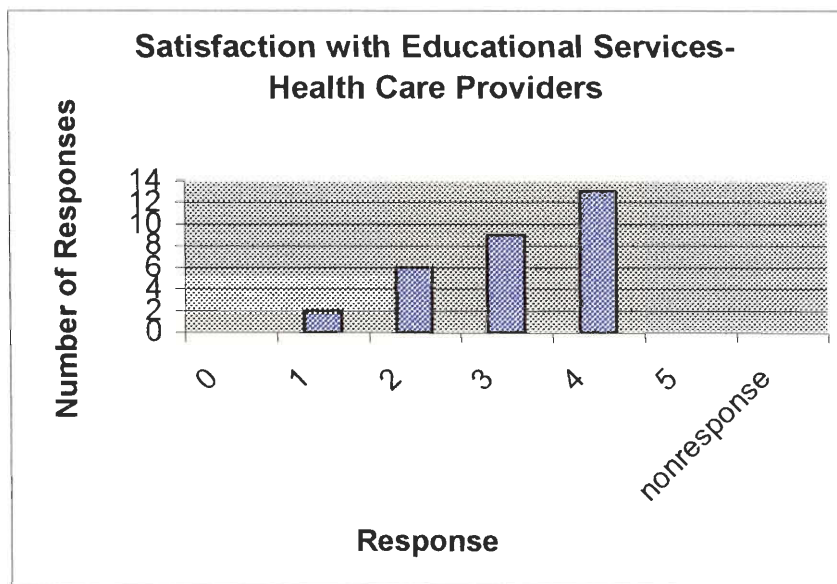
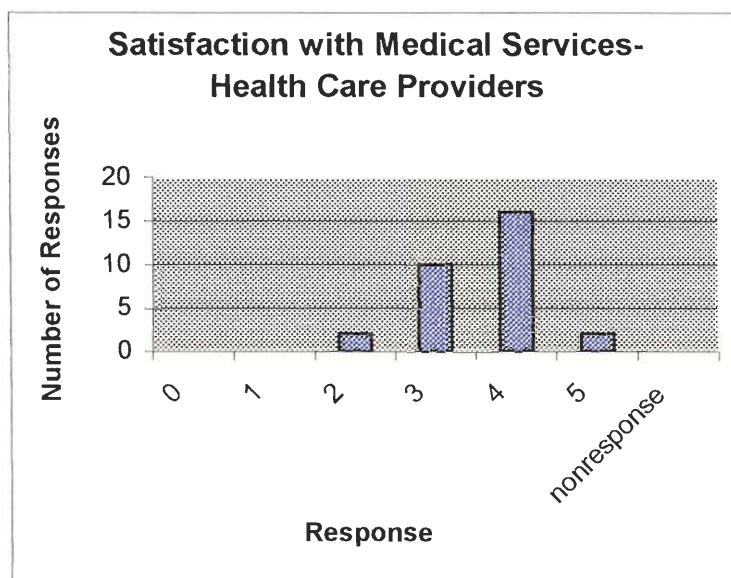
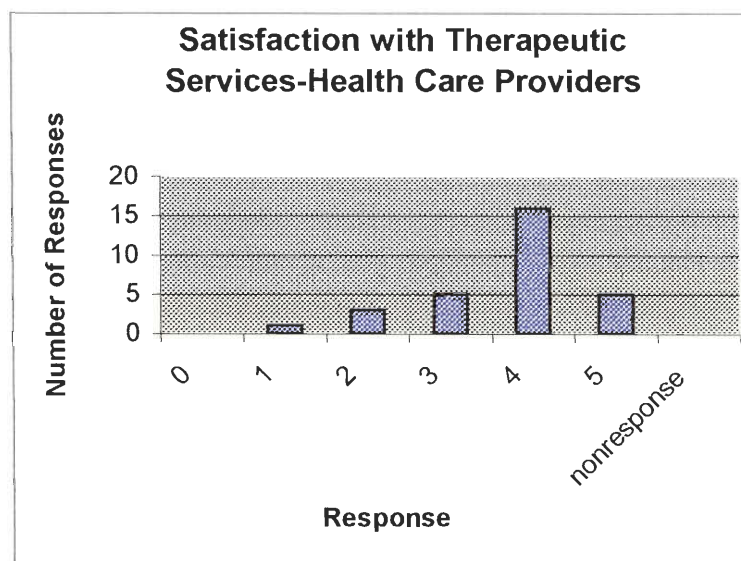


Figure 22: Frequency Histogram for Question 2-Health Care Providers**Figure 23: Frequency Histogram for Question 3-Health Care Providers**

Availability and Usage of Services

In order to evaluate the services available to and used by those on the Foundation's mailing list, two questions dealing with these matters were included in the questionnaire, and were as follows:

- Indicate the services that are available in your city or town.
- Indicate which of these services you use for your child.

A list of services was provided and the respondents were asked to mark those that are available to them and those that they use. Again, this information was tallied for the three age groups discussed above. The same question regarding availability was presented in the questionnaire given to the health care providers, as well as an additional question asking which services they provide, and this data was also tallied.

Age categories.

As stated above, we organized the responses from these questions according to the age categories: birth to three years, three to twenty-one years and twenty-one years and older. This was done so that an analysis of this data would result in suggestions for services that should be provided to these specific age groups. We will also be able to recognize any gaps in services within each age group. Tables showing availability and usage of services for each age bracket can be seen below in Tables 1 through 3. The percent of services available and used was calculated for all age groups based on the total number of respondents from that age group. The percent availability will later be analyzed against one hundred percent, and also evaluated with respect to the percent used.

Table 1: Availability and Usage of Services-Birth to Three Years

Birth to Three Years				
Services	Available	Percent Available	Used	Percent Used
Occupational Therapy	24	77%	25	81%
Social Work	17	55%	10	32%
Dental	17	55%	8	26%
Audiologist	14	45%	14	45%
Physical Therapy	23	74%	21	68%
Transportation	10	32%	2	6%
Home Care	3	10%	1	3%
Neurologist	4	13%	1	3%
Nutritionist	13	42%	10	32%
Ophthalmologist	12	39%	10	32%
Cardiologist	12	39%	12	39%
Other	4	13%	10	32%

Table 2: Availability and Usage of Services-Three to Twenty-One Years

Three to Twenty-One Years				
Services	Available	Percent Available	Used	Percent Used
Occupational Therapy	91	75%	84	69%
Social Work	55	45%	16	13%
Dental	44	36%	32	26%
Audiologist	37	31%	20	17%
Physical Therapy	60	50%	28	23%
Transportation	59	49%	38	31%
Home Care	10	8%	4	3%
Neurologist	20	17%	2	2%
Nutritionist	27	22%	8	7%
Ophthalmologist	36	30%	32	26%
Cardiologist	30	25%	29	24%
Other	24	20%	42	35%

Table 3: Availability and Usage of Services-Twenty-One Years and Older

Twenty-One Years and Older				
Services	Available	Percent Available	Used	Percent Used
Occupational Therapy	12	24%	2	4%
Social Work	12	24%	3	6%
Dental	13	26%	12	24%
Audiologist	6	12%	3	6%
Physical Therapy	11	22%	0	0%
Transportation	11	22%	8	16%
Home Care	10	20%	3	6%
Neurologist	6	12%	0	0%
Nutritionist	6	12%	2	4%
Ophthalmologist	10	20%	9	18%
Cardiologist	8	16%	5	10%
Other	0	0%	9	18%

All responses placed in the “other” category by respondents from all three age groups are compiled below in Table 4. This information allows us to take services into consideration that were not mentioned on our questionnaire.

Table 4: Responses from “Other” Category-All Age Categories

All Age Categories				
Other Services	Available	Percent Available	Used	Percent Used
Psychologist	1	0.5%	2	1.0%
Speech Therapy	27	13.4%	46	22.8%
Pediatrician	0	0.0%	1	0.5%
Dermatologist	0	0.0%	2	1.0%
Endocrinologist	0	0.0%	2	1.0%
Geneticist	0	0.0%	2	1.0%
Urologist	0	0.0%	1	0.5%
Allergist	0	0.0%	1	0.5%
Independent Living	0	0.0%	1	0.5%
Physical Education	0	0.0%	1	0.5%
Swimming	0	0.0%	1	0.5%
Mental Health	0	0.0%	1	0.5%

Health care providers.

From the thirty responses received from health care providers, we assembled a compilation of expert opinions regarding the availability of certain services. This compilation included the responses to the following two questions:

- If you provide a Down Syndrome service and/or provide treatment for a condition related to Down Syndrome, indicate it below.
- Indicate the services that are available for Down Syndrome patients in your city or town, different from the ones you offer.

As stated before, a list of services was included with each question. This combining of responses was done because the second question contained the phrase “different from the ones you offer.” Combining these responses allowed us to ensure that all services available in a particular area were tallied. This investigation was conducted in order to determine if a trend exists between the availability responses from both the health care providers and the respondents from the Foundation’s mailing list. This data is presented in Table 5, including the percent of services available based on the total number of questionnaire received from the health care providers.

Table 5: Availability-Health Care Providers

Health Care Providers		
Service	Available	Percent Available
Occupational Therapy	24	80%
Social Work	23	77%
Dental	11	37%
Audiologist	18	60%
Physical Therapy	23	77%
Transportation	12	40%
Home Care	6	20%
Neurologist	10	33%
Nutritionist	22	73%
Ophthalmologist	16	53%
Cardiologist	13	43%
Other	17	57%

Table 6 below is an expansion of the “other” category presented in Table 5 above. This table includes a list of all services not incorporated into our questionnaire, but instead, ones that the health care providers indicated to also be available for Down Syndrome children ages birth to three.

Table 6: Responses from “Other” Category-Health Care Providers

Health Care Providers		
Other Services	Available	Percent Available
Psychologist	5	17%
Speech Therapy	5	17%
Pediatrician	4	13%
Ear, Nose, and Throat	1	3%
Doctor	3	10%
Parent Orientation	1	3%
Orthopedic	1	3%
Transition Therapy	1	3%

Interviews

As was stated in our Methodology, we conducted interviews with professional who are knowledgeable in the field of Down Syndrome. This information will supplement the data gathered from our questionnaires. We choose to interview the following individuals: Dr. Lillian Gonzalez, a pediatrician and Vice-President of the Board of Directors at la Fundación Puertorriqueña Síndrome Down; Dr. Lourdes del Campo, the Director of the Bayamón Pediatric Clinic; Ms. Maribel Rodríguez, the Supervisor of Early Intervention at the San Juan Metro Pediatric Clinic; and Carmen Avilés-Ortiz, the Executive Director of la Fundación Puertorriqueña Síndrome Down.

Dr. Lillian Gonzalez

Our first interview took place with Dr. Lillian Gonzalez (2000), Vice President of the Board of Directors at la Fundación Puertorriqueña Síndrome Down. Dr. Gonzalez was able to supply us with many informative details about the care of Down Syndrome individuals. She practices Pediatric Endocrinology on Down Syndrome patients, among others, and has a daughter with Down Syndrome.

From scientific publications read in the past, Dr. Gonzalez (2000) speculates that there are about 12.5 to 16.7 Down Syndrome births per 10,000 live births, and is not of the opinion that Down Syndrome is decreasing. When we asked about the intellectual functionality of Down Syndrome individuals, we were told that most are moderately mentally retarded, having an IQ of 40 to 54. Beyond this broad classification, there are no recognized labels applied to Down Syndrome individuals, as these have set up barriers for children's development in the past.

Dr. Gonzalez (2000) asserts that most Down Syndrome children age birth to three years receive care at one of the seven regional pediatric clinics, as do most children needing therapies and treatments. The Individuals with Disabilities Education Act (IDEA) protects Down Syndrome individuals, and all those with disabilities, by stipulating that all states must provide the proper care to help individuals achieve their maximum potential. In practice, this means that all states must provide thirteen related services based on the needs of individuals, integrating early intervention programs into these services. From her experience, Dr. Gonzalez believes that there are an adequate number of services for the Down Syndrome population, and has found adequate access to services, inexpensive fees, and ample literature. From her perspective, the therapeutic

and medical needs of Down Syndrome individuals are being met. There are few who choose not to take advantage of the services offered through the clinics, and she attributes this to private care or denial of the child's condition.

Dr. Lourdes del Campo

Dr. Lourdes del Campo (2000), Director of Bayamón Pediatric Clinic, generously volunteered her time to give us information about the services provided by the clinics, as well as other details about how the clinics are run. As of March 2000, the Bayamón Pediatric Clinic had thirty-five Down Syndrome children age birth to three years in its care. The clinic does not provide primary care; every child receiving services from the clinic has a primary physician responsible for basic medical care. The clinic is responsible for providing related services to children birth to three, such as physical and speech therapies. According to Dr. del Campo, Down Syndrome individuals and their families at the clinic are informed about what they need and what is available to them. She feels that between the numerous services offered at the clinic and therapies furnished by external arrangements with other agencies, all of the necessary services are available to families with a Down Syndrome child. Those limited by monetary restrictions are given an economic evaluation performed by a social worker. This evaluation is used to help those who qualify by providing benefits, such as transportation reimbursement. We also learned that each of the clinics receives money to promote their services. One way this is done is through newspapers.

Ms. Maribel Rodríguez

We spoke with Ms. Maribel Rodríguez (2000), Supervisor of the Early Intervention Program at San Juan Metro Pediatric Clinic. She informed us that currently

the clinic has sixty-four Down Syndrome children in its care. From Ms. Rodríguez, we discovered that occupational therapy, physical therapy, home care, speech therapy, social work, psychology and nursing services are all free. Reimbursement for transportation is also available if the family inquires and meets the economic status requirements. One issue mentioned by Ms. Rodríguez, was the lack of staff at the San Juan Metro clinic, especially with home care providers.

All care is started as soon as families arrive with their child at the clinic, and is continued until the child turns three. Ms. Rodríguez (2000) stresses that it is very important that care for a Down Syndrome child be started as soon as possible. If a Down Syndrome child starts therapies at an age later than one year, it is very difficult for them to make up for that lost time.

Ms. Rodríguez (2000) revealed that there is a strong emphasis on keeping patients at their local regional clinic. Many parents bring their children to the San Juan Metro Pediatric Clinic. Some of them are then referred to a clinic in their area. The San Juan Metro Pediatric Clinic then contacts the respective clinic to notify them of an incoming patient. Once the information is received by these clinics, the service coordinator places follow-up telephone calls to those families.

Ms. Rodríguez (2000) also informed us that a current goal of the pediatric clinics is to make the transition between the Department of Health and the Department of Education easier. This objective is being achieved through a series of meetings with the family and representatives from both departments during the transition period. To further ensure that children are not left without treatment, their care is continued at the clinic until treatment is started at schools.

Dr. Carmen Avilés-Ortiz

Dr. Carmen Avilés-Ortiz (2000), Executive Director of la Fundación Puertorriqueña Síndrome Down, and our liaison, has provided us with much important information about the Foundation, as well as about the Department of Health and the Department of Education. We learned that all private pediatricians do refer their patients to the pediatric clinics for treatments. Once the patient arrives at the clinic, assessments for each child's development are made.

Dr. Avilés (2000) informed us that at la Fundación Puertorriqueña Síndrome Down physical and speech therapy is emphasized from birth to twenty-four months. Once the Down child is able to walk, occupational therapy and preschool services replace physical therapy, while speech therapy continues. As with the pediatric clinics, there is no minimum age for accepting a child into the program. At age three weeks to a month an evaluation is conducted on the child to develop a physical therapy routine. Parents are then immediately oriented and therapists begin training the parents to help their children with exercises at home. This is done because sometimes the amount of therapy children receive is dictated by how often they can make it and not how often they need it.

Since we utilized the database information to help compose our questionnaires, as well as for mailing addresses, it was important to find out some information about this database, relied upon by the Foundation. Dr. Avilés (2000), told us that most of their database was filled during the 1997 Interactive Qualifying Project, and the database is updated as information comes in.

Analysis of Results

In order to provide meaningful information to the Foundation, the data collected must be analyzed. In this chapter, the birth to three year population estimate will be evaluated in light of the number obtained from the seven pediatric clinics. Selected results from our questionnaires, both from those on the mailing list and also from the health care providers at the pediatric clinics, are also interpreted in this chapter.

Comparison of Estimated Population with Known Data

As stated above in the Results chapter, a lower, middle and upper estimate were calculated for the Down Syndrome population up to three years. These approximations are as follows: 206, 239 and 303. We contacted the seven pediatric clinics and requested information about the number of Down individuals treated at each: the cumulative number is 170. A tabulation of this information can be seen in Table 7.

Table 7: Clinic Information

Clinic Location	Number of Down Syndrome Patients
Arecibo	29
Bayamon	35
Caguas	N/A
Fajardo	10
Mayaguez	32
Ponce	N/A
San Juan Metro	64
Total	170

Since the pediatric clinics only treat children up to three years of age, the clinic tabulation was compared with our estimate of the Down population up to three years old. When compared it was found that the 170 children treated at the clinics is seventy-one percent of our mean estimate of 239. However, this number does not include the

pediatric clinics in Caguas and Ponce, as we never received this information from them, despite repeated requests. Therefore, as expected, our estimate slightly exceeds that of the total number of Down individuals treated at the seven pediatric clinics. From our interviews with Doctor Lillian Gonzalez (2000) and Doctor Carmen Avilés (2000) we have learned that although the vast majority of children do receive care from the clinics, there are some Down Syndrome children receiving private care through their health insurance. According to Ms. Maribel Rodríguez (2000), the Supervisor of the Early Intervention Program at the San Juan Metro Pediatric Clinic, private care is sometimes preferred by San Juan residents due to the shortage of workers at the clinic. Another reason for the numerical discrepancy could be because we had to extrapolate birth number and life span data.

Analysis of Questionnaires

In order to draw conclusions from our questionnaires, all data needed to first be analyzed. The ordinal questions from both the questionnaires sent to those on the Foundation's mailing list and the questionnaires sent to the health care providers are analyzed below using statistical methods. Services and suggestions were most accurately analyzed using graphical methods.

Statistical Evaluation of Ordinal Questions

Figures 3 through 23 seen in the Results chapter were analyzed using mean and standard deviation. Calculating the mean allowed us to gauge the general consensus for each question. The standard deviation revealed the variation of response within each

question, while allowing us to determine the validity of our results. A more detailed discussion of these statistical tools can also be seen in the Literature Review.

Age categories.

The mean and standard deviation were calculated for Figures 3 to 23 representing the following age groups, respectively: birth to three years, three to twenty-one years, and twenty-one years and older. Below, in Table 8, can be seen the statistical evaluation of the responses to the ordinal questions for each of the three age categories. This table shows a consistently lower satisfaction rating as compared to the need rating for all age groups.

Table 8: Statistical Evaluation of Ordinal Questions

Birth to Three Years						
	Education-Need	Education-Satisfaction	Medical-Need	Medical-Satisfaction	Therapeutic-Need	Therapeutic-Satisfaction
Mean	4.71	3.95	4.32	3.96	4.64	4.00
Standard Deviation	0.56	1.19	1.04	1.27	0.91	1.10
Probability of mean being greater than 3	99.7%	80%	90%	77%	96.3%	82.5%
Three to Twenty-One Years						
Mean	4.46	3.28	4.11	3.61	4.32	3.29
Standard Deviation	0.82	1.36	0.93	1.13	0.88	1.26
Probability of mean being greater than 3	96%	58%	89%	70%	94%	59%
Twenty-One Years and Older						
Mean	4.54	2.75	4.12	3.12	4.09	2.60
Standard Deviation	0.66	1.33	1.09	1.39	1.24	1.51
Probability of mean being greater than 2	99.99%	70%	97.5%	83%	95%	62%

As can be seen by looking at Table 8, the respondents from the birth to three year category were in agreement with the statements dealing with the perceived need for and satisfaction with services. The means for this age group are the highest of the three age brackets analyzed. These means were tested against three using the Student's Probability

t-Table; the probabilities that the means were greater than three were quite high for each of the six questions. The high need for and satisfaction with the services is most likely due to the emphasis placed on early intervention services. Because of the stress placed on early intervention by professionals, the services provided are more comprehensive and satisfactory to the parents of these Down individuals.

Table 8 also presents the statistical results for the age group from three to twenty-one years. Again, the respondents are in agreement with the statements concerning their child's need for services. However, the satisfaction with services is only slightly above neutral. The overall mean for this age group is slightly lower than that of the birth to three year category. Due to the 121 responses received from this age category, over fifty percent of the total respondent population, there is an increased accuracy, supported by the high probabilities, that the mean is greater than three for most questions. The two statements dealing with the satisfaction of educational and therapeutic services had probabilities just under sixty percent.

The analysis of the responses from the twenty-one years and older category can also be seen in Table 8. For this category, the need for services remains the same as the three to twenty-one year bracket. However, the satisfaction with these services drops slightly below neutral, indicating that there are many dissatisfied with the services available. Because some of the means are less than neutral, they had to be tested against two. Due to the large number of respondents who indicated that the questions were not applicable to them, our means were derived from a smaller set of data, possibly causing them to be less accurate. However, we still calculated overall high probabilities that the means were greater than two.

Health care providers.

The ordinal questions in the questionnaire sent to the health care providers at the seven pediatric clinics dealt with their feelings about whether or not their patients' educational, medical and therapeutic needs are being met. The responses to these three questions were statistically analyzed and the results can be seen in Table 9 below.

Table 9: Statistical Evaluation of Ordinal Questions-Health Care Providers

Health Care Providers	Educational	Medical	Therapeutic
Mean	3.10	3.6	3.70
Standard Deviation	0.96	0.72	0.99
Probability of mean being greater than 3	82.5%	79.0%	76.0%

From the thirty responses received, the means were centered between neutral and agree, suggesting that health care providers feel that the services for their patients are adequate. Each respondent answered all three questions, and no questions were given a rating of not applicable. All three questions demonstrated a high probability that the true mean was greater than three.

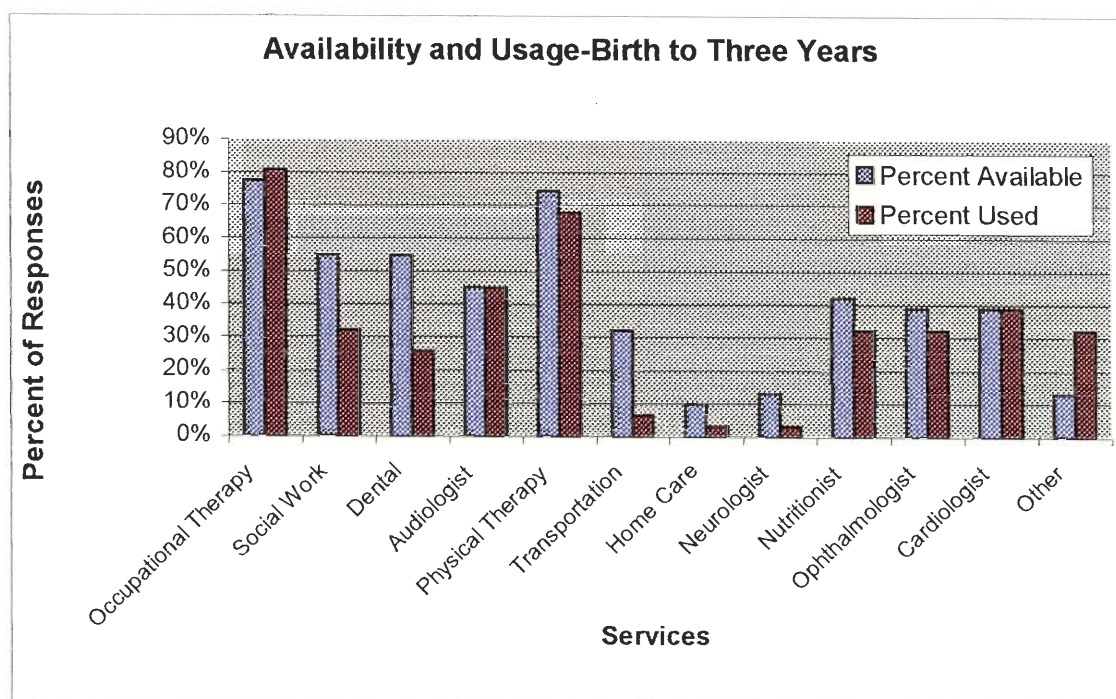
Evaluation of Services

We determined that the best way to analyze the satisfaction with services was to compare the percent of available services to one hundred percent. We also used the percent of available services and the percent of used services to ascertain if all services assumed to be available were used. Using the availability and usage results from those on the Foundation's mailing list, we were able to create three separate graphs categorized by age. The availability data from the health care providers also gave us material to be compared with that from the mailing list respondents. The expert information received from our interviews was used to further support our findings. We compiled the

suggestions from all respondents, which helped us to draw conclusions and make recommendations for the expansion of services.

Availability and usage-age categories.

We were able to derive an availability and usage bar graph for ages birth to three years from the information provided in the questionnaires. Figure 24, which contains this information, demonstrates that the percent of available services is always higher than the percent of used services. From looking at the graph, it can be seen that the majority of the respondents for the birth to three year group are aware that occupational therapy, social work, dental and physical therapy are available to them. For the remaining services, the percentages of available services as compared to one hundred percent are fairly low, home care and neurological services being among the lowest. This most likely indicates that the services are either unavailable, not easily accessible, cost prohibitive, or that the respondents are unaware that these services do in fact exist. From our interviews, we know that those who are involved with the pediatric clinics are thought to be fully aware of the services that are available to them. However, there are still some individuals who are not receiving care at these clinics and therefore may believe that these services do not exist. Ms. Rodriguez (2000) has informed us that many of these services are available without fees or at a minimal cost for those who do not have health insurance. This fact leads us to believe that the cost is not prohibitive. This information suggests that perhaps the actual problems are low accessibility and lack of availability for certain services.

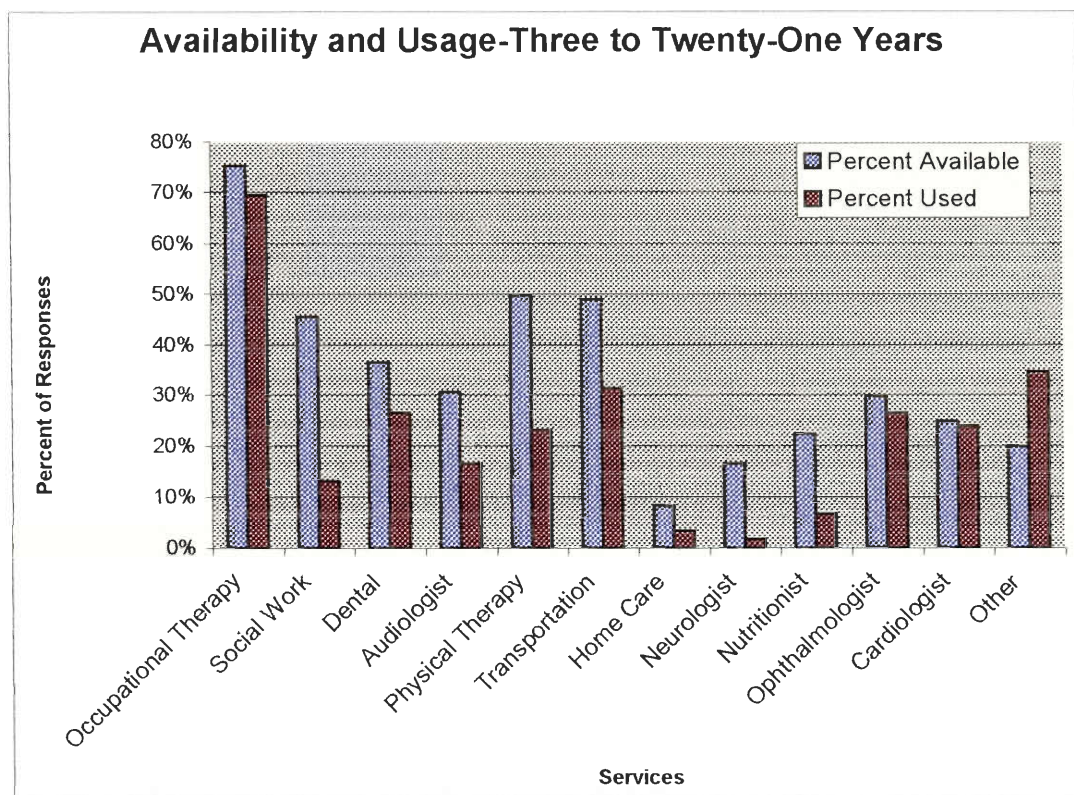
Figure 24: Availability and Usage-Birth to Three Years

Some analysis was also done on Figure 24, above, concerning the ratio between the percent of available services and the percent of used services. This figure portrays on average a fifty percent or greater usage-availability ratio for most services. The best case appears to be that of physical therapy, where the percent availability is high as well as having a high usage-availability ratio. The discrepancy seen with occupational therapy, where the percent used exceeds the percent available, could have resulted from the unclear format of our questionnaire. It can be seen that transportation, home care and neurological services have a rather low usage-availability ratio for this age group. The combination of low availability and an even lower usage-availability ratio for these services indicates that there is a problem with availability. However, the low ratio could also represent a low demand for a particular service or a perceived problem with that service. These results are further supported by the information gathered from our

interviews. We learned that although home care is available, it is understaffed and for this reason it is not as desirable as it could be. As far as transportation is concerned, we were told that those who qualify for reimbursement are more likely to be aware that it is available. This service could be thought to be inconvenient since the participant is responsible for arranging transportation as well as for submitting necessary paperwork.

Figure 25 below, showing data of availability and usage for the three to twenty-one age group, again shows that the percent of availability is always higher than the percent used. From the graph, it can be seen that only occupational therapy has an availability above fifty percent, as compared to one hundred percent. All other services have a less than moderate percent of availability, with home care, neurology, and nutrition ranking among the lowest. Again, as we know from our interviews, home care is understaffed. This supports the respondents' perception that home care is not readily available.

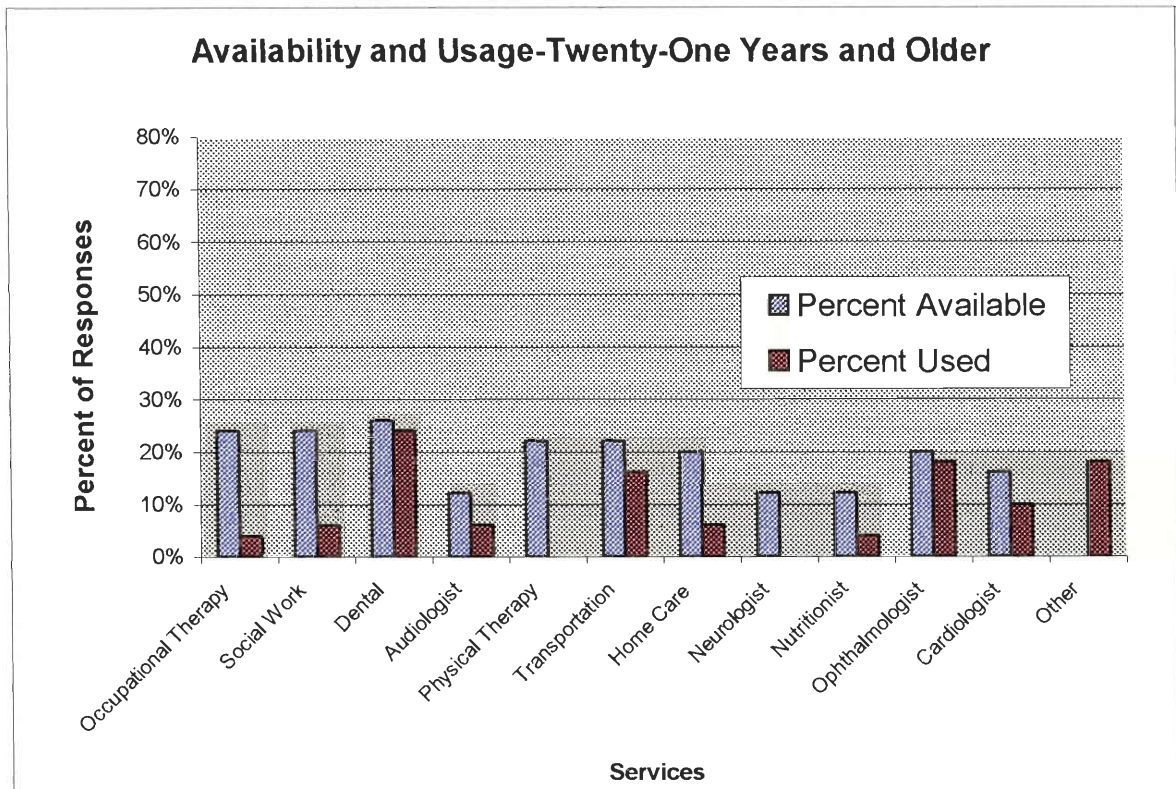
Figure 25: Availability and Usage-Three to Twenty-One Years



As done for the birth to three year age category, here we again compared availability with the usage-availability ratio. The graph above depicts the close relationship between the percent availability and percent usage for occupational therapy. This relationship indicates that most of those who know about this service take advantage of it. From our interview with Dr. Avilés, we know that there is a strong emphasis on occupational therapy during this age period. Cardiology and ophthalmology also show a high usage-availability ratio. Social work, home care, neurology and nutrition are services that have an extremely low ratio. This could be due to disinterest in these services because they are either not needed, inconvenient or insufficient.

Figure 26 below, is a bar graph of the percent of services available and the percent of services used by the twenty-one years and older category. All services have drastically low availability percentages, with no service having an availability above thirty percent. This can be interpreted in one of two ways; either the services are not available or this age group is not aware of what services are available to them. From analyzing the responses from all those who answered the open-ended question, which invited the respondents to provide us with additional information, we found that every response from this age group was a complaint concerning the lack of services. Another reason for this low availability could be because some of the services listed did not entirely apply to those twenty-one years and older. Therefore, these respondents might be unaware if these services exist, if they do not need them. From our case study performed in Worcester, Massachusetts at the Seven Hills Foundation Inc., we know that the greatest need for this age group is vocational and social training programs, which helps to integrate these individuals into the community.

Figure 26: Availability and Usage-Twenty-One Years and Older

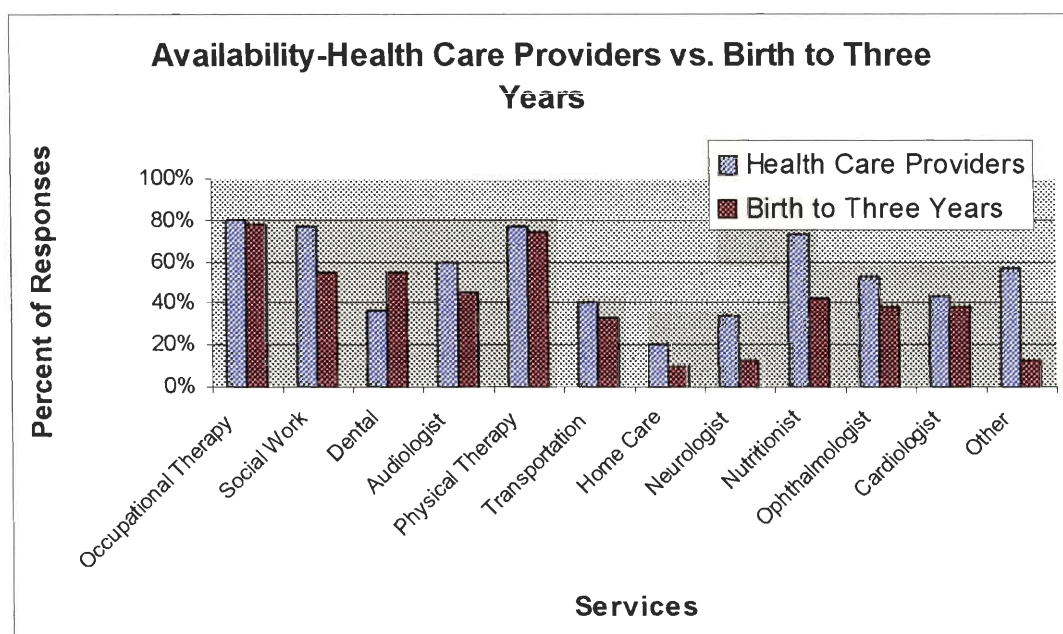


Even though the percent of services available and the percent of services used are both low for dental care and ophthalmology, Figure 26, above, shows that their usage-availability ratios are approaching one. This close agreement between perceived availability and usage is most likely because individuals who need these services benefit greatly from them, and thus take advantage of them. The ratio for transportation and cardiology are both relatively high for this age group, leading us to believe that the majority of those Down Syndrome individuals who know these services are available are taking advantage of them.

Availability-health care providers vs. birth to three years.

The questionnaires sent to the health care providers contained, among others, a question about available services. This information was useful because it was compared to the availability information from those on the Foundation's mailing list. This allowed us to check the responses from those on the mailing list against expert opinions concerning the services that are available. Comparing the percent of services available according to the health care providers to the percent of services available according to the mailing list respondents from the birth to three years age category yielded Figure 27.

Figure 27: Availability-Health Care Providers vs. Birth to Three Years



In observing Figure 27, it was seen that the consensus from the health care providers was that the majority of the services listed are highly available. These results were confirmed through all of our interviews with professionals. We learned that these professionals believe that all necessary services are available, although some could be improved upon. The low percentage of availability as compared to one hundred percent

for dental, transportation, home care, neurology and cardiology that was indicated by the health care providers demonstrated that these services are scarce. As was stated previously, a low percentage of availability could mean that either these services are not widely available or not available through the pediatric clinics. Because these responses were received from medical professionals, the most probable inference was that these services are not widely available, which poses a serious problem.

When all possible information was gathered about all respondents, an accurate comparison of the responses concerning the percent of available services could be made between the health care providers and the birth to three year respondents. As can be seen from looking at Figure 27, a higher percentage of the responding health care providers are aware of available services, with the exception of dental care. This was the expected outcome because the health care providers, working in a medical environment, are more informed of the services that are available to those who need them. From our data, it appears that there is a similar awareness level regarding the availability of occupational therapy, physical therapy, and cardiology. Presumably, there is adequate communication between the clinics and the Down Syndrome families receiving care at these clinics.

The differences in perceived availability between the health care providers and the birth to three year respondents could also be due to one of two factors, other than the professional knowledge of the health care providers. The first could be unawareness on the part of the birth to three year respondents concerning the services available and the second being that the services are deemed too inconvenient to use. The visible difference in the dental category, where the respondents from the birth to three years category perceive a higher percent availability for this service, could be because dental care is not

a service specific to Down Syndrome conditions. For this reason, some of the responding health care providers may not have had this service in mind when filling out our questionnaire concerning Down Syndrome.

Conclusions and Recommendations

Our most beneficial contribution to the Down Syndrome population of Puerto Rico and to la Fundación Puertorriqueña Síndrome Down comes in the form of conclusions and recommendations. Our first objective, determining the Down Syndrome population in Puerto Rico, was accomplished through the use of population studies, birth number and life span data, as previously explained. The results from these calculations are presented below.

Our second objective, assessing the services for Down Syndrome individuals in Puerto Rico, was accomplished through the use of questionnaires and interviews. As aforementioned, the responses to our questionnaires may not have accurately reflected the sample pool due to our nonresponse issue. The telephone calls placed to the nonrespondents yielded results similar to those of our respondents, which gave us more confidence in these results. For this reason, we can make conclusions and recommendations concerning the Down Syndrome services in Puerto Rico.

We decided that the most effective way to finalize our study was to make recommendations distinct to each of the three age groups analyzed. These age groups have different needs and concerns, and this breakdown is helpful in assessing the need for care of all Down Syndrome individuals. We have also included recommendations specific to la Fundación Puertorriqueña Síndrome Down.

The Down Syndrome Population

From our calculations, we estimated that there are on average 2607 Down Syndrome individuals living in Puerto Rico today. This number was our mean estimate

based on a Down Syndrome birth prevalence rate of 13.2 per 10,000 live births. The lower and upper limits for our estimate were based on Down Syndrome birth prevalence rates of 11.5 and 16.9, respectively. This gave us a range of 2250 to 3307 Down Syndrome individuals on the island.

Through our research, it was found that a strong emphasis is placed on early intervention, and for this reason we also approximated the Down Syndrome population for birth to three years. Using the same Down Syndrome birth prevalence rates as above, the mean estimate was determined to be 239 Down Syndrome children age birth to three years. This approximation yielded a range of 206 to 303 Down Syndrome children.

These findings can be used by various governmental and private Down Syndrome agencies, specifically la Fundación Puertorriqueña Síndrome Down, to acquire funding to expand their services, as well as other uses specific to their needs.

Birth to Three Years

A comparison of our birth to three estimate, the mean value being 239, to the number gathered from the five of the seven pediatric clinics shows that approximately seventy-one percent of the children of this age group are receiving services from the pediatric clinics. This indicates that the majority of children are obtaining services from the seven regional clinics.

Overall, the results gathered from the birth to three years age category point to a high availability and usage of most services. Therefore, these services are ideal and have only very minor problems, if any. Of the remaining services, a few indicate a high availability and a low usage, while others indicate both a low availability and a low

usage. For those services where there is high availability and low usage, we can infer that these services either need improvement or do not have a high demand. Whereas, the services that have a low availability and a low usage need major reform. These conclusions were further supported by our comparison of the percent of availability between the health care providers and the birth to three year age bracket. It was seen here that when the availability indicated by the health care providers far exceeded the availability designated by the birth to age three respondents, it was concluded that a lack of communication exists between the clinics and Down Syndrome families. When both sample pools were in agreement that the availability for a service was low, then there is significant need for improvement of this service. Our suggestions illustrated below can help in these problem areas.

When addressing these problems, it is our suggestion that those services that need the most improvement are given first priority. From our interviews, we learned that all of the necessary services to maximize a Down individual's potential are available to some degree at the clinics, although some are in short supply. From our data, it appears that these problematic services include: transportation, home care, and neurology. Making these services readily available and more accessible is the first way to begin improvements. From our interview with Ms. Rodríguez (2000), we know that one problem with some services is that they are understaffed. Therefore, increasing the number of individuals providing these services would be one way in which to achieve this goal. As specified by Ms. Rodríguez, home care is one service, which lacks the proper amount of personnel necessary to provide the best care possible to Down Syndrome individuals. In order to increase the work force, additional funds must be

acquired. Even though these pediatric clinics provide treatment to all children from birth to three years, knowing the number of Down individuals of this age who need treatment could help each clinic advocate for more funds from the Department of Health.

As stated above, it was concluded that there is a lack of communication between the pediatric clinics and Down Syndrome families with respect to those services for which the percent of perceived availability from the health care provider responses greatly exceeds that of the responses from the birth to three years category. The most effective method for alleviating this problem is for the pediatric clinics to increase and improve their advertising. From our interviews at the Bayamón and San Juan Metro Clinics, we know that the government allots a certain amount of money to each clinic to use on advertising. Currently, services offered at the clinics are promoted at local high schools and advertised in newspapers. We feel that more informative advertising, such as explaining each service in detail, would help in increasing the awareness of particular services. For instance, we know from our interviews at the pediatric clinics that transportation reimbursement is available to those who qualify financially. However, the responses we received indicated that very few people are aware that transportation reimbursement is available, and even fewer people take advantage of it.

We have several suggestions for more comprehensive advertising. One idea is to have a liaison between the hospital's maternity ward and pediatric wings and the local pediatric clinic. This liaison would visit the regional hospitals and promote the importance of getting a Down individual involved with one of the appropriate pediatric clinics. The clinics could also use various types of media to maximize advertising, such as newspapers, television, radio, billboards, or the Internet.

By providing an open-ended question in our questionnaire with regards to other information the respondent felt was necessary, we were able to obtain suggestions concerning specific problems with the current services. Through our analysis of these questions, it was found that the transition that takes place at the age of three, from receiving services from the Department of Health to receiving services from the Department of Education, is a difficult one. Many parents of Down individuals age birth to three years find it difficult to obtain information on preschool services. Ms. Rodríguez (2000) informed us that this problem has been acknowledged, and steps are currently being taken to make the transition easier. A series of meetings with parents, health care providers from the clinics, and professionals from the Department of Education have recently been instituted to make this transition easier for all those involved. Another helpful tool in aiding the parents through this transition could be to have an informed person place follow-up telephone calls to each family going through this transition period to ensure that their Down Syndrome child is still receiving the appropriate care.

Three to Twenty-One Years

Overall, all those responding for this age group agreed with the statements that their child needs educational, medical and therapeutic services. However, their overall satisfaction with the services being received was somewhat less than the need for these services. This could be attributed to the fact that the services are not completely adequate to meet their needs. This inadequacy could be due to low accessibility, low knowledge of availability, and possibly even due to a lack of professional services.

Under the federal Education for All Handicapped Children Act of 1975, a child is entitled to all of the educational and therapeutic care necessary to help them reach their potential. In spite of this, a common complaint to the open-ended question on our questionnaire was that there are not enough therapies in the public school system for Down Syndrome children. Our analysis of the responses also shows a significant drop in therapeutic satisfaction from the birth to three year category to the three to twenty-one year group. Speech therapy is just one example of the services that was frequently mentioned by the respondents as being too scarce.

As mentioned for the birth to three year age bracket, optimal care can be obtained by increasing the number of professionals providing services. For this age group, there would need to be an increase in the number of professionals providing therapies through the schools for Down Syndrome individuals. Another suggestion for optimizing the care of Down Syndrome individuals ages three to twenty-one would be to implement additional programs specific to each child's needs. These programs could include: developmental services, recreational activities, and educational curriculums.

Twenty-One Years and Older

Our results show a great lack of services for the twenty-one years and older group. It also must be realized that the services listed as well as the ordinal questions are more applicable to younger Down Syndrome individuals. However, from the open-ended responses, it is clear that Down individuals of this age group are not receiving the attention that is given to younger ages. The ordinal statements referring to the need for educational, medical and therapeutic services received ratings that indicate there is a

strong need for such services. Examining the responses concerning satisfaction from this age group, it is very apparent that many of these Down individuals are extremely unhappy with the services available to them.

From the case study done in Worcester, Massachusetts at the Seven Hills Foundation Inc., described in the Literature Review, we learned that the major need for this age group is vocational training programs. Successful programs at the Seven Hills Foundation incorporate job skills and social skills into a training program that prepares older Down individuals for job placement in the community. For example, Down individuals from the Seven Hills Foundation have been placed in clerical and cashiering positions in the local area.

We strongly recommend that the services provided to school age children be extended past the age of twenty-one, through the Department of Mental Retardation. We also feel that initiating vocational and social interaction programs such as those at the Seven Hills Foundation would be extremely beneficial to this age group.

Recommendations for La FPSD

Many of the responses received from those on the mailing list at la Fundación Puertorriqueña Síndrome Down show contentment with the services that are being received. The Foundation plays an important role in promoting inclusion therapy, which is the philosophy of placing Down Syndrome individuals with non-Down Syndrome individuals in the hopes that they will acclimate to and become effective members of society. The Foundation implements this philosophy by placing Down children in a preschool setting with those children who do not have Down Syndrome.

Our mean estimate for the Down population from birth to age three of 239, corroborated by the number received from the pediatric clinics, indicates that there are a number of young children on the island of Puerto Rico who need services. This number along with our mean estimate for the total Down Syndrome population of 2607 Down individuals on the island will help the Foundation to acquire funding from the federal government. The Executive Director, Dr. Carmen Avilés, and the Board of Directors at the Foundation hope that they will gain funding to expand their current services by informing the government of the number of Down Syndrome children on the island that need care.

If the Foundation is successful in receiving adequate funding to expand, many new services could be implemented as well as advertised. The first step could be to advertise, in detail, what services are currently available, and in turn accept more children into their care. As more people enroll in the Foundation, the current services could be expanded as seen necessary. This expansion could include: a larger staff, an additional facility in another area, and the establishment of programs to meet the needs of other age groups. For example, one additional program may be an after school session providing tutoring and recreational activities for elementary school aged Down children, as well as similar programs for those children in high school. It may also be possible to have high school aged Down children help with the programs established for younger participants. Resources permitting, a vocational program could also be implemented to benefit those Down individuals who are twenty-one years or older.

As these ideas are implemented, additional advertisement will be necessary. The major thrust of promotion should be done through the schools. This could be

implemented through informative sessions held at local schools for parents and teachers to attend. It might also be helpful to have guidance counselors contacting those families who they feel would most benefit from the services at the Foundation. Other forms of advertisement should include radio, television, billboards, newspapers and the Internet.

Appendix A: La Fundación Puertorriqueña Síndrome Down

Much of the following information is from Browne, Heck, and Prytko's Preparing for a Down Syndrome Facility for the PRDSF IQP and Jacobson, Lovett, and Pires' Organizational and Administrative Planning for the PRDSF IQP.

In 1986, Miriam Perez de Martinez founded the Puerto Rico Down Syndrome Society in her home in Dorado, Puerto Rico. Her family and neighbors helped in giving advice over the telephone to families with a Down Syndrome member. The Society became incorporated in 1989. Dr. Acisclo Marxuach became affiliated with the Society in 1990. His granddaughter was diagnosed with Down Syndrome, and having been born in the United States, she and her family received immediate medical and professional assistance. Dr. Marxuach felt that the Down Syndrome cases in Puerto Rico deserved the same immediate care. In 1991, the Society transformed into la Fundación Puertorriqueña Síndrome Down (FPSD) in San Juan, Puerto Rico. After six years of involvement, Dr. Marxuach became the Executive Director. As the Executive Director, he worked to effect changes in Puerto Rico's health system, which lacked the support that is readily available for Down cases in the United States.

Dr. Marxuach and his colleagues encountered several obstacles in setting up the Foundation. Before the establishment of the FPSD, there had been no organization of its kind in Puerto Rico. Therefore, creating the Foundation's agenda, defining its mission, and establishing its program proved to be a great challenge. In addition, the Foundation was confronted with a widely scattered Down population. The last step was to organize the parents of Down children in a support group.

Regardless of these problems, continuous financial and moral support from individuals, industries, non-profit organizations, and government organizations in Puerto Rico have enabled the FPSD to establish support service programs in the metropolitan San Juan area. Today the FPSD maintains wide-spread credibility as an effective health care organization. The Foundation opened the first childcare and pre-school management program in Puerto Rico. They have also added therapeutic services to its early intervention program. These services include:

- The Start Up program, which assists the parents of newborn Down babies by helping them and teaching them how to work with their babies.
- A child integrated day care, offered from birth to age five, which supports the Down toddlers and their siblings, allowing their parents to work.
- A family training and monthly support group which was created to instruct and help the entire family deal with the syndrome.
- Physical, speech and occupational therapy services, which are provided for all Down children.
- Social and recreational programs that incorporate children and adults.
- The newsletter "Eslabon" which attempts to inform the entire community about Down Syndrome.

In July of 1999, Carmen Avilés-Ortiz became the Executive Director of the FPSD. Dr. Marxuach is still actively involved in the Foundation as one of its directors. As the Foundation continues to grow financially and in additional personnel, there are many goals that it would like to implement. Some of these goals are:

- Improvements in the overall cost of operation.
- The extension of services in order to reach people outside of the metropolitan area.
- The construction of a permanent site in the San Juan area.

- The creation of jobs and job placement services for young Down adults.
- The expansion of the public relations program.
- The introduction of classrooms for children ages six to ten.
- The introduction of internship and Big Brother/Big Sister programs.

With these programs, the FPSD hopes to be able to reach a larger number of Down families needing these services. In addition, the Foundation plans to increase the adequacy of the current facilities along with establishing more facilities. The hope is that one of these new facilities will be centrally located in San Juan. If these goals are met, it will greatly expand the Foundations potential to help the Down Syndrome population in Puerto Rico.

Appendix B: Table for Determining Sample Size

This table was taken from How to Conduct Your Own Survey by Priscilla Salant and Don A. Dilman (1994:55).

Population size	Sample size for the 95 percent confidence level					
	±3% sampling error		±5% sampling error		±10% sampling error	
	50/50 split	80/20 split	50/50 split	80/20 split	50/50 split	80/20 split
100	92	87	80	71	49	38
250	203	183	152	124	70	49
500	341	289	217	165	81	55
750	441	358	254	185	85	57
1,000	516	406	278	198	88	58
2,500	748	537	333	224	93	60
5,000	880	601	357	234	94	61
10,000	964	639	370	240	95	61
25,000	1,023	663	378	234	96	61
50,000	1,045	674	381	245	96	61
100,000	1,056	678	383	245	96	61
1,000,000	1,066	682	384	246	96	61
100,000,000	1,067	683	384	246	96	61

Appendix C: Cover Letters, Questionnaires, and Reminder

Letter

C1: English

Cover Letter for Those on the Foundation's Mailing List

April 3, 2000

Dear Sir or Madam:

Approximately three years ago, the Puerto Rican Down Syndrome Foundation began to compile statistical information about the Down Syndrome population in Puerto Rico. In the database that was prepared, we have information about you and your Down Syndrome child. Of course, we wish to maintain this information as accurately as possible. For this reason, we are sending this questionnaire to you that will allow us to update this information in addition to knowing the needs of your child.

The information that you provide will allow us to solicit available funds from the federal and state governments for educational and therapeutic services. These funds will be used to design service programs that will be available in your community, as well as to keep families informed of other services and opportunities available in Puerto Rico. For this reason, we would appreciate it if you would complete the attached questionnaire and return it in the envelope provided as quickly as possible.

Remember that the information you provide to us will be maintained in strict confidentiality. By answering and returning this questionnaire, you are helping the Foundation to continue defending the rights of the Down population.

If you have any questions about the questionnaire, you can contact us at 268-3696.

Thank you for your time.

Sincerely,

Carmen Avilés-Ortiz, Ed. D.
Executive Director

Questionnaire for Those on the Foundation's Mailing List

Please answer all questions if possible.

General Information

Child's Name _____ Middle Initial _____ Last name 1 _____
Last name 2 _____

Date of birth _____

Gender _____

Postal address _____

City _____

Zip Code _____

Work telephone _____

Residential address _____

City _____

Zip Code _____

Home telephone _____

Family Information

Father's name _____

Age of father _____

Occupation of father _____

Mother's name _____

Age of mother _____

Occupation of Mother _____

Is there another member of your family with Down Syndrome? ____ Yes ____ No
____ Indicate

Education of your child

Mark the educational services that your child receives.

- ____ Early intervention
- ____ Preschool
- ____ Elementary school
 - ____ Special education room
 - ____ Partial integration in a regular room
 - ____ Total integration in a regular room
- ____ Special school
- ____ Middle school
 - ____ Independent life program
 - ____ Pre-vocational
 - ____ Integration in a regular room
- ____ High school
 - ____ Vocational program
 - ____ Integration in a regular room
- ____ In the home
 - ____ "Home Bound" Services
- ____ Vocational rehabilitation

Medical Information

Name of your child's doctor _____

Indicate which of the following prenatal services the mother received:

- ☐ Alpha Feto-protein
- ☐ Amniocentesis
- ☐ Chorionic villus sampling (CVS)
- ☐ Ultrasound
- ☐ Biochemical tests
- ☐ Unknown
- ☐ Nothing

If you know the results of the chromosome test that was done on your child, indicate it.

☐ Trisomy 21 ☐ Mosaicism ☐ Translocation

Mark the health conditions that your Down Syndrome child has.

- | | | |
|---|---------------------------------------|----------------------------------|
| <input type="checkbox"/> Asthma | <input type="checkbox"/> Visual | <input type="checkbox"/> Cardiac |
| <input type="checkbox"/> Respiratory | <input type="checkbox"/> Dental | <input type="checkbox"/> Thyroid |
| <input type="checkbox"/> Gastrointestinal | <input type="checkbox"/> Over-weight | <input type="checkbox"/> Nasal |
| <input type="checkbox"/> Hearing | <input type="checkbox"/> Others _____ | <input type="checkbox"/> Nothing |

Indicate the services that are available in your city or town.

- | | | |
|---|---|--|
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Physical therapy | <input type="checkbox"/> Nutrition |
| <input type="checkbox"/> Social Work | <input type="checkbox"/> Transportation | <input type="checkbox"/> Ophthalmologist |
| <input type="checkbox"/> Dental | <input type="checkbox"/> Home care | <input type="checkbox"/> Cardiologist |
| <input type="checkbox"/> Audiologist | <input type="checkbox"/> Neurologist | <input type="checkbox"/> Others _____ |

Indicate which of these services you use for your child.

- | | | |
|---|---|--|
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Physical therapy | <input type="checkbox"/> Nutrition |
| <input type="checkbox"/> Social Work | <input type="checkbox"/> Transportation | <input type="checkbox"/> Ophthalmologist |
| <input type="checkbox"/> Dental | <input type="checkbox"/> Home care | <input type="checkbox"/> Cardiologist |
| <input type="checkbox"/> Audiologist | <input type="checkbox"/> Neurologist | <input type="checkbox"/> Others (Indicate) |

Do you have transportation available in order to use these services? ☐ Yes ☐ No

What other services does your Down Syndrome child need?

For example, indicate if you need a special doctor in order to treat other conditions or special therapy.

If there is other information that you consider important, write it below.

Evaluation of the Services

Please, respond to the questions by circling the number that indicates how you feel about the following statements.

- 0 = Not applicable
- 1 = Strongly disagree
- 2 = Disagree
- 3 = Neutral
- 4 = Agree
- 5 = Strongly agree

1. My child needs educational services specific to his/her Down Syndrome condition.

0 1 2 3 4 5

2. I am satisfied with the educational services that my child receives.

0 1 2 3 4 5

3. My child needs medical services specific to his/her Down Syndrome condition.

0 1 2 3 4 5

4. I am satisfied with the medical services that my child receives.

0 1 2 3 4 5

5. My child needs therapeutic services specific to his/her Down Syndrome condition.

0 1 2 3 4 5

6. I am satisfied with the therapeutic services that my child receives.

0 1 2 3 4 5

Reminder Letter for Those on the Foundation's Mailing List

April 12, 2000

Dear Sir or Madam:

As you already know, the Puerto Rican Down Syndrome Foundation sent you a questionnaire regarding the Down Syndrome population. If you have already responded to this questionnaire, we thank you for your help and promptness. If not, please consider its importance and return it at your earliest convenience.

We look forward to hearing from you, and please feel free to contact us at (787) 268-3696 with any question you may have.

Thank you.

The Puerto Rican Down Syndrome Foundation

Cover Letter for Pediatric Clinics

April 3, 2000

Dear Service Provider:

Approximately three years ago, the Puerto Rican Down Syndrome Foundation began to compile statistical information about the Down Syndrome population in Puerto Rico. In spite of our struggles to maintain the statistics accurately, we know that we are lacking in our abilities to compile this information. For this reason, we are sending this questionnaire so that you can help us to identify the needs of the Down Syndrome children and adults in our country. We would appreciate it if you could distribute these questionnaires to the doctors and the therapists in your center.

The information that you provide will allow us to solicit available funds from the federal and state governments for educational and therapeutic services. These funds will be used to design service programs that will be available in your community, as well as to keep families informed of other services and opportunities available in Puerto Rico. For this reason, it is important that the service providers complete the attached questionnaire and return it in the envelope provided as quickly as possible.

Remember that the information you provide to us will be maintained in strict confidentiality. By answering and returning this questionnaire, you are helping the Foundation to continue defending the rights of the Down population.

If you have any questions about the questionnaire or if you need additional copies, you can contact us at 268-3696.

Thank you for your time.

Sincerely,

Carmen Avilés-Ortiz, Ed. D.
Executive Director

Cover Letter for Health Care Providers

April 3, 2000

Dear Service Provider:

Approximately three years ago, the Puerto Rican Down Syndrome Foundation began to compile statistical information about the Down Syndrome population in Puerto Rico. In spite of our struggles to maintain the statistics accurately, we know that we are lacking in our abilities to compile this information. For this reason, we are sending this questionnaire so that you can help us to identify the needs of the Down Syndrome children and adults in our country.

The information that you provide will allow us to solicit available funds from the federal and state governments for educational and therapeutic services. These funds will be used to design service programs that will be available in your community, as well as to keep families informed of other services and opportunities available in Puerto Rico. For this reason, we would appreciate it if you would complete the attached questionnaire and return it in the envelope provided as quickly as possible.

Remember that the information you provide to us will be maintained in strict confidentiality. By answering and returning this questionnaire, you are helping the Foundation to continue defending the rights of the Down population.

If you have any questions about the questionnaire, you can contact us at 268-3696.

Thank you for your time.

Sincerely,

Carmen Avilés-Ortiz, Ed. D.
Executive Director

Questionnaire for Health Care Providers

Evaluation of Services

Please, indicate your profession. _____

If you provide a Down Syndrome service and/or provide treatment for a condition related to Down Syndrome, indicate it below.

<input type="checkbox"/> Occupational therapy	<input type="checkbox"/> Physical therapy	<input type="checkbox"/> Nutrition
<input type="checkbox"/> Social Work	<input type="checkbox"/> Transportation	<input type="checkbox"/> Ophthalmologist
<input type="checkbox"/> Dental	<input type="checkbox"/> Home care	<input type="checkbox"/> Cardiologist
<input type="checkbox"/> Audiologist	<input type="checkbox"/> Neurologist	<input type="checkbox"/> Others (Indicate)

Please, respond to the following statements by circling the number that indicates how you feel about them.

0 = Not applicable
 1 = Strongly disagree
 2 = Disagree
 3 = Neutral
 4 = Agree
 5 = Strongly agree

1. You feel that the educational needs of your patients are being satisfied.

0 1 2 3 4 5

2. You feel that the medical needs of your patients are being satisfied.

0 1 2 3 4 5

3. You feel that the therapeutic needs of your patients are being satisfied.

0 1 2 3 4 5

What are the most common health conditions of your Down Syndrome patients?

<input type="checkbox"/> Asthma	<input type="checkbox"/> Visual	<input type="checkbox"/> Cardiac
<input type="checkbox"/> Respiratory	<input type="checkbox"/> Dental	<input type="checkbox"/> Thyroid
<input type="checkbox"/> Gastrointestinal	<input type="checkbox"/> Over-weight	<input type="checkbox"/> Nasal
<input type="checkbox"/> Hearing	<input type="checkbox"/> Others _____	<input type="checkbox"/> None

Indicate the services that are available for Down Syndrome patients in your city or town, different from the ones you offer.

- | | | |
|---|---|--|
| <input type="checkbox"/> Occupational therapy | <input type="checkbox"/> Physical therapy | <input type="checkbox"/> Nutrition |
| <input type="checkbox"/> Social Work | <input type="checkbox"/> Transportation | <input type="checkbox"/> Ophthalmologist |
| <input type="checkbox"/> Dental | <input type="checkbox"/> Home care | <input type="checkbox"/> Cardiologist |
| <input type="checkbox"/> Audiologist | <input type="checkbox"/> Neurologist | <input type="checkbox"/> Others (Indicate) |

Please offer a short answer to the following questions.

What are the essential services that an agency should have to tend to the Down Syndrome population?

If there is other information that you feel is important, write it below.

C2: Spanish

Cover Letter for Those on the Foundation's Mailing List

3 de abril del 2000

Estimado(a) señor (a):

Hace aproximadamente tres años que la Fundación Puertorriqueña Síndrome Down comenzó a recopilar información estadística de la población Síndrome Down en Puerto Rico. En el banco de datos que se preparó tenemos información acerca de usted y su hijo(a) Síndrome Down. Sin embargo, queremos mantener esta información lo más actualizada posible. Por tal razón, estamos enviándole este cuestionario que nos permitirá actualizar la información y además conocer otras necesidades que tenga su hijo(a).

La información que usted provea nos ayudará a solicitar fondos disponibles al gobierno federal o estatal para educación/servicios terapéuticos, continuar colaborando en el diseño de programas de servicios que estén disponibles cerca de sus comunidades, y para mantener a las familias informadas en cuanto a otros servicios y oportunidades en Puerto Rico. Por eso, le agradeceremos que usted complete el cuestionario adjunto y lo devuelva en el sobre predirigido a la mayor brevedad posible.

Recuerde que la información que usted nos provea se mantendrá en estricta confidencialidad. Al usted contestar y devolver el cuestionario está ayudando a la Fundación a continuar abogando por los derechos de esta población.

De tener alguna duda sobre el cuestionario puede comunicarse a nuestras oficinas al 268-3696.

Gracias por su tiempo.

Cordialmente,

Carmen L. Avilés Ortiz, Ed. D.
Directora Ejecutiva

Questionnaire for Those on the Foundation's Mailing List

Por favor, conteste tantas las preguntas como sea posible.

Información General

Nombre de su hijo(a) _____ Inicial _____ Apellido 1 _____
Apellido 2 _____

Fecha de nacimiento _____
Género _____

Dirección Postal _____
Pueblo _____
Código Postal _____
Teléfono del Trabajo _____

Dirección Residencial _____
Pueblo _____
Código Postal _____
Teléfono de la Casa _____

Información de la Familia

Nombre del Padre _____
Edad del Padre _____
Ocupación del Padre _____

Nombre de la Madre _____
Edad de la Madre _____
Ocupación de la Madre _____

¿Tiene Ud. otro Miembro de la familia con Síndrome Down? _____ Sí _____ No
Indique _____

Educación de su hijo(a)

Marque el servicio educativo que su hijo(a) recibe.

- _____ Intervención Temprana
- _____ Preescolar
- _____ Escuela Elemental
 - _____ Salón de Educación Especial
 - _____ Integrado Parcialmente en el Salón Regular
 - _____ Integrado Totalmente en el Salón Regular
- _____ Escuela Especial
- _____ Escuela Intermedia
 - _____ Programa Vida Independiente
 - _____ PreVocacional
 - _____ Integrado en el Salón Regular
- _____ Escuela Superior
 - _____ Programa Vocacional
 - _____ Integrado en el Salón Regular
- _____ En el Hogar
 - _____ Servicios "Home Bound"
- _____ Rehabilitación Vocacional

Información Médica

Nombre del Médico de su hijo(a) _____

Indique si la madre recibió cernimiento prenatal en las siguientes:

- ☐ Alpha feto-proteína
- ☐ Amniocentesis
- ☐ Biopsia de Vellosidades Coriónicas
- ☐ Ultrasonografía
- ☐ Pruebas Bioquímicas
- ☐ Desconozco
- ☐ Nada

Si conoce los resultados de una prueba de cromosoma que le hicieron a su hijo(a), indíquelo.

☐ Trisomia 21 ☐ Mosaico ☐ Translocación

Marque las condiciones de salud que tiene su hijo Síndrome Down.

- | | | |
|---|--------------------------------------|------------------------------------|
| <input type="checkbox"/> Asma | <input type="checkbox"/> Visuales | <input type="checkbox"/> Cardíacos |
| <input type="checkbox"/> Respiratorias | <input type="checkbox"/> Dentales | <input type="checkbox"/> Tiroides |
| <input type="checkbox"/> Gastrointestinales | <input type="checkbox"/> Sobrepeso | <input type="checkbox"/> Nasaes |
| <input type="checkbox"/> Auditivos | <input type="checkbox"/> Otras _____ | <input type="checkbox"/> Ninguna |

Indique los servicios que están disponibles en su ciudad o pueblo.

- | | | |
|--|---|--|
| <input type="checkbox"/> Terapia Ocupacional | <input type="checkbox"/> Terapia Física | <input type="checkbox"/> Nutrición |
| <input type="checkbox"/> Trabajo Social | <input type="checkbox"/> Transportación | <input type="checkbox"/> Oftalmología |
| <input type="checkbox"/> Dental | <input type="checkbox"/> Cuidado en el hogar | <input type="checkbox"/> Cardiología |
| <input type="checkbox"/> Audiologicos | <input type="checkbox"/> Servicios neurologicos | <input type="checkbox"/> Otros (Indique) _____ |

Indique los servicios que usa Ud. para su hijo(a).

- | | | |
|--|---|--|
| <input type="checkbox"/> Terapia ocupacional | <input type="checkbox"/> Terapia física | <input type="checkbox"/> Nutrición |
| <input type="checkbox"/> Trabajo Social | <input type="checkbox"/> Transportación | <input type="checkbox"/> Oftalmología |
| <input type="checkbox"/> Dental | <input type="checkbox"/> Cuidado en el hogar | <input type="checkbox"/> Cardiología |
| <input type="checkbox"/> Audiologicos | <input type="checkbox"/> Servicios neurológicos | <input type="checkbox"/> Otros (Indique) _____ |

¿Tiene Ud. transportación dispnible para usar estos servicios? ☐ Si ☐ No

¿Qué otros servicios necesita su hijo(a) con Síndrome Down?

Por ejemplo, indique si necesita un doctor especial para tratar otras condiciones o terapia especial.

Si hay otra información que Ud. considere importante, indíquela aquí.

Evaluación de los Servicios

Por favor, responda Ud. a las preguntas circulando las mismas en el número que indica como se siente en cuanto a esto.

0 = No aplica

1 = No estoy de acuerdo fuertemente

2 = No estoy de acuerdo

3 = Neutral

4 = Estoy de acuerdo

5 = Estoy de acuerdo fuertemente

1. Su hijo(a) necesita servicios educativos específicos para su condición Síndrome Down.

0 1 2 3 4 5

2. Estoy satisfecho(a) con los servicios educativos que recibe mi hijo(a).

0 1 2 3 4 5

3. Su hijo(a) necesita servicios médicos específicos para su condición Síndrome Down.

0 1 2 3 4 5

4. Estoy satisfecho(a) con los servicios médicos que recibe mi hijo(a).

0 1 2 3 4 5

5. Su hijo(a) necesita servicios terapéuticos específicos para su condición Síndrome Down.

0 1 2 3 4 5

6. Estoy satisfecho(a) con los servicios terapéuticos que recibe mi hijo(a).

0 1 2 3 4 5

Reminder Letter for Those on the Foundation's Mailing List

12 de abril del 2000

Estimado(a) Señor(a):

Como es de su conocimiento, la Fundación Puertorriqueña Síndrome Down le envió un cuestionario en relación a la población Síndrome Down. Si ya respondió a este cuestionario, gracias por su ayuda y su rápida respuesta. Si no, por favor considere su importancia y devuélvalo a la mayor brevedad posible.

Esperamos su pronta respuesta y cualquier duda favor comunicarse con nuestras oficinas al (787) 268-3696.

Gracias,

La Fundación Puertorriqueña Síndrome Down

Cover Letter for Pediatric Clinics

3 de abril del 2000

Estimado Proveedor de servicios:

Hace aproximadamente tres años que la Fundación Puertorriqueña Síndrome Down comenzó a recopilar información estadística de la población Síndrome Down en Puerto Rico. A pesar de todos nuestros esfuerzos por mantener la estadística actualizada, reconocemos que nos falta mucho por recopilar. Necesitamos información de proveedores de servicios, y por tal razón, le estamos enviando este cuestionario para que nos ayude a identificar otras necesidades que tengan los niños, jóvenes y adultos Síndrome Down en nuestro país. Le agradeceremos que usted pueda distribuir estos cuestionarios a los médicos y terapeutas de su centro.

La información que ellos provean nos ayudará a solicitar fondos disponibles al gobierno federal o estatal para educación/servicios terapéuticos, continuar colaborando en el diseño de programas de servicios que estén disponibles cerca de sus comunidades, y para mantener a las familias informadas en cuanto a otros servicios y oportunidades en Puerto Rico. Por eso, es tan importante que los proveedores de servicios completen el cuestionario adjunto y lo devuelva en el sobre predirigido a la mayor brevedad posible.

Recuerde que la información que ellos nos provean se mantendrá en estricta confidencialidad. Al ellos contestar y devolver el cuestionario está ayudando a la Fundación a continuar abogando por los derechos de esta población.

De tener alguna duda sobre el cuestionario o si necesita cuestionarios adicionales, puede comunicarse a nuestras oficinas al 268-3696.

Gracias por su tiempo.

Cordialmente,

Carmen L. Avilés Ortiz, Ed. D.
Directora Ejecutiva

Cover Letter for Health Care Providers

3 de abril del 2000

Estimado Proveedor de servicios:

Hace aproximadamente tres años que la Fundación Puertorriqueña Síndrome Down comenzó a recopilar información estadística de la población Síndrome Down en Puerto Rico. A pesar de todos nuestros esfuerzos por mantener la estadística actualizada, reconocemos que nos falta mucho por recopilar. Necesitamos información de proveedores de servicios, y por tal razón, le estamos enviando este cuestionario para que nos ayude a identificar otras necesidades que tengan los niños, jóvenes y adultos Síndrome Down en nuestro país.

La información que usted provea nos ayudará a solicitar fondos disponibles al gobierno federal o estatal para educación/servicios terapéuticos, continuar colaborando en el diseño de programas de servicios que estén disponibles cerca de sus comunidades, y para mantener a las familias informadas en cuanto a otros servicios y oportunidades en Puerto Rico. Por eso, le agradeceremos que usted complete el cuestionario adjunto y lo devuelva en el sobre predirigido a la mayor brevedad posible.

Recuerde que la información que usted nos provea se mantendrá en estricta confidencialidad. Al usted contestar y devolver el cuestionario está ayudando a la Fundación a continuar abogando por los derechos de esta población.

De tener alguna duda sobre el cuestionario puede comunicarse a nuestras oficinas al 268-3696.

Gracias por su tiempo.

Cordialmente,

Carmen L. Avilés Ortiz, Ed. D.
Directora Ejecutiva

Questionnaire for Health Care Providers

Evaluación de los Servicios

Por favor, indique su ocupación. _____

Si proporciona Ud. un servicio para Síndrome Down y/o provee Ud. tratamiento para una condición relacionada a Síndrome Down, indíquelo debajo.

<input type="checkbox"/> Terapia Ocupacional	<input type="checkbox"/> Terapia Física	<input type="checkbox"/> Nutrición
<input type="checkbox"/> Trabajo Social	<input type="checkbox"/> Transportación	<input type="checkbox"/> Oftalmología
<input type="checkbox"/> Dental	<input type="checkbox"/> Cuidado en el hogar	<input type="checkbox"/> Cardiología
<input type="checkbox"/> Audiologicos	<input type="checkbox"/> Servicios neurologicos	<input type="checkbox"/> Otros (Indique) _____

Por favor, responda Ud. a las preguntas circulando las mismas en el número que indica como se siente en cuanto a esto.

- 0 = No aplica
- 1 = No estoy de acuerdo fuertemente
- 2 = No estoy de acuerdo
- 3 = Neutral
- 4 = Estoy de acuerdo
- 5 = Estoy de acuerdo fuertemente

1. Considera usted que sus pacientes reciben la educación que necesitan.

0 1 2 3 4 5

2. Considera usted que sus pacientes reciben los servicios médicos que estos necesitan.

0 1 2 3 4 5

3. Considera usted que sus pacientes reciben los servicios terapéuticos que estos necesitan.

0 1 2 3 4 5

Indique cuáles son las condiciones de salud más comunes de sus pacientes Síndrome Down.

<input type="checkbox"/> Asma	<input type="checkbox"/> Visuales	<input type="checkbox"/> Cardíacos
<input type="checkbox"/> Respiratorias	<input type="checkbox"/> Dentales	<input type="checkbox"/> Tiroides
<input type="checkbox"/> Gastrointestinales	<input type="checkbox"/> Sobrepeso	<input type="checkbox"/> Nasales
<input type="checkbox"/> Audutivos	<input type="checkbox"/> Otras _____	<input type="checkbox"/> Ninguna

Indique los servicios que están disponibles para pacientes Síndrome Down en su ciudad o pueblo, diferente de los que Ud. proporciona.

<input type="checkbox"/> Terapia ocupacional	<input type="checkbox"/> Terapia física	<input type="checkbox"/> Nutrición
<input type="checkbox"/> Trabajo Social	<input type="checkbox"/> Transportación	<input type="checkbox"/> Oftalmología
<input type="checkbox"/> Dental	<input type="checkbox"/> Cuidado en el hogar	<input type="checkbox"/> Cardiología
<input type="checkbox"/> Audiologicos	<input type="checkbox"/> Servicios neurologicos	<input type="checkbox"/> Otros (Indique) _____

Por favor, ofresca Ud. una respuesta corta a las siguientes preguntas.

¿Qué servicios esenciales que debe tener una agencia que atienda la población Síndrome Down ?

Si hay otra información que Ud. considere importante, escribela debajo.

Appendix D: Population Information

D1: Population Statistics from the Department of Health

AÑO CALENDARIO CALENDAR YEAR	POBLACIÓN* POPULATION	NACIMIENTOS LIVE BIRTHS		DEFUNCIONES TOTALES TOTAL DEATHS		DEFUNCIONES DE NIÑOS MENORES DE UN AÑO INFANT DEATHS	
		Núm. No.	TASA (1) RATE	Núm. No.	TASA (1) RATE	Núm. No.	TASA (2) RATE
1939	1845000	73044	39.6	32631	17.7	8214	112.5
1940	1878000	72388	38.5	34477	18.4	8212	113.4
1941	1912000	76130	39.8	35551	18.6	8849	116.2
1942	1946000	78405	40.3	32218	16.6	8104	103.4
1943	1980000	78393	39.6	29065	14.7	7470	95.3
1944	2014000	82585	41.0	29843	14.8	8216	99.5
1945	2049000	86582	42.3	28886	14.1	8083	93.4
1946	2083000	88723	42.6	27570	13.2	7437	83.8
1947	2117000	91496	43.2	25411	12.0	6541	71.5
1948	2151000	87746	40.8	26204	12.2	6884	78.5
1949	2185000	85638	39.2	23391	10.7	5787	67.6
1950	2218000	83455	38.5	21917	9.9	5835	68.3
1951	2224000	84007	37.8	22371	10.1	5635	67.1
1952	2202000	80200	36.4	20504	9.3	5339	66.6
1953	2182000	77380	35.5	17966	8.2	4898	63.3
1954	2195000	78008	35.5	16871	7.7	4511	57.8
1955	2235000	79221	35.4	16243	7.3	4368	55.1
1956	2237000	78177	34.9	16607	7.4	4334	55.4
1957	2252000	76068	33.8	16022	7.1	3829	50.3
1958	2295000	76128	33.2	16099	7.0	4088	53.7
1959	2321000	74933	32.3	15870	6.8	3602	48.1
1960	2358000	76015	32.2	15841	6.7	3325	43.7
1961	2404000	75563	31.4	16361	6.8	3123	41.3
1962	2455000	76677	31.2	16575	6.8	3192	41.6
1963	2513000	77382	30.8	17386	6.9	3467	44.8

Tabla 1 - ESTADISTICAS DEMOGRAFICAS EN PUERTO RICO POR AÑOS
Table 1 - DEMOGRAPHIC STATISTICS IN PUERTO RICO BY YEARS
PUERTO RICO, 1996

Años Years	POBLACION * POPULATION	Nacimientos Vivos Live Births		Mortalidad General Total Deaths		Mortalidad Infantil Infant Deaths		Muertes Maternas Maternal Deaths		Mortuatos Stillbirths		Matrimonios Marriages		Divorcios Divorces	
		Número	Tasa 1/	Número	Tasa 1/	Número	Tasa 2/	Número	Tasa 3/	Número	Tasa 2/	Número	Tasa 1/	Número	Tasa 1/
1996	3,733,326	63,259	17.0	29,871	8.0	665	10.5	11	17.4	708	11.1	32,572	11.7	13,172	4.7
1995	3,719,317	63,518	17.0	30,196	8.1	809	12.7	9	14.2	650	10.1	32,514	11.7	13,648	4.9
1994	3,685,729	64,325	17.4	28,444	7.7	738	11.5	5	7.7	646	9.9	33,200	12.3	13,724	5.1
1993	3,621,538	65,242	18.0	28,494	7.9	874	13.4	9	13.8	734	11.1	33,262	12.6	14,198	5.4
1992	3,578,980	64,481	18.0	27,397	7.7	822	12.7	14	21.7	649	10.0	34,222	9.6	14,227	5.5
1991	3,549,160	64,516	18.2	26,328	7.4	841	13.0	13	20.2	631	9.7	33,222	12.9	13,571	5.3
1990	3,527,796	66,555	18.9	26,148	7.4	893	13.4	13	19.5	666	9.9	33,080	12.9	13,695	5.3
1989	3,497,287	66,692	19.1	25,987	7.4	952	14.3	13	19.5	620	9.2	31,642	12.5	13,838	5.5
1988	3,461,385	64,081	18.5	25,123	7.3	810	12.6	11	17.2	647	10.0	32,214	12.9	13,930	5.6
1987	3,433,345	64,393	18.8	23,954	7.0	916	14.2	11	17.1	626	9.6	33,285	13.6	14,611	6.0
1986	3,406,229	63,551	18.7	23,387	6.9	873	13.7	10	15.7	642	10.5	32,335	13.4	13,554	5.6
1985	3,378,126	63,629	18.8	23,194	6.9	947	14.9	8	12.6	657	10.2	30,306	12.7	14,686	6.2
1984	3,348,754	63,321	18.9	21,733	6.5	991	15.7	6	9.5	673	10.5	29,695	12.3	13,698	5.7
1983	3,321,848	65,742	19.8	21,499	6.5	1,140	17.3	4	6.1	710	10.7	29,632	12.8	13,164	5.7
1982	3,290,435	69,336	21.1	21,522	6.5	1,193	17.2	8	11.5	757	10.8	30,385	13.3	14,084	6.2
1981	3,251,847	71,365	21.9	21,197	6.5	1,325	18.6	12	16.8	775	10.7	31,916	14.3	14,247	6.4
1980	3,203,956	73,060	22.8	20,486	6.4	1,386	19.0	6	8.2	820	11.1	33,167	15.1	15,276	6.9
1979	3,160,700	73,781	23.3	20,390	6.5	1,469	19.9	8	10.8	854	11.6	33,768	15.7	14,791	6.9
1978	3,121,600	75,066	24.0	19,876	6.4	1,390	18.5	4	5.3	950	12.7	33,253	16.0	14,753	7.1
1977	3,074,100	75,151	24.4	19,895	6.5	1,507	20.1	10	13.3	1,007	13.4	34,541	16.9	12,085	5.9
1976	3,018,300	72,883	24.1	19,893	6.6	1,472	20.2	9	12.3	1,035	14.2	33,741	17.1	12,357	6.3
1975	2,938,800	69,691	23.7	19,073	6.5	1,455	20.9	11	15.8	1,047	15.0	32,731	17.2	12,905	6.8
1974	2,890,000	70,082	24.2	19,490	6.7	1,609	23.0	19	27.1	1,100	15.7	33,410	17.9	11,688	6.3
1973	2,872,300	68,821	24.0	19,257	6.7	1,667	24.2	9	13.1	1,158	16.8	34,221	18.5	12,593	6.8
1972	2,865,100	68,914	24.1	19,011	6.6	1,866	27.1	27	39.2	1,219	17.7	33,555	18.2	13,269	7.2
1971	2,779,300	71,117	25.6	18,144	6.5	1,957	27.5	20	28.1	1,280	18.0	32,069	18.4	10,770	6.2
1970	2,716,000	67,438	24.8	18,080	6.7	1,930	28.6	18	26.7	1,276	18.9	29,653	10.9	9,713	3.6
1969	2,706,000	67,577	25.0	17,669	6.5	2,005	29.7	24	35.5	1,367	20.2	29,741	11.0	9,509	3.5
1968	2,665,000	67,989	25.5	17,481	6.6	1,986	29.2	12	17.6	1,394	20.5	29,036	10.9	8,929	3.4
1967	2,634,000	70,755	26.9	16,780	6.4	2,317	32.7	26	36.7	1,673	23.6	26,406	10.0	7,728	2.9
1966	2,612,000	75,735	29.0	17,506	6.7	2,850	37.6	34	44.9	1,798	23.7	25,542	9.8	7,517	2.9
1965	2,583,000	79,586	30.8	17,719	6.9	3,421	43.0	40	50.3	2,072	26.0	25,184	9.7	8,035	3.1

1964	2,542,000	78,837	31.0	18,556	7.3	4,074	51.7	46	58.3	2,132	27.0	23,773	9.4	7,460	2.9
1963	2,491,000	77,382	31.1	17,386	7.0	3,467	44.8	42	54.3	2,186	28.2	23,465	9.4	6,309	2.5
1962	2,447,000	76,677	31.3	16,575	6.8	2,192	28.6	58	75.6	2,187	28.5	22,883	9.4	6,565	2.7
1961	2,402,000	75,563	31.5	16,361	6.8	3,193	42.3	44	58.2	2,202	29.1	21,440	8.9	5,697	2.4
1960	2,360,000	76,015	32.2	15,841	6.7	3,325	43.7	38	50.0	2,276	29.9	20,580	8.7	5,386	2.3
1959	2,322,000	74,933	32.3	15,870	6.8	3,602	48.1	67	89.4	2,407	32.1	20,133	8.7	5,423	2.3
1958	2,299,000	76,128	33.1	16,099	7.0	4,088	53.7	65	85.4	2,534	33.3	19,603	8.5	5,113	2.2
1957	2,260,000	76,068	33.7	16,022	7.1	3,829	50.3	75	98.6	2,917	38.3	19,044	8.4	5,031	2.2

* Población al 1^o de julio. 1/ Tasa por 1,000 habitantes. - Rates per 1,000 inhabitants. 2/ Tasas por 1,000 nacidos vivos. - Rates per 1,000 live births.

3/ Tasa por 100,000 nacidos vivos. - Rates per 100,000 live births.

Fuente: Departamento de Salud, SAPFESI, División de Estadísticas, San Juan, PR.

D2: Increased Survival Rate of Persons with Down Syndrome

This table was taken from Down Syndrome: Living and Learning in the Community edited by Lynn Nadel and Donna Rosenthal (1995:239).

Year	Survival rate
1944-55	60% dead before 10 years
1963	25% surviving to the age of 30 years
"	4% surviving to the age of 50-55 years
1970	71% alive at 30 years
	79% alive at 30 years (without heart disease)

D3: Population Spreadsheet

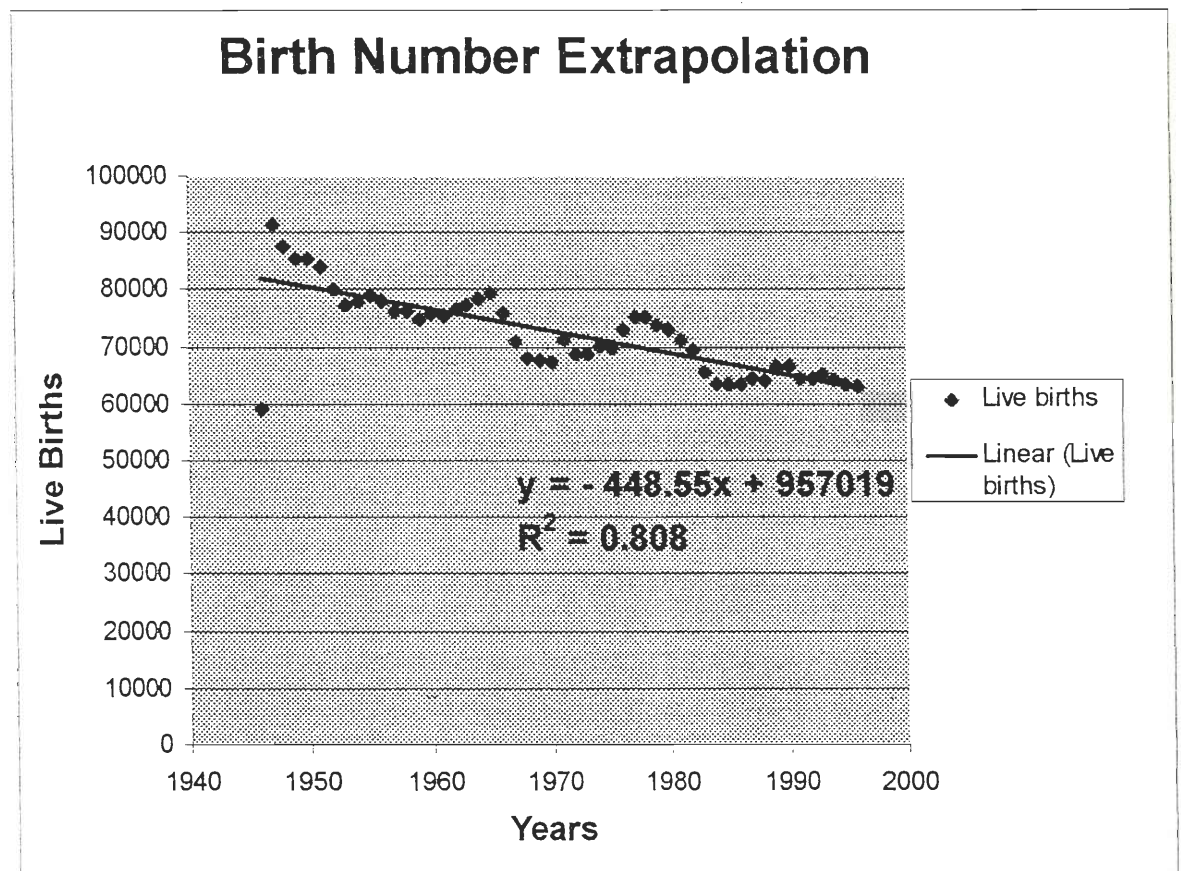
Total Down Syndrome Population Estimate								
Years	Live births	Percent Alive in the Year 2000	Birth Prevalence Rate Lower Bound	Down Individuals Alive in the Year 2000	Birth Prevalence Rate Mid-Range	Down Individuals Alive in the Year 2000	Birth Prevalence Rate Upper Bound	Down Individuals Alive in the Year 2000
1946	59149	0	1/870	0	1/751	0	1/592	0
1947	91496	0	1/870	0	1/751	0	1/592	0
1948	87746	0	1/870	0	1/751	0	1/592	0
1949	85638	0	1/870	0	1/751	0	1/592	0
1950	85455	0	1/870	0	1/751	0	1/592	0
1951	84007	0	1/870	0	1/751	0	1/592	0
1952	80200	0	1/870	0	1/751	0	1/592	0
1953	77380	0	1/870	0	1/751	0	1/592	0
1954	78008	0	1/870	0	1/751	0	1/592	0
1955	79221	0	1/870	0	1/751	0	1/592	0
1956	78177	0	1/870	0	1/751	0	1/592	0
1957	76068	0	1/870	0	1/751	0	1/592	0
1958	76128	0	1/870	0	1/751	0	1/592	0
1959	74933	0	1/870	0	1/751	0	1/592	0
1960	76015	0	1/870	0	1/751	0	1/592	0
1961	75563	6	1/870	5	1/751	6	1/592	7
1962	76677	13	1/870	12	1/751	13	1/592	17
1963	77382	20	1/870	18	1/751	21	1/592	27
1964	78370	28	1/870	25	1/751	29	1/592	37
1965	79586	35	1/870	32	1/751	37	1/592	47
1966	75735	42	1/870	37	1/751	43	1/592	54
1967	70755	50	1/870	40	1/751	47	1/592	59

1968	67989	57	1/870	44	1/751	51	1/592	65
1969	67577	64	1/870	50	1/751	58	1/592	73
1970	67438	71	1/870	55	1/751	64	1/592	81
1971	71117	72	1/870	59	1/751	69	1/592	87
1972	68914	73	1/870	58	1/751	67	1/592	85
1973	68821	74	1/870	59	1/751	68	1/592	86
1974	70082	75	1/870	61	1/751	70	1/592	89
1975	69691	76	1/870	61	1/751	71	1/592	90
1976	72883	77	1/870	65	1/751	75	1/592	95
1977	75151	78	1/870	68	1/751	78	1/592	99
1978	75066	79	1/870	68	1/751	79	1/592	100
1979	73781	80	1/870	68	1/751	79	1/592	100
1980	73060	81	1/870	68	1/751	79	1/592	100
1981	71365	82	1/870	67	1/751	78	1/592	99
1982	69336	83	1/870	66	1/751	77	1/592	97
1983	65742	84	1/870	63	1/751	73	1/592	93
1984	63321	85	1/870	62	1/751	72	1/592	91
1985	63629	86	1/870	63	1/751	73	1/592	92
1986	63551	87	1/870	63	1/751	73	1/592	93
1987	64393	88	1/870	65	1/751	75	1/592	95
1988	64081	89	1/870	65	1/751	76	1/592	96
1989	66692	90	1/870	69	1/751	80	1/592	101
1990	66555	91	1/870	69	1/751	80	1/592	102
1991	64516	92	1/870	68	1/751	79	1/592	100
1992	64481	92	1/870	69	1/751	79	1/592	101
1993	65242	93	1/870	70	1/751	81	1/592	103
1994	64325	94	1/870	70	1/751	81	1/592	103
1995	63518	95	1/870	70	1/751	81	1/592	102
1996	63259	96	1/870	70	1/751	81	1/592	103
1997	61265	97	1/870	68	1/751	79	1/592	101
1998	60816	98	1/870	69	1/751	80	1/592	101
1999	60368	99	1/870	69	1/751	80	1/592	101

2000	19973	100	1/870	23	1/751	27	1/592	34
			Total	2250	Total	2607	Total	3307

Birth to Three Years Down Syndrome Population Estimate								
Years	Live births	Percent Alive in the Year 2000	Birth Prevalence Rate Lower Bound	Down Individuals Alive in the Year 2000	Birth Prevalence Rate Mid-Range	Down Individuals Alive in the Year 2000	Birth Prevalence Rate Upper Bound	Down Individuals Alive in the Year 2000
1997	40843	97	1/870	46	1/751	53	1/592	67
1998	60816	98	1/870	69	1/751	80	1/592	101
1999	60368	99	1/870	69	1/751	80	1/592	101
2000	19973	100	1/870	23	1/751	27	1/592	34
			Total	206	Total	239	Total	303

D4: Graph of Extrapolation of Birth Numbers



Appendix E: Student's Probability t-Table Service

df/p	0.40	0.25	0.10	0.05	0.025	0.01	0.005	0.0005
1	0.324920	1.000000	3.077684	6.313752	12.70620	31.82052	63.65674	636.6192
2	0.288675	0.816497	1.885618	2.919986	4.30265	6.96456	9.92484	31.5991
3	0.276671	0.764892	1.637744	2.353363	3.18245	4.54070	5.84091	12.9240
4	0.270722	0.740697	1.533206	2.131847	2.77645	3.74695	4.60409	8.6103
5	0.267181	0.726687	1.475884	2.015048	2.57058	3.36493	4.03214	6.8688
6	0.264835	0.717558	1.439756	1.943180	2.44691	3.14267	3.70743	5.9588
7	0.263167	0.711142	1.414924	1.894579	2.36462	2.99795	3.49948	5.4079
8	0.261921	0.706387	1.396815	1.859548	2.30600	2.89646	3.35539	5.0413
9	0.260955	0.702722	1.383029	1.833113	2.26216	2.82144	3.24984	4.7809
10	0.260185	0.699812	1.372184	1.812461	2.22814	2.76377	3.16927	4.5869
11	0.259556	0.697445	1.363430	1.795885	2.20099	2.71808	3.10581	4.4370
12	0.259033	0.695483	1.356217	1.782288	2.17881	2.68100	3.05454	4.3178
13	0.258591	0.693829	1.350171	1.770933	2.16037	2.65031	3.01228	4.2208
14	0.258213	0.692417	1.345030	1.761310	2.14479	2.62449	2.97684	4.1405
15	0.257885	0.691197	1.340606	1.753050	2.13145	2.60248	2.94671	4.0728
16	0.257599	0.690132	1.336757	1.745884	2.11991	2.58349	2.92078	4.0150
17	0.257347	0.689195	1.333379	1.739607	2.10982	2.56693	2.89823	3.9651
18	0.257123	0.688364	1.330391	1.734064	2.10092	2.55238	2.87844	3.9216
19	0.256923	0.687621	1.327728	1.729133	2.09302	2.53948	2.86093	3.8834
20	0.256743	0.686954	1.325341	1.724718	2.08596	2.52798	2.84534	3.8495

21	0.256580	0.686352	1.323188	1.720743	2.07961	2.51765	2.83136	3.8193
22	0.256432	0.685805	1.321237	1.717144	2.07387	2.50832	2.81876	3.7921
23	0.256297	0.685306	1.319460	1.713872	2.06866	2.49987	2.80734	3.7676
24	0.256173	0.684850	1.317836	1.710882	2.06390	2.49216	2.79694	3.7454
25	0.256060	0.684430	1.316345	1.708141	2.05954	2.48511	2.78744	3.7251
26	0.255955	0.684043	1.314972	1.705618	2.05553	2.47863	2.77871	3.7066
27	0.255858	0.683685	1.313703	1.703288	2.05183	2.47266	2.77068	3.6896
28	0.255768	0.683353	1.312527	1.701131	2.04841	2.46714	2.76326	3.6739
29	0.255684	0.683044	1.311434	1.699127	2.04523	2.46202	2.75639	3.6594
30	0.255605	0.682756	1.310415	1.697261	2.04227	2.45726	2.75000	3.6460
inf	0.253347	0.674490	1.281552	1.644854	1.95996	2.32635	2.57583	3.2905

Glossary

Alpha-fetoprotein – an antigen produced in the fetal liver that can appear in certain diseases in adults, and whose level in amniotic fluid can be used to detect certain fetal abnormalities, including Down Syndrome

Amniocentesis – percutaneous transabdominal puncture of the uterus to obtain amniotic fluid

Amniotic fluid – the fluid within the amnion that surrounds the fetus and protects it from injury

Atrioventricular septal defect - a defect in the small part of the membranous septum of the heart just above the septal cusp of the tricuspid valve, separating the right atrium from the left atrium

Blepharitis – inflammation of the eyelids

Cerumen – the brownish yellow, waxy secretion from the ear

Chorion – the cellular, outermost extra-embryonic membrane

Chorionic villi – threadlike projections growing in tufts on the external surface of the chorion

Chorionic villus sampling (CVS) – a procedure using chorionic villi cells to determine if the fetus is a Down Syndrome case

Conjunctivitis – inflammation of the eyes, characterized by redness and often accompanied by discharge

Endocardial cushion defect - a defect in either of a pair of mounds of embryonic connective tissue covered by endothelium, which eventually grow together and divide the canal into right and left atria

Hypothyroidism – lower than normal production of chemicals by the thyroid gland, resulting in slowed metabolism, weight gain, and fatigue

Hypotonia – reduced tension or pressure in a part of the body. The term is used particularly to refer to low pressure in the eyeball or arteries, and reduced muscle tone. Hypotonia in babies is known as floppy infant syndrome, and has many causes.

Meiosis – a special method of cell division, occurring in maturation of sex cells, by means of which each daughter cell nucleus receives one half the number of chromosome characteristics of the somatic cells of the species

Sensorineural hearing impairment – hearing impairment caused by dysfunction of the neural elements involved in the conduction or interpretation of nerve impulses

Sleep apnea – temporary absence of breathing caused by upper airway obstruction during sleep, associated with frequent awakening and often with daytime sleepiness

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