# Involvement of Portuguese-Speaking Parents in the Education of Their Special-Needs Children

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#### Abstract

The purpose of this study was to investigate the involvement of Portuguese-speaking families in the education of their special-needs children. The qualitative methods of participant observation and ethnographic interviewing were used to explore the following research questions: How do these parents want to be involved in their children's education, and what are their feelings about parent involvement? Participants were parent(s) from each of nine families who were foreign born, Portuguese-speaking, and had at least one child in special education. Findings were analyzed within two major categories: (a) the special-needs children in their families, and (b) the families' experiences with their children's education.

The focus in this article concerns findings that emerged from data discussed under the following thematic statements: We have to ask for what we want and fight for our children, and lacking proficiency in English makes it more difficult for us to procure the services to which our children are entitled.

The experiences of parents of children with special needs are usually more difficult, extensive, and complex than those of parents of non-handicapped children. These problems can be further complicated if parents are non-English speaking, if English is a second language for them, or, in some cases, solely by the fact that they are recognized as belonging to an ethnic minority. The qualitative study on which this article is based was designed to explore the attitudes toward parent involvement in their children's education by a number of Portuguese-speaking parents of children with special needs. The focus of this article concerns the aspects of the findings that deal with the effect that issues of language and ethnicity seemed to have for these parents in their efforts to "deal with the system," and on suggestions the parents had for improving opportunities for parental involvement.

# Purpose

The purpose of this study was to understand Portuguese-speaking parents' actual involvement and their feelings about their involvement in the education of their special-needs children. Exploring the experiences of these parents from their own perspectives may provide educators with new insights into parent involvement in bilingual/special education settings. It can also allow non-Portuguese-speaking educators to enter the world of Portuguese-speaking parents, and, by extension, may highlight some of the difficulties limited English proficiency (LEP) parents may face. Several studies document the attitudes toward parent involvement of various ethnic groups, primarily Hispanic (e.g., Harry, 1992a) and Asian (Matsuda, 1994; Yao, 1993), but only a few of these studies explore the parents' experiences with involvement or inquire into their needs and wishes. More particularly, no studies have been located on the involvement of parents of Portuguese-speaking bilingual/special education students.

The importance of a greater understanding of the Portuguese-speaking population becomes evident when it is noted that, according to the 1990 census, Portuguese is the 10th most widely spoken minority language in the United States. Between 1980 and 1990, the number of people in the United States who were born in countries where European languages other than Spanish are spoken declined by 13.8%. During the same period, the number of people in this country who were born in Portugal and Brazil (countries where Portuguese is spoken) increased by 15.9%. This increase is due largely to greater numbers of Brazilians entering this country (Waggoner, 1993). Continuing immigration from Brazil should ensure that the numbers of Portuguese speakers in the United States will continue to increase. Margolis (1994,1997) points out that even at the most conservative estimate, there is probably an undercount of the Brazilian population in the various regions of the United States ranging from 33% to over 80%. Portuguese-speaking immigrants have thus become a largely invisible minority, and most appear to prefer that status (Margolis, 1994, 1997). However, that does not lessen the importance of the educational needs of these families.

My overall research questions were: (a) How do Portuguese-speaking parents of special-needs children want to be involved in their children's education? and (b) What are their expressed feelings about their involvement? It is consistent with qualitative research methods that the focus of the study may be further shaped in process by the emergent findings (Ely, Anzul, Friedman, Garner, & McCormack-Steinmetz, 1991). The parents appeared to feel that they could not adequately explain their attitudes toward parental involvement without describing the experience of being the parent of a handicapped child, and this became an additional focus for the study. The following subquestion then emerged as important: How do these participants describe their experience as bilingual parents of handicapped students in their relations with the school system?

## **Theoretical Framework**

The literature on parent involvement is quite extensive in general education, special education, and bilingual education. (Useful reviews of these studies are provided by Chavkin, 1993; Epstein, 1988; Graves & Gargiulo, 1993.) There is also a growing body of literature that deals specifically with parent involvement in bilingual/special education settings (Baca & Cervantes, 1998; Harry, 1992b). Although much has been written about the importance of parent involvement, a focus on how parents want to be involved is a fairly recent development. Nieto (2000) stresses this need and a few researchers have investigated it (Dauber & Epstein, 1993; De Leon, Ortiz, Sena, & Medina, 1996).

Nieto (1985, 1992, 2000) has consistently argued that schools need to change the way they look at parent involvement. She believes that in bilingual education, parent involvement programs may have actually discouraged parent participation. She suggests that the goal of parent involvement in bilingual education should be to educate and empower parents. Before parents can become involved, they must learn that they have the power to change the status quo. Ultimately, the schools must be "run by or with the community rather than for it" (1985, p. 187).

Perhaps the most comprehensive statement of what parent involvement may mean for LEP parents was made by Careaga (1988) in a study in which he stated, "for many parents of limited English proficient students, however, involvement may be hindered by language barriers, limited schooling, different cultural norms, or a lack of information" (pp. 1–2). In his opinion, the challenge to bilingual education is to set up parent involvement programs that overcome these obstacles; before these programs can be developed, educators must find out the needs of the community, which is done by finding out about these parents' lives and looking at their interests and concerns. Once these factors are understood, Careaga argues that educators would have taken the first step toward developing meaningful parent involvement programs.

Baca and Cervantes (1998), as a result of their work with LEP minority parents, emphasize the need to take into account the parents' language, culture, and attitudes toward handicapped children when developing and implementing a parent involvement program. Even though Public Law 94-142, now known as PL 101-476 (IDEA), mandates parent participation, there is evidence in the literature that participation by LEP parents of exceptional children is minimal. To the extent that this perception is generally accurate, lack of participation may be due to several factors. These include lack of knowledge by parents of their rights, as well as conflicts between the attitudes and perceptions of professionals and those of the parents about a wide range of topics dealing with special education. In addition, professionals often perceive

parental deference to them and preoccupation with such basic needs as feeding and clothing the child as apathy or lack of interest in education (Baca & Cervantes, 1998).

### Method

The qualitative methods of ethnographic interviewing and participant observation were seen as particularly appropriate to the purpose of the study. Through these methods researchers seek to understand the experiences of other people and the meanings they make of their experiences (Ely et al., 1991; Seidman, 1991).

## Selection of Setting and Participants

The focus in this study was on foreign-born LEP or bilingual, Portuguese-speaking families that had at least one child enrolled in a special education program. I selected a nearby urban area with a large Portuguese population as the setting. This is a long-established community where Portuguese speakers have been represented in the school system as students, teachers, and administrators for at least two generations. It also has a growing number of Brazilians.

I had already gained entry into the community through a pilot study. I had become acquainted with a Portuguese-speaking official at the central board of education who worked with bilingual programs. He gave me the names of special-education teachers and administrators who he thought could help me, as well as the name of a Portuguese friend with a special-needs child. I also received a few names from a teacher. I contacted these potential participants; others were obtained through "snowballing," as one participant suggested another (Seidman, 1991, p. 45). Some potential participants did not meet my criteria; others were not able to arrange time for interviews. For those who were able to participate and who met the criteria, permission forms were obtained and pseudonyms were assigned to protect confidentiality.

At least three interviews, approximately 90 minutes each (Seidman, 1991), were held with each participant. Interviews were held in the participants' homes or, in the case of two participants, in another location they selected as more convenient. The participants were given the choice of speaking in either Portuguese or English. Seven of the nine families chose to speak in Portuguese. All interviews were tape recorded and the tapes were transcribed and translated into English as needed. These transcripts then became part of my log.

In all cases, I visited the participants' homes, met all members of the families, and spent time observing, talking with, and/or playing with the special-needs children and their siblings, as appropriate. Although I had not deliberately sought participants whose children's disabilities were of a serious

nature, through the selection process described above, this turned out to be the case. I therefore considered it important to observe the children in their natural family settings as a supplement to the interview data. Detailed notes compiled after each observation and interview session became part of the ongoing log. Concurrent analysis of the gradually accumulating log data was used to help shape future interviews.

New participants were added until I attained a saturation of categories (Seidman, 1991) for analysis (i.e., no additional data yielding new categories or thematic material were being documented). In all, I interviewed nine families for use in this study. All were two-parent families, and there were siblings in all but one of the families. The interview participants were the mothers of the families in eight of the nine families. In one family, both mother and father were present for all interviews.

## Analysis of Data

All data collected in the log were analyzed inductively, moving from specific raw units of information, for which codes were established during initial analysis, to larger categories (Ely et al., 1991; Lincoln & Guba, 1985). The original categories were then reviewed, refined, and combined as necessary. A few examples of final categories include family attitudes toward having a special-needs child, daily care requirements, parents' relations with school personnel, and opportunities for involvement in child's school.

After all categories were established and raw data was grouped under category headings, I studied the data for thematic connections within and among them. Themes were defined as "a statement of meaning that (a) runs through all or most of the pertinent data, or (b) one in the minority that carries heavy emotional or factual impact" (Ely et al., 1991, p. 150). Following the steps outlined by Ely et al. (1991, pp. 150–152), a thematic analysis was undertaken of the final categories. Thematic statements were constructed that expressed the understandings and feelings of the participants, and the discussion of findings was organized according to these thematic elements.

# **Findings**

Analysis of the interview data yielded two major categories: (a) families and their children with special needs, and (b) families and the children's education. Because the focus of this article is on ways in which language and ethnicity seemed to affect the parents' efforts to deal with the educational establishment, the findings reported here are taken primarily from the second category and concludes with the parents' suggestions for improving opportunities for parental involvement. However, the efforts of all members of the families to meet the special needs of these children, and the parents' attitudes toward this aspect of their lives, is of particular relevance to parental involvement in these children's education and will be touched on here briefly.

## The Families and Their Children with Special Needs

One thematic statement that emerged from analysis of data on families and their children was, "My special-needs child requires a lot of extra help and attention." For example, one mother described how, beyond the care that most 3-year-olds require, she had to take her daughter, who has cerebral palsy, to her physical therapists at least twice a week. She not only had to learn from these therapists how to work with the child at home, but also how to perform such "simple" tasks as holding, carrying, and bathing her.

As these children grow older their needs may change, but they still usually require more care than other children. A father told me that he was the one who shaved his 15-year-old son who has Down's syndrome, and how he had to take him to school because he had refused to ride the school bus. This father also reported that he took his son "everywhere" with him, not only to expose him to a variety of experiences, but also for him to walk for exercise. In all cases, much time was devoted by family members including siblings to the physical care of the child and to whatever therapies were dictated by the nature of the child's disability. Meeting these daily needs and helping the children to become independent to the extent possible were seen by the parents as a large part of each child's educational program.

A second theme stated, "Involvement in the education of my child with special needs consumes far more time than involvement in the education of my other children." They pointed out that these children's schools had more meetings and that there were more parent conferences than in the schools of their non-handicapped children. However, although all the participants stated that involvement in the school is important, almost all of them expressed the opinion that the most important, as well as the most time-consuming involvement takes place at home.

## Parental Involvement in School

As I reviewed the data on involvement in school of these parents of LEP special-needs children, I was struck by just how "normal" this involvement was. From what they told me, most of these parents were taking advantage of the opportunities for involvement offered by the schools. A typical comment was offered by one of the mothers: "I'm involved in everything. I'm involved in the school. If they need anything done, I'm there. . . . Everyone knows me at the school."

## Another mother reported:

I try to go to all the conferences at Benito's school. I try to keep in touch with the teachers so that I know what is going on and what they are doing with him. The school has an open-door policy, and you can go in to visit any time you want. They have an art auction every year to raise money for the school. Everybody is involved in the

committees. They want everyone involved. They also have scouting there. They have a home-school association, which I am part of. They allow you to help in the classroom and with field trips. I try to help as much as I can. Sometimes it is hard because I work, but if it is after 2 in the afternoon, I can be there to help.

A limited knowledge of English was by no means an insurmountable obstacle to these parents' involvement. Even those participants with the most limited command of English seemed able to keep abreast of developments. Two mothers reported that when they went to meetings at their children's schools, they usually took another family member to act as an interpreter. Another mother said that although she did not attend many meetings at the school, she was in frequent telephone contact with her daughter's program coordinator.

Work schedules and transportation were hindrances to attending school meetings for some of the parents. Because of the severe nature of these students' disabilities, most of them were not placed in a neighborhood school. At the time of the interviews one father and one mother made a one-hour trip twice a day to take their children to and from school. Another mother only attended school meetings that were scheduled during the day because she felt the school neighborhood was unsafe at night.

When discussing their attitudes toward parent involvement, almost all of these participants mentioned that they liked to be involved and wanted to be involved in their children's education. One mother stated:

It is very important to be involved in your child's education, especially when you have a handicapped child. If we are not involved, they won't do anything. They will be passive and uninterested in the world and people around them. If all children, including handicapped children, had the support of both parents, they would do much better and they would achieve more. We as parents must be involved in all phases of our children's lives, whether they are handicapped or not.

Several of the participants expressed the view that by being involved in their children's education they were able to be better informed about what was being done for their children. As one mother said: "By participating in Quim's education, I found that I learned to understand what he was learning and why he was learning it."

Although participation in special-needs children's education can be very similar to that of a non-handicapped child, what seemed to be different was the intensity. One of the parents described it this way:

It is different because I am more dedicated to participating in Elia's education. I knew that my other children didn't need me the way she does. They were able to tell me if something was wrong at school. Elia is not able to do that. She tells me things that are happening, but

I never know if what she says is accurate. It is different also because she has therapy, and I have to help her with her therapy at home.

Several of the parents reported that as soon as they had recovered from the initial shock of learning that their child had special needs, the first thing they did was to learn all they could about the child's disabilities by conferring with physicians, special education specialists, social workers, and therapists. All of these families emphasized their realization that they have specific rights and responsibilities and it was incumbent for them to learn all they could so that their children would receive an appropriate education and the services to which they were entitled.

All of the parents "went to bat" for their child at some time or another. In general, they had to become increasingly aware of the range of services available to them and their children. However, they spoke with some annoyance and resentment of the extent to which they had to fight for what they thought was due their children. The realization of the severity of their child's condition was a beginning step in their transformation toward becoming an advocate and being more actively involved in the child's education.

## Portuguese-Speaking Parents in an Urban School District

Issues around the experiences of these LEP parents in an urban school district were discussed under the theme, "We have to ask for what we want and fight for our children. Lacking proficiency in English makes it more difficult for us to understand the school system and learn how to procure the services to which our children are entitled."

Most of the children in the study were born here, but three of the families had come from Portugal to the United States, especially because they perceived that the educational system here would offer advantages not available to them in Portugal. Although they reported that they did indeed find the educational opportunities they were looking for, it was also their impression that in Portugal the services would have come to them automatically, whereas, here they had to learn how to be advocates for their children and to cope with "the system."

Three participants specifically addressed language and ethnicity as barriers to obtaining services for their special-needs children. One mother, whose daughter has spina bifida, commented that she did not think that the schools in the Portuguese community where she lived were as good as the schools in a neighboring town where she had lived earlier and in which the population was "largely American." She believed that there was a general lack of interest in the Portuguese community on the part of the board of education and a lack of cooperation between the board and the community:

The Portuguese people are not well represented here. We need an advocate for us because the parents complain and the board doesn't

do anything. The Portuguese parents have to learn to be advocates for themselves, too, so that they can help each other.

The father whose son has Down's syndrome reported that when he went on one occasion to the administrative offices in his district, "There wasn't anyone there who speaks Portuguese and who could help us." He went on to say:

When the board of ed[ucation] says that the parents are welcome to go and talk to them about any problem that we have, it is just to say that they are doing something when, in fact, they don't do anything. It is just a formality. I found that it was a waste of my time to go to the board.

He recounted that he had had a problem with his son and had gone to talk to his son's case manager, and he felt that they did not listen to what he had to say. He said that this experience was so frustrating that he would probably not bother to go the next time he was called for a meeting.

One of the parent participants, whom I have called Mrs. Tavares, also worked in the school system in this city. She spoke not only about her experiences as a parent of a special-needs child, but also about her observations of how the professionals dealt with the Portuguese parents. She did not think that the Portuguese parents in general were knowledgeable about their rights, especially when it came to obtaining services for their special-needs children. She went on to say that most of these parents still had the "old-world Portuguese mentality" that the schools knew best and would do whatever was necessary for their children. Consistent with her dual roles as parent of a special-needs child and special education specialist, Mrs. Tayares expressed many of the attitudes of both the parents whom I interviewed and the professionals I encountered while designing the study. She felt that many Portuguese parents were not knowledgeable about their rights and that an advocate might help them become more so. She said she understood the pressures that kept many of the Portuguese parents from being involved, and at the same time she criticized them for not making their children's education a higher priority.

The school personnel I met perceived themselves as reaching out to parents. They believed that parents should be more assertive in seeking out the help that the children need. It seemed possible to me that the conflicting attitudes of parents and school personnel might, to some extent, constitute an impasse for cultural reasons. As we have noted, some of the Portuguese parents in the study claimed to be accustomed to government agencies taking greater initiative and being more directive. Most of the parents in this study, however, stated that it was necessary for them to keep after the professionals "all the time" in order to get the information they needed about their children's education. And even Mrs. Tavares stated that were she not an insider, she would get the same "run-around" from the professionals as "all the other parents."

Interestingly enough, the parent participants who I interviewed also saw parents in the Portuguese community, in general, as not being sufficiently involved. They felt that they were the exceptions. It is possible that the severity of the needs of their children stimulated them to pursue a greater degree of involvement than the "typical" Portuguese parents of children who were in special education but had less severe problems.

## What Schools Can Do to Facilitate Involvement

When asked what could be done to increase parental involvement in their children's education, these participants responded with a variety of suggestions. The most common of these was for establishing some place, either a support group in the schools or a separate center where the parents could get together with other parents and their children. Some of the participants suggested that the parents themselves should have a strong voice in the running of such groups and that the groups would offer not only the opportunity for parents and children to get to know one another, but also such diverse services as English as a second language classes, parenting workshops, discussion groups, and a sibling support group. Mrs. Tavares touched on several points mentioned by other parents:

Another thing would be to have more things locally for parents. Have them available so that the parents are able to attend conferences and attend meetings in different neighborhoods so that they can pick where they want to go. Another thing that we could have is a speaker in the parents' native language. We don't have that, so a lot of Portuguese parents don't go anywhere because they are not bilingual. If it is not offered in Portuguese, they don't go. Also, there are not many professionals who are bilingual. We should have more professionals who are bilingual.

Several of the parents said that the schools should make more of an effort to reach out to the Portuguese-speaking parents, especially to teach them what parental involvement is and that in this country it is considered important for them to be involved in their children's education. A complete list of participant suggestions is included as part of the discussion on implications for practice in the following section.

## Discussion and Implications for Practice

All of the parents in this study were of the opinion that the special education services their children received in this country were superior to those that would be available to them in Portugal or Brazil. This was true for both of the parents whose children were born here and of those who came here for the sake of their children with special needs. The parents who had come here from Portugal felt that although services were better here they were

easier to obtain there. They noted that in Portugal when one had a handicapped child the services seemed to flow to that child almost automatically. All of the parents reported that dealing with the special education system in this country was quite a struggle for them. Unlike the parents described by Carrasquilo (1990), most of these parents seemed quite well informed about the educational system, their rights, and the services available to their children. They stated, however, that it was necessary to keep after the professionals all the time to get the information they needed about their children's education. This is consistent with Harry's (1992b) finding that parents who are from a different cultural and linguistic background are at a disadvantage when dealing with the educational system.

In light of the above findings, it is hardly surprising that the parents in this study who were the least proficient in English were the ones who had the least knowledge of the educational system or of their rights. Two of these parents reported that when dealing with the special education system they had to be accompanied by someone who spoke English fluently and was more familiar with the workings of "the system."

Findings regarding the parents' attitudes about the opportunities for involvement offered by their children's schools were summed up by the thematic statement: "The schools do a lot to support and involve the parents of special-needs children, but we have ideas about how they could do even better." Their suggestions are echoed in some of the more recent bilingual and special-education literature (e.g., Coelho, 1994; Correa, 1989; Harry, 1992c; Violand-Sanchez, 1991) and are summarized below:

- 1. All schools should have parent support groups. These were available in the schools of some but not all of the families studied.
- All schools should have centers that offer a wide range of activities not only for parents but also for the special-needs children and their siblings.
  Some of the participants reported such centers now existing in their children's schools.
- 3. Classes should be offered in parent education or parenting skills. One parent reported that parenting skills were sometimes offered as part of the early-intervention program in which her son was enrolled.
- 4. Child care should be provided so that parents could attend meetings. Such care was available for the children and siblings at the school attended by one of the children.
- 5. Meetings should be scheduled at times convenient for working parents and transportation provided for those who need it. The school of two of the families studied here did have meetings both during the day and again in the evening.

6. Bilingual interpreters, translators, and liaisons should be trained from the community and made available to those who need them. Although some of the schools in the community did have staff members available who could translate, there were none in those schools that served only special-needs children.

Findings in the present study were limited to the stories of nine families. In my experience as an educator and parent advocate, however, and from my reading of the literature, these findings may well hold true in other bilingual communities and for other parents of special-needs children of other ethnic minorities. Implications for practice are discussed under two broad metathemes: "What these children can do is immensely more important than what they cannot do," and "Parents of such children need to be viewed as very rich resources." The first of these metathemes is outside the scope of this article. I have, however, appended a footnote regarding an unanticipated finding relating to the children's abilities as bilingual speakers.

Findings under the second metatheme, "parents as rich resources," indicated that not only did the parents in this study have a great deal of knowledge about their own children, but, as speakers of another language and members of another culture, they had a great deal of knowledge about their own culture in addition to the skills of their various professions and occupations. From what the parents related both directly and indirectly, it appeared very often that special education personnel did not consider the parents as important resources in their children's education. On the contrary, at times educators and administrators seemed to have an almost adversarial relationship with the parents. For a long time other researchers (e.g., Alexander, 1982) have realized that professionals usually regard parents of special-needs children as lacking information rather than as rich sources of information.

One parent, who had been a nurse in Portugal, was keenly aware of the importance of hygiene for her own special-needs child. When she offered to talk about hygiene at her child's school, she was immediately turned down. She said that she did not know exactly why this was so, but felt that her limited English skills may have been the reason. Society in general, and we as educators in particular, must learn to pay more than lip service to the idea of valuing the talents and contributions of immigrants.

There appears to be a widely held belief among teachers that many parents, especially minorities, immigrants, and those of low socioeconomic status are not interested in participating in their children's education (Chavkin, 1989). However, studies exist that indicate that these parents are interested in and want to be actively involved in their children's education (Chavkin, 1989; Williams, 1991). The present study supports such prior research and presents a group of parents who are not only already highly involved but also have suggestions for further and more effective involvement.

Ideas for developing programs for parent involvement should not only be initiated by schools but also solicited from parents. Parents need to feel that what they say is valuable and deserves to be taken into consideration. Beyond this, parents need to see some of their suggestions put into practice and to help assess these as part of a professional dialogue. This study confirms Nieto's (1992) contention that we need to ask parents what they want and listen well to the answers.

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## **Endnotes**

<sup>1</sup> A particularly relevant topic is language use within the families. Parents were evaluated along a continuum of fluency in English. An unanticipated finding was expressed by the theme, "The learning problems of these children have not prevented them from learning a second language." I documented that, to the extent that each special-needs child was able to speak at all, he or she appeared to be equally fluent in both English and Portuguese.

<sup>2</sup>It is interesting to note here that in some of these families the children who seemed to be most proficient in speaking both languages and who had the greatest interest in the Portuguese language and culture were the children with special needs. One of the mothers remarked that her non-handicapped children understood Portuguese but did not speak it because they preferred to speak in English. It seemed to me that this interest on the part of the special-needs child might be due to the close ties that some researchers have noted between mothers and their special-needs children (Hardman, Drew, Egan, & Wolf, 1993). The parents reported that they took these children with them "everywhere," while their non-handicapped children might be more involved in their peer culture. The 3-year-old girl with cerebral palsy could already speak both Portuguese and English and knew that she spoke Portuguese at home and English at school. At the same time, her non-handicapped siblings were just starting to learn English.