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ABSTRACT
                This study investigated leadership development among
immigrant Latino parents of children with disabilities. Nineteen members of
grassroots organizations in the Chicago area participated in the study.
Naturalistic inquiry was used as the research approach that included a
combination of inductive and deductive analysis. The inductive analysis
revealed that parents' conceptualization of community leadership was about
doing things for each other and also served as a means to address unmet
needs. The deductive analysis showed that connections with other parents,
balancing personal and community interests, being an immigrant, and
empowerment were the elements most frequently identified as key to their
leadership development. The findings highlight the need among Latino parents
of children with disabilities to be more informed about the culturally
appropriate services, how to access these services, and strategies for
navigating service systems for immigrants who do not speak English. The
findings expand scientific knowledge about community leadership in its
application to a new population in that personal, communal, ideological, and
spiritual connections between people are the essence of the leadership
process among ordinary citizens. Personality, formal training, and management
skills are not the only skills necessary for community leadership
development, particularly with disadvantaged groups. (Contains 54
references.) (Author/JDM)

AN ANALYSIS OF LEADERSHIP DEVELOPMENT AMONG

IMMIGRANT LATINO PARENTS OF CHILDREN WITH DISABILITIES

BY

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THESIS

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2

SUMMARY

The present study was a qualitative investigation of leadership development among immigrant Latino parents of children with disabilities. Participants were 19 members of two grassroots organizations in the Chicago land area. The research approach used was naturalistic inquiry (Lincoln & Guba, 1985), which included a combination of inductive and deductive analysis. The inductive part of the analysis revealed that the parents' conceptualization of community leadership was about doing things for each other, such as helping and acquiring/sharing information/knowledge. Inductive analysis also indicated that the parents became involved in community organizations as a means to address unmet needs, their own and those of other parents like them. The more active parents presented more community oriented reasons for becoming involved in community organizations, which can be succinctly described as an awareness of the community's needs and concerns, and a desire to work collectively to address them. The less active parents offered more individualistic reasons for becoming involved in community organizations, such as acquiring support and assistance for themselves and/or their children. The deductive part of the analysis showed that connections with other parents, balancing personal and community interests, being an immigrant, and empowerment were the elements most frequently identified by the parents as key to their leadership development. Self-efficacy was not among the most frequently identified factors. Despite its low frequency, a discussion of self-efficacy is included because it was initially proposed as an exploratory factor relevant to the parents' leadership development. In addition, differences in critical consciousness between the more active and less active parents were noted and discussed. The findings from this study highlight the need, among immigrant Latino parents of children with disabilities, for information/knowledge and culturally appropriate services.

I. INTRODUCTION

A.   Background

Leaders (religious, political, military, corporate, or communal) have always existed and fascinated those who follow them. They have been the subject of many studies, and in some cases, the impact of their work has earned them a place in history (e.g., Cesar Chavez, Mahatma Gandhi, Martin Luther King, Jr.). Leadership has been a widely studied topic, particularly in the organizational literature, but only recently have researchers focused on *community* leadership. Early studies of leadership concentrated on corporate leadership, with emphasis on systems of rewards and punishments, and control and scrutiny rather than innovation, individual character, and the courage of convictions (Johnson & Johnson, 1997). Very little is known about the process through which ordinary citizens evolve into community leaders, particularly about what motivates or inspires people of disempowered groups to challenge the very institutions that marginalize and oppress them.

The purpose of this study was to understand leadership development from the perspective of a group of immigrant Latino parents of children with disabilities. The emphasis was on learning about how people with limited resources (i.e., low socioeconomic status, language and other cultural barriers) manage to surpass these obstacles in their struggle for social justice and equality. Because the leadership development of this particular population has not been previously examined, this study is exploratory in nature. Nonetheless, much was learned from the growing literature on community leadership to inform and guide the present study.

1

B.   Community Leadership

Past research has identified various factors as important in the development of community leadership. In a study on the development of leaders in citizen organizations, Kieffer (1984) characterized the participants in his study as individuals who acknowledged their personal transformation from being powerless to becoming socio-politically empowered, made a transition into proactive and multi-issue involvement, and showed continued commitment to local political processes or grassroots leadership roles. Thus, Kieffer (1984) called our attention to the meaning of sense of empowerment in the development of community leadership.

If the participants in Kieffer's (1984) study expressed their sense of empowerment by becoming involved in grassroots efforts, we may infer that leaders believe that social change is possible through organization and action (Freire, 1973). According to Glidewell et al., (1998), "to make change you must feel and believe that that reformation is possible" (p. 82). Therefore, perceiving change as possible seems essential to the leaders' organizing to take actions toward social change. Consequently, leaders are agents of social change. Community leaders are often referred to as agents of social change not only because they are usually the ones who initiate the community's organization, but also because they encourage others to become involved in the process of social change (Balcazar, Keys, Kaplan, & Suarez-Balcazar, in press; Balcazar, Keys, & Suarez-Balcazar, in press; Hernandez, 1998). Glidewell et al., (1998) maintained that among the tasks of a good leader is to find ways to get others to feel and believe that social change is possible. Thus, self-confidence in your ability to effect social change, and your ability to build

this confidence in others, plays an important role in community leadership (Clark, 1994; Lesmeister, 1996).

Another important factor in the development of community leadership is the leaders' ability to balance the competing demands of the family and the community. Although it is true that community leaders usually integrate self interests with broader community concerns, it is necessary to recognize that leadership is taxing (Clark, 1994; Kelly, 1992). Leadership requires the willingness and time to voluntarily work in the service of others, usually from a marginal position that lacks resources (Hernandez, 1998; Selsky & Smith, 1994). In fact, Hernandez (1998) affirmed that one of the major problems in the development of community leadership is the scarcity of people who are "willing and able to pay the personal price of being a leader" (p. 276). Kelly (1992) maintained that without determination, a sense of community, a vision, and a spiritual basis for their lives, the challenge of attending to personal and altruistic interests could make leaders feel fragmented.

It is precisely this last element that other authors argue is missing from the traditional studies of leadership—"soul." Some authors consider "soul" to be essential to leadership because it represents the "deeper and more enduring elements of courage, spirit, and hope" (p. 5, Bolman & Deal, 1994). These elements are important when people address problems in their families, communities, and society. One of the participants in the work reported by Glidewell et al. (1998) stated it very simply and candidly: "Leaders may not see the vision / They feel it / They feel something / That's it. It's inside you" (p. 77). Perhaps this is where the unique

value of community leadership lies. Community leadership is beyond the tangible gains people stand to make, it is more about the spiritual connection of people for a collective sense of integrity. It is the hope to change their oppressive conditions that serves as inspiration to bring about social change for themselves.

According to Kelly (1992), community leadership entails an effort to forge personal, communal, ideological, and spiritual links that unite people and organizations. These interrelationships take place in diverse settings, as people seek to address concerns and accomplish their goals (Clark, 1994; Hernandez, 1998). The functions of leadership are to motivate, capacitate, coordinate, and guide a collection of people (Glidewell et al., 1998). Advocacy skills, as well as interpersonal and organizational skills, have been noted as being associated with community leadership (Depp, 1993; Tandon et al., in press). Rather than viewing leadership as the individual accomplishments of a particular person, Kelly (in press) identified community leadership as a collective process that engaged different people in different contexts, and with varied skills. Agreeing with this notion of leadership, other authors have commented on the amazing results brought about by groups of people who work collaboratively, albeit lacking resources and power (Clark, 1994). Similarly, Kieffer (1984) maintained that there are people who emerge as leaders in community settings, regardless of the socially and economically oppressive conditions in which they live.

C.   Leadership Development Through Community Involvement

Citizen involvement in community issues is considered an important connection to community leadership (Tandon, Azelton, & Kelly, in press). Cruze (1988) proposed that if leaders are cognizant of the community's concerns, then it is possible for citizens to organize around certain causes. Hernandez (1998) added that through training and organization "grassroots groups … initiate the emergence of community leadership" (p. 270). We can infer from these two sources that their conception of community leadership entails knowledge of community issues and taking action to address these issues. This seems to imply that community leaders are people who are aware of the relationship between their individual needs and the larger social, political, and economic concerns. Community leaders might also be those who persist in their organizing efforts, even when their most immediate individual needs are not met—persons who Hernandez (1998) called "individuals interested in [social] change" (p. 277).

Leadership development among the poor and underserved is cultivated by community organizing, as organizing efforts within these communities has been increasing in response to social and health concerns (Chavis, 1995). Organizing at the grassroots level is a step in the direction of social change. As Alinsky (1971) wrote, people must organize in order to take action: organizing yields power, and power produces change. Some parents of children with disabilities have turned to their own inner strengths and collective efforts to address their families' needs and compensate for the lack of services for their children, poor relationships with service providers, and the system's general failure to address their needs (Grosser & Vine, 1991; Zirpoli, Wieck, & McBride, 1989). Advocacy on behalf of children with disabilities is a pressing

need, otherwise, the quality of their lives will be at risk (Miles, 1996; Zirpoli et al., 1989). Writing about empowerment and the self-advocacy movement, Miller and Keys (1996) asserted that "...collaborative relationships ... between self-advocates...allows them to accomplish what no one individual could achieve on his or her own" (p. 316).

Among the disadvantaged communities that are initiating organizing and advocacy efforts are immigrant families of children with disabilities. These families face the stressors of cultural adjustment (i.e., new language, unfamiliar service systems, and intimidating institutions), as well as those of caring for the special needs of their child (Lequerica, 1993). Therefore, they require services that can be tailored to their particular situation, and service providers who are willing to and capable of providing special understanding (Lequerica, 1993). Zea et al. (1997) maintained that the "understanding of culture and the role it plays in adjustment to disability and rehabilitation is essential to providing appropriate services for Latinos with disabilities" (p. 233). Unfortunately, appropriate services for immigrant families of children with disabilities are more the exception than the rule (Kearse Brookins, 1993; Gutierrez & Ortega, 1991; Heller, Markwardt, Rowitz, & Farber, 1994; Lequerica, 1993; Shapiro & Simonsen, 1994; Zuniga, 1992). Recognizing this reality, the parents of these children are now following in the steps of their mainstream counterparts by organizing to address their needs, and advocating for their rights. Because people of color have only recently begun to organize around these issues, the literature provides virtually no information on this phenomenon as it pertains to this particular population. For this reason, the discussion of parental community participation and organization is based on what has been reported about mainstream parents of children with disabilities.

Before discussing community organizations and parental organizing, it is important to highlight that although the literature refers to "parents" as advocates, it also acknowledges the leading role of women as the main participants in organizing and advocating for their children. A couple of explanations have been offered for this phenomenon. Throughout his writing, Mlawer (1993) purposely refrained from using the male pronoun. He explained that because women are still primarily responsible for child rearing, they are the ones who are expected to become parent advocates. Probably the most prominent explanation for maternal involvement in advocacy for children with disabilities is the fact that many women are abandoned by their husbands upon the birth of a child with a disability or the diagnosis of a disability of one of their children (Miles, 1996). This is an extremely difficult position for women to be in, and being an immigrant woman with a child with a disability may add additional strain to this situation. Due to their deprivation, these women may be in desperate need of emotional, social, and economic support. Yet their efforts to meet the more immediate survival needs of their families may keep them from reaching out to parent groups or organizations.

Mlawer (1993) recognized that parents of children with disabilities have different priorities, when he argued that their lack of interest to become advocates does not mean that they are ignorant, unfit as parents, or not concerned. On the contrary, he asserted that parents have other concerns that take priority over advocacy (e.g., survival needs), and that until these basic needs are met, it is difficult for parents to focus on advocacy activities for their children with disabilities. Further, Mlawer (1993) maintained that this is particularly true for those parents who live in or near poverty. Because of the lack of money, poor parents do not have easy access to

transportation and child care, hindering their involvement in advocacy activities. Kieffer (1984) wrote that "...survival is, in itself, a full-time occupation. As such, engagement in citizen action is inescapably an additional burden—particularly for those whose incomes are already so very low" (p. 17). If self-advocacy adds impossible burdens to one's life, then it is difficult to perceive advocacy as something that is beneficial (Mlawer, 1993). Furthermore, Kieffer (1984) contended that political and economic resources are inextricably related. Therefore, lower-income citizens may refrain from community activities that may challenge established economic interests. In the case of undocumented immigrant Latinos, attracting attention is a daily preoccupation, as the mere act of requesting services may place them at risk for deportation (Zuniga, 1992). Consequently, these families may perceive community activism more as a threat to what little stability they have acquired by immigrating, than as a promise for a better quality of life for their children with disabilities. Fear of risking the limited opportunities they have found in this country possibly prevents immigrant Latino parents of children with disabilities from becoming more actively involved in advocacy efforts.

Some studies document the very low levels of minorities' and the poor's participation in civic enterprises (Cruze, 1988). Within racial minorities, there is also lower involvement of parents of children with disabilities in their children's education, when compared to other parents (Westling, 1997). Furthermore, the dramatic need for support groups for Latino parents of children with special needs has been noted, as well as the "paucity of Spanish-language support groups for Latino families" (Zuniga, 1992). Through community organizing people develop a sense of self-efficacy and acquire power to effect social change. If parents of color have not had

opportunities to participate in community organizing, they have in turn not had a chance to realize their capacity to exercise greater control over their personal situations and their communities.

Pizzo (1983) identified three ways in which parents' organization of and participation in mutual support groups helps them acquire more control over personal and community concerns: (1) the establishment of new communities, (2) the end of personal isolation, and (3) the creation of a new belief in themselves. Self-help groups are like new communities, and within these communities the parents can collectively develop effective solutions for common concerns. This is especially important for parents of children with disabilities, as the issues they face might be too novel for them to rely solely on their primary support network of family, friends, and even professionals, who may not have all the answers or fully appreciate their present dilemmas. This rationale is particularly applicable to immigrant parents. When people immigrate, they leave behind their families and established network of friends, diminishing the sources of support available to them, and making it more likely for them to become isolated. Moreover, immigrant parents usually have limited access (if any) to information about their rights as residents in this country, much less about the services and benefits to which they are entitled as parents of a child with a disability. The relevance of this argument is even greater for families of undocumented immigrant status. Undocumented immigrants may be reluctant to seek services and other resources for fear of deportation, or because they believe that given their legal status they are not entitled to any services (Zuniga, 1992).

Lack of knowledge about their rights, and possible language barriers, may lead immigrant families to withdraw from or even reject services (Lequerica, 1993). Consequently, these parents run the risk of becoming isolated. Fortunately, as Pizzo (1983) and Shapiro and Simonsen (1994) proposed, parental organizing can also help end this isolation. Rosenberg (1984) maintained that participation in a support group is stimulated by a sense of marginalization, as people with similar stressors and stigmatization experiences seek to reaffirm and strengthen themselves. Shapiro and Simonsen (1994) found that isolation and alienation were lessened when Latino families met each other in support groups. Similarly, a study by Gutierrez and Ortega (1991) revealed that through the establishment of contact with other group members and the sharing of their experiences with each other, Latinos in group settings find mutual support, acceptance, and understanding. Parental organizing may be critical for Latino parents of children with disabilities, whose immigration and acculturation pressures may be aggravated when having to care for the special needs of their children. Forming groups with others of similar backgrounds provides the opportunity to identify common experiences, and as Pizzo (1983) argued, "[Group settings] are also places where parents, in concert with one another, create a new belief in themselves" (p. 82). Through collective efforts, parents of children with disabilities become more confident in their ability to address shared concerns more effectively.

Kieffer (1984) commented on participation in grassroots organizations:

> Rather than serving mainly to increase emotional support,
> [participation in grassroots organizations] strives to articulate the
> embeddedness of individual conflicts in a more explicitly political

frame of reference. As such, engagement in an organization helps to

recast both consciousness and capacity in social and political, rather

than simply personal and emotional terms (p. 21).

In other words, through their involvement in community organizations, people come to realize

that their experiences are not just a unique, individual circumstance, but also a societal, political

situation (Gutierrez & Ortega, 1991). Freire (1973) acknowledged this by commenting that he

"was convinced that the Brazilian people could learn social and political responsibility only by

experiencing that responsibility, through intervention in the destiny of their children's

schools..." (his italics, p. 36). It is when people realize that their concerns are not removed from

those of society in general that they develop their ability to effect social change (Selener, 1997).

Mlawer (1993) posited that quality community organizing can result in the acquisition of power,

representing the true political empowerment of parents. According to Alinsky (1971), power is

essential to the process of change because "No one can negotiate without the power to compel

negotiation" (p. 119).

In sum, the literature presented thus far suggests that community organizing is essentially

important for Latino parents of children with disabilities. Through participation in organizations

parents can develop a sense of collectivity and self-efficacy. From their confidence, and their

collective effort, people can draw the power to bring about change in their lives. Nonetheless,

there are many potential barriers to community involvement for people from disadvantaged

groups. People of color have unequal access to resources and power, and this situation is worse

for people of color with disabilities. However, through collaborative efforts they may take action

to change their living conditions. The perception that change is possible appears to be an important link between community participation and community leadership. Participation in community organizations transforms people's social and political consciousness and capacity, probably because community organizations provide opportunities for people to take action toward change, and in the process develop a sense of self-efficacy and empowerment.

In the present study, self-efficacy and empowerment are exploratory elements proposed as key to the parent's perception of social reform as a possibility. These factors should be especially salient among leaders, as not only must they feel and believe that change is possible, but they must also influence others to share this believe. The belief in reform is part of the collective, collaborative process of leadership. It is an ideological and spiritual connection between people, and a way of building the capacity of groups and organizations.

Self-efficacy is a consequence of life experiences, from which we learn that through our actions we can have an effect on the environment and on events in our lives (Bandura, 1995; 1997). Despite the dearth of research in self-efficacy related to leadership, there are authors who argue that without a strong sense of self-efficacy a person may assume that s/he cannot do anything to make a difference, making it improbable that s/he will willingly take on a leadership role (Sashkin, 1992). Self-efficacy refers to people's beliefs, judgments, and expectations about their abilities, which in turn determine the initiation and persistence of behaviors and actions (Depp, 1993; Maddux, 1995). These beliefs, judgements and expectations are formed through performance accomplishments, vicarious experiences, verbal persuasion, and physical states

(e.g., stress, stamina, mood; Bandura, 1995; Depp, 1993). Self-efficacy is domain specific, which means that it is relative to the behaviors in specific situations or contexts (Depp, 1993; Maddux, 1995). A person's beliefs about their capabilities will determine how they think, feel, behave, and motivate themselves (Depp, 1993; Bandura, 1995). Self-efficacy influences people's goal setting, commitment to the pursuit of their goals, and persistence when facing setbacks (Bandura, 1995; Maddux, 1995). Consequently, people become part of activities and environments because they perceive themselves to be self-efficacious in those domains (Bandura, 1995; Depp, 1993).

Bandura (1995) has posited that in communities in which people live in impoverished conditions, parents' beliefs that they can influence the course of their children's lives are a greater contributor to the beneficial guidance of their children than those of parents who live in advantaged conditions. This occurs because, due to poor external resources, the disadvantaged must constantly rely on their internal resources. Further, Bandura (1995) maintained that under detrimental circumstances, families and populations of color are more self-efficacious because they believe that they can change things for the better. It is this possibility of bringing about change that makes families with efficacious perspectives more satisfied and attached to their communities.

Moreover, he argued that group accomplishments and social change stem from self-efficacy, because those who have a low sense of self-efficacy feel powerless to alter policies and practices at any level (Bandura, 1995). This argument highlights the importance of self-

efficacy as it relates to social action, and the need to enhance the self-efficacy of marginalized groups. Bandura (1995) maintained that this need for collective efficacious efforts increases with the rise in perceived collective powerlessness. Yet, he reminded us that the disproportionate distribution of power is perpetuated if people do not demand and exercise control over the resources and conditions that affect their lives (Bandura, 1995). Furthermore, Bandura (1995) indicated that people who have a sense of collective efficacy engage in efforts and utilize resources to deal with external obstacles to the changes they seek. Thus, it seems that empowerment (taking actions to bring about change) is rooted in self-efficacy.

When reviewing the factors that contribute to community empowerment, Kieffer (1984) concluded that the transition from perceiving oneself as a helpless victim to accepting oneself as an assertive and efficacious citizen is a key empowering transformation. Empowerment can be defined as the ongoing process of gaining personal, interpersonal, or political power so that individuals, families, and communities can take action to increase their access and control over valued resources, and improve their quality of life (Fawcett et al., 1994; Gutierrez, 1995; Rappaport, 1981; Singh et al., 1995). Empowerment is not granted, it is attained through conscientization, democratizing, solidarity, and leadership (Selener, 1997). Empowerment is an autonomous, transforming process, built through actions for structural social and political change (Kieffer, 1984; Selener, 1997). People's empowerment is an outcome of the direct interaction between individuals and their environment (Fawcett et al., 1994; Kieffer, 1984).

Like self-efficacy, empowerment is context specific, indicating that the extent to which people have control over relevant aspects of their lives changes according to the environment and other situational characteristics. For example, Daly Pizzo (1993) defined parent empowerment as obtaining and using resources needed to nurture and protect children, such as "adequate income, goods and services, a supportive network of other adults, time, legal authority, and personal skills and attributes" (p. 9). Through participation in community organizations, parents are likely to gain power and resources to reach their goals (Maton & Salem, 1995). Empowerment is believed to aid in the development of citizens to become leaders in community organizations and become agents of social change (Tandon et al., in press).

If we apply Bandura's (1995) position to the present study (group attainments and social change are rooted in self-efficacy), then we may infer that for immigrant Latino parents of children with disabilities to be effective in their advocacy efforts, they must believe that they can change the situations in which they live. Moreover, if part of the social change to which they can contribute involves the procurement and utilization of resources needed to nurture and protect their children, then they are likely to become empowered parents (Daly Pizzo, 1993). As logical as these deductions may be, they are only conjectures. Because the current state of scientific literature only allows for inferences about leadership development among immigrant Latino parents of children with disabilities, sense of self-efficacy and empowerment are explored as possible explanations.

D.   Purpose of the Present Study

Accordingly, the purpose of the present study was to document the leadership development of immigrant Latino parents of children with disabilities. Specifically, this exploratory study represents an effort to understand the process through which and the reasons the parents become involved in community activities to advocate for their children, the key elements that influence their community involvement, and the distinctions between the parents who are more involved and those who are less involved. Self-efficacy and empowerment are proposed as key elements to the process of the parents' leadership development.

This study is a component of the Americans with Disabilities Act (ADA, Public Law 101-336) capacity building research project (Balcazar & Keys, 1998). The ADA is a federal law that was passed in 1990 to protect the civil rights of individuals with disabilities. The ADA was designed to remove barriers faced by people with disabilities in employment, local and state government services, public accommodations, transportation, and telecommunication. The objective of the ADA project is to further the implementation of the ADA within Latino and African American communities. The ADA project is part of a larger program based at the University of Illinois at Chicago (UIC), called Advocacy and Empowerment of Minorities with Disabilities. This program seeks to develop model programs that will address the needs of the growing number of African-Americans and Latinos with disabilities in Chicago. Projects conducted under this program attempt to provide people with disabilities and their families with empowering strategies for improving their quality of life and that of other members of their community.

II. Method

A.   Research Approach

The methodology used in the present study was Lincoln and Gubas' (1985) naturalistic inquiry, because it interfered as little as possible with the context of the parents' lives. Naturalistic inquiry refers to "doing what comes naturally" or conducting research in the natural setting of the phenomenon of interest (Lincoln & Guba, 1985, p. 187). Furthermore, naturalistic inquiry emphasizes the importance of accurately capturing the multiple realities encountered in the research process, and altering as little as possible the natural setting of the phenomenon of interest. This particular approach was appropriate for the present study because both the literature on community leadership and parents of children with disabilities is scarce, limiting the extent to which the development of the present study could be informed by previous research. Further, if the objective was to understand and document the process through which and the reasons leadership is developed within the community of immigrant Latino parents of children with disabilities, becoming involved in that community was the most appropriate thing to do, to learn how leadership is manifested within this community and how the members of this community experience leadership.

B.   Organizational Context

People who qualified for participation in this study were immigrant Latino parents of children with disabilities who participate in one of two community organizations that advocate for children with disabilities in the Chicago land area. These two organizations were among the

17

various community partners of the ADA project at UIC. Participants were involved in various ways in these community organizations, which provide services to families of children with disabilities.

Organization A is a grassroots, community-based organization that is presently serving approximately fifty families and a total of 106 children. Forty-three of the children have disabilities, and the remaining sixty-three are their siblings who do not have disabilities. Ninety-eight percent of the organization members are Latino (mostly first generation Mexican immigrants), and the remaining two percent are African American. Organization A was originally founded as a support group for and by a small group of immigrant Latino parents of children who are deaf. Through their support group meetings, the parents realized the need to promote the integration and socialization of their children. Consequently, they formed the organization, through which they sought to overcome barriers to better the lives of their children, and integrate their families into the community. The board of directors of Organization A is made up by parent members who are committed to the organization and its activities. To this day, Organization A has not been successful in obtaining significant amounts of funding, therefore, the members of the organization have implemented most of their programs with their own voluntary services and small donations. The services provided by Organization A include weekly American Sign Language courses taught by the parents themselves, a monthly parent support group, social gatherings for the families, special events (e.g., trips to the circus, museums, theme parks), and occasional arts and sports activities for the families. The majority

of the members of Organization A do not speak English, including the founders and current board members.

Organization B is also a grassroots, community-based organization that began as a parent support group for and by immigrant Latino parents of children with disabilities. Its main function is to provide the community with referrals and information. The board of directors of Organization B is composed of various leaders in the local community of Latinos with disabilities who are not necessarily parents of children with disabilities. In fact, only four of approximately ten board members are parents of children with disabilities. The executive leader of Organization B invites those leaders who are committed to the community of Latinos with disabilities to become part of the organization's board. Organization B has received a significant amount of funding that is being used for a toll free telephone line, and to cover the expenses of their monthly parent meetings. These meetings are intended to enhance the knowledge of the parents about their children's disabilities, the laws that protect them, and their rights. The executive leader of Organization B has designed and copyrighted didactic games to inform the parents about issues that concern their children with disabilities, and to increase their knowledge in ways that are entertaining. Although most of the members of Organization B are first generation immigrants and do not speak English, the executive leader is a second generation immigrant and is fluent in English. Therefore, the needs of Organization B differ from those of Organization A in that having an English-speaking leader makes certain resources more

accessible. Also, Organization B's ability to network with influential people and navigate service systems is less difficult.

C.   Participants

Participants were nineteen immigrant Latino parents of children with disabilities who were members of two grassroots organizations that advocate for children with disabilities. At an initial meeting of the ADA project, I introduced the study to representatives from the organizations by telling them that I was interested in documenting the experiences of their members to develop an understanding of what motivates them to become involved in community organizations. During the meeting the representatives provided feedback about this project. They demonstrated great interest and stated that they wanted to learn more about leadership development in their communities.

I arranged a meeting with the executive leaders of each organization to inform them that I would like to recruit them for participation, given their leading roles in the formation and development of their respective organizations. The executive leaders agreed to participate. Before concluding this meeting, the executive leaders indicated that the best way to attain a sample of more active and less active leaders would be to recruit both members who were on the organizations' board of directors and those who were not. Members who were on the board would represent the more active leaders, because they were more involved in the development of activities for their respective organizations, were responsible for networking with other community members and organizations, and for obtaining resources for the organizations.

Members who were not on the board would represent the less active leaders, because they participated in their respective organizations' activities, but were not involved in the planning and development of these activities.

The executive leader of each organization nominated the remaining participants based on their level of involvement in their respective organizations, and requested that each parent be compensated fifty dollars for their participation. After consulting with the principal investigators of the ADA project, the request for compensation was granted. There were a total of nineteen participants, ten members of Organization A and nine members of Organization B. Five of the participants from Organization A were members of the board of directors. Organization B had four immigrant Latino parents of children with disabilities on its board, therefore, I only recruited these four board members for participation. The remaining ten participants were five members from each organization who were not board members. The executive leaders approached members of their organization, told them about this study, and inquired about their interest in participating. If the members demonstrated interest, the executive leaders obtained their consent to have me contact them. Once I established contact with each member, I informed them of what participation in this study would entail (i.e., time commitment, instruments to be completed, information to be requested, and compensation and benefits), to ensure that this was a commitment they were willing to make. If the members remained interested, we made arrangements to meet to conduct the interview.

All of the participants were Latinos (predominantly Mexican) and one participant was biracial (Latino-European). Almost all of the participants were first generation immigrants (84%), and the mean number of years they had lived in the United States was seventeen (ranging from four to forty-eight years). Most of the participants (79%) chose to be interviewed in Spanish, because they did not speak English. The majority of the participants were female (79%), which is an accurate representation of the population of interest, in which the majority of advocates are women. Participants ranged in age from thirty to more than fifty years old, and 68% were married or in a common law relationship. In terms of highest level of education, 42% completed high school, 32% indicated they had attended some vocational school or college, and 26% only completed elementary school. Yearly household income ranged from $10,000 – $20,000 for 42% of the participants, and for 21% of the participants the range was $20,000 – $30,000. The mean number of people per household was four, ranging from two to seven. Sixty-eight percent of the participants were employed, and of those employed 77% worked full-time. Less than half of those employed did manual labor (42%), 32% were housewives, 21% worked in social services, and one person worked as administrative staff at a government office.

D.   Measures

Two instruments were used in the present study: a demographic information sheet, and a semi-structured qualitative interview (see Appendix A for a copy of the demographic information sheet, and Appendix B for a copy of the leadership interview). The purpose of the instruments

was to gather information on the factors that might influence the active involvement of immigrant Latino parents of children with disabilities in community leadership roles.

1. **Demographic information.** The demographic characteristics obtained included age, gender, marital status, ethnicity, country of origin, immigrant generation, immigration status, age at time of immigration, educational level, employment, occupation, income, number of adults and children in the household, and organization(s) of which the participant was a member. Another relevant characteristic that was included was whether the participant had a disability, the age and type of disability of their child, and whether they had any other relatives with disabilities.

2. **Interview.** The development of the semi-structured interview was influenced by conversations with the participating organizations and faculty and students at the University of Illinois-Chicago, reviews of the community leadership literature, and Kelly et al.'s (1993) interview schedule for the development of African American community leaders. Prior to administering the interview, each organization reviewed the instrument and offered suggestions about how to improve the interview. Once the suggestions were implemented, each organization received a final version of the interview, which was made up of fifty-eight questions. The leadership interview included items that asked about community involvement in general, specific involvement related to the participant's organization, experiences as an immigrant parent of a child with a disability, leadership development, having a child with a disability, self-efficacy, empowerment, social support, role models, and leadership skills.

I back-translated all of the measures following Brislin's (1970) procedure. Specifically, I translated the instruments from English to Spanish, and then another bilingual person blindly translated the instruments from Spanish back into English. Two other bilingual people examined the two versions of the measures and checked for differences in meaning. Consequently, minor changes were made to ensure that the two versions were analogous to each other. In accord with Brislin's (1970) recommendations, the back-translation process was repeated until a faithful translation of the measures was achieved (for the present study it was repeated it once). All of the measures were available in both Spanish and English, and the participants had the option to choose between the two languages. I am fluent in both languages and administered the measures in Spanish or English, according to the each participant's preference.

E. Procedure

1. Initial contact and entrée. Because the present study is a component of the ADA project (Balcazar & Keys, 1998), I made initial contact with both organizations through the events sponsored by this project. In an effort to familiarize myself with the organizations, the participants in their environments and their multiple realities (i.e., members of organizations, parents of children with disabilities, non-English-speaking immigrants, working poor), as well as to build trust, I have been continuously involved with both organizations for approximately two years (Lincoln & Guba, 1985). My prolonged engagement with both organizations has been mostly in the capacity of liaison between them and the ADA project team, and as a translator.

With Organization A, I function as their translator during meetings or workshops, and I also translate documents for them. In addition, I attend their monthly board meetings, as well as any events in the community to which I am invited. Moreover, I have worked directly with the leaders of Organization A in developing and implementing a needs assessment for their organization, writing a grant proposal, and helping them network with other larger community agencies. I plan to continue collaborating with this organization, helping them prepare their by-laws and rules of order, and applying for non-profit certification and funding. My involvement with Organization B has been less extensive, given their different needs. I attend monthly board meetings and any other activities in which Organization B wants me to participate. Thus far, I have assisted them by providing translation services, helping them seek information that is needed by the members, and editing an application for the renewal of a grant.

2. **Piloting process.** Two pilot administrations of the measures were completed with two immigrant Latino parents of children with disabilities who were active in the community. The participants were paid $20 for the two-hour interview. Based on these pilot interviews, the topics of the interview were reorganized. Specifically, the pilot participants indicated that discussing their more personal experiences at the beginning of the interview, rather than at the end, facilitated their understanding of the remaining topics. After completing the pilot process, the participants commented that the instruments were relevant and appropriate for them and other parents like them. They also reported that they were comfortable throughout the interview, and suggested that future participants be provided with an information booklet regarding access to

services for parents of children with disabilities. I obtained this material from the Chicago

Public Schools, and distributed it to the parents when we met to conduct the interview.

2. **Natural setting.** When coordinating with the parents to conduct the interview, I

suggested that we do so at the organization's offices or in their homes, to enhance my

understanding of the parents' experiences in their natural setting (Lincoln & Guba, 1985).

However, in order to accommodate their multiple commitments and ensure their comfort during

the interview, the participants also had the option to be interviewed at UIC or somewhere else.

Using this person-in-context approach, the majority of the parents (ten) chose to be

interviewed in their homes, given their busy work and family schedules. Six of the parents chose

UIC as a convenient place for their interviews, out of concern that I would have to travel too far

to reach their homes at nighttime. One parent chose her organization because that was where

she spent most of her time. Another parent chose her lunch hour on two consecutive days

because that was the only free time that she had available. Lastly, one parent chose a park during

her child's soccer game, also because that was the only free time she had available.

Interacting with some of the parents in their natural settings afforded me the opportunity

to better understand their multiple realities. In attempting to access the neighborhoods in which

the parents lived, I experienced the poor transportation with which they dealt on a daily basis. I

was also made aware, by residents of the neighborhoods, of the safety issues that I might

encounter. In addition, being in the parents' homes allowed me to become familiar with their

living conditions at a more individual level. The issues of transportation and safety were clearly

a concern for most of the parents, and in fact prompted some of them to choose UIC as a

convenient place to be interviewed. Furthermore, those who chose alternative places for data

collection helped me recognize the different strategies used by the parents to manage their

various commitments and limitations of time and resources (e.g., being flexible with their free

time, engaging in more than one activity at the same time). These opportunities added to my

ability to document the parents' community involvement and their leadership development (e.g.,

being more attentive to essential details that the parents underestimated as routine) , and

enhanced my understanding of the elements related to the parents' level of participation in their

community (e.g., experiencing difficulties that were obstacles to the parents' more active

involvement, such as transportation and safety).

4. **Process of conducting the interviews.** The informed consent form described the

study and assured the parents confidentiality. After I reviewed the form with them and answered

any questions they had, I asked them to sign it. I provided a specific sign-off space on the

consent form for permission to quote without attribution (quoting without identifying the source;

Lincoln & Guba, 1985). All of the parents consented to being quoted without attribution (see

Appendix C for a copy of the informed consent form).

After providing informed consent, the participants completed the demographic

information sheet. I assisted half of the participants, at their request, by reading the questions to

them and writing their responses. At this point I conducted the interview. I audio-taped the

interview, and also observed the participants during the interview and kept relevant notes on the

parents' reactions to questions and comfort in answering them. In general, the parents appeared

comfortable during the interview, with the exception of one parent who seemed intimidated by

the tape recorder. After I turned off the tape recorder she was more open to providing

information, therefore, my notes for this particular interview were more detailed than the others.

However, she was still timid and did not provide as much information as other parents.

The parents' commitment to participate in the study included their involvement, over a

period of two years, in various phases of the research process. Specifically, the parents'

participation entailed : 1) completion of the demographic sheet and the interview; 2) individually

reviewing their interview transcripts with me; 3) participating in a meeting at which I presented,

and discussed with them, overall themes as they related to leadership development. In addition

to the monetary compensation of fifty dollars, the parents received a copy of Chicago Public

Schools Parents' Guide for the Educational Rights of Students with Disabilities. This guide was

available in Spanish and English.

F.   Data Analysis

Two bilingual undergraduate research assistants transcribed all interviews verbatim in

their original language (Spanish or English), in order to make sure that meaning was not lost, and

the information was not taken out of context. More importantly, keeping the information in its

original language ensured that it remained analogous to the participants' experiences. After the

interviews were transcribed, I reviewed them for accuracy (read transcript as I listened to the tape

recorded interview) and made the necessary corrections. I did not keep a record of the quantity

of corrections made because they were grammatical corrections, such as spelling errors and

missing articles (e.g., the, an). These corrections did not change the content of the interviews.

The total number of single-spaced, transcribed pages per interview ranged from seventeen to

thirty-nine. Altogether, the transcription of the interviews yielded a total of 462 single-spaced

pages.

   1. **Pre-analysis member checking.** Member checks, as described by Lincoln & Guba

(1985), involve the sharing of data, analytic categories, interpretation, and conclusions with the

participants for the purpose of enhancing the credibility (internal validity) of the study. After

completing the transcription of the interviews, I conducted a member check. I provided each

parent with a written copy of their own interview transcript, asked them to review it on their own

time, and scheduled a meeting with them to discuss their reactions to or comments about the

interview. Most of the parents were satisfied with their transcripts and did not wish to make any

changes, keeping that copy of their transcript as the final version that would be used for analysis.

On the other hand, five of the parents revised their transcripts by correcting factual errors and

providing additional information. I met with these parents to discuss their revisions and then

made the revisions. I did not keep a record of the quantity of corrections made because they

were not many of them and they were not errors made during transcription. The corrections

involved clarification of details (e.g., who was involved in a particular situation, the year the

situation took place) and sequence of events. Once the transcripts were revised I delivered them

to each parent, informing them that this would be the final version of the transcript to be used for analysis[1].

The approach used to analyze the data was exploratory, and a combination of deductive and inductive analysis. According to Lincoln and Guba (1985), deductive data analysis is guided by a priori theory or variables, whereas inductive data analysis uncovers underlying information and makes it explicit. Initial analyses were deductive in that the coding of information was guided by the interview questions, which targeted specific information. At the same time, I expected and allowed for additional information to emerge that was not directly targeted by a question. In this sense, the analysis was inductive.

2. **Phase one: Creating codes.** In the first step of analysis, I examined each interview individually to identify and code information. I placed each code into one of two categories: a priori or emergent. Codes under the a priori category were those that belonged to information that was a direct response to particular interview questions, and therefore their labels were based on that question. For example, in one question I asked the parents how they defined a community leader; I coded any part of their response that was a direct answer to this question *"community leader definition"* and placed it under the a priori category. Codes under the emergent category were those that represented information that was not a direct response to any particular interview question, but emerged throughout the interview as relevant to the parents and their experiences. The labels used for emergent codes were based on the content or theme of the

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[1] I conducted additional member checks during and after analysis, the outcomes of these member checks are reported at the end of the Data Analysis section of this paper.

information. For example, I used the label *"personal/community interests"* to code information

in which the parents discussed issues relevant to the balancing of personal and community

commitments.

As I created each code, I defined it based on the information it represented. For the a

priori codes, I also wrote the number of the question that guided that information. As coding

progressed, I revised the list of codes by creating new codes and expanding some of the old

codes. In some instances, I split a code into two codes if it seemed that it contained information

that was best represented by more than one theme. For example, I used the code *"immigrant"*

for general experiences the parents reported that were related to being an immigrant, including

discrimination. As coding progressed, it became apparent that the parents experienced

discrimination, not just as immigrants, but also as parents of children with disabilities, and as

people without disabilities. Consequently, I created the code *"discrimination"* and used it for

any information that referred to any kind of discrimination. I then used the *immigrant* code only

for general experiences the parents reported that were related to being an immigrant, excluding

discrimination. By the time I finished coding all the interviews I had compiled a list of a total of

eighty-nine codes, of which forty-eight were a priori codes and forty-one were emergent codes.

After completing this first step of coding I had a more thorough knowledge of the data.

Consequently, I examined each interview a second time, following the aforementioned

procedures. The purpose of this second step of coding was to ensure that I examined each

interview with a better understanding of the data and a complete list of codes. The eighty-nine

codes were maintained in this second step of coding. Although I did not create any new codes, I did refine codes that already existed, by clarifying their definition to be more inclusive of the information the code represented (see Appendix D for a copy of the list of eighty-nine codes and their definitions).

3. **Phase two: Analyzing codes.** The list of eighty-nine codes was reviewed to select the codes that would become the focus of analysis. Based on the purpose of this study and the research questions, a total of ten codes were chosen (definition of a community leader, roles of a community leader, skills a community leader should have, process of community involvement, reasons for community involvement, connections with other parents, personal and community interests, experiences as immigrants, sense of self-efficacy, and empowerment). The main objective of this study was to gain insight into the parents' understanding and experience of leadership in their community. Therefore, the ten codes selected for further analyses were organized into two major themes: (1) conceptualization of community leadership, and (2) practice of community leadership.

Although assessing the parents' conceptualization of community leadership was not an original research question, the importance of examining this information emerged in the process of conducting the interviews. Assessing the parents' conceptualization of community leadership provided information about their understanding of leadership in their community, which in turn became the basis for answering the research questions. Examining the parents' practice of community leadership provided information about their experience of leadership in their

community, and specifically answered the research questions about the process through which they became involved in community activities and the reasons for becoming involved in community activities, the key elements that influenced their community involvement, and the role of self-efficacy and empowerment in the parents' community involvement. The distinctions between those parents who were more involved in their community and those who were less involved were assessed by examining the two main themes—conceptualization and practice of community leadership.

The first theme, conceptualization of community leadership, was made up of three a priori codes that provided the parents' perspective on the definition of a community leader, the roles of a community leader, and the skills a community leader should have. I further analyzed each of these three codes to obtain a more detailed knowledge of the parents' understanding of community leadership. For example, among the roles of a community leader the parents identified were: looking for, acquiring, and sharing information/knowledge (among others). No emergent codes revealed information about the parents' conceptualization of community leadership. Table I presents an overview of the first theme (conceptualization of community leadership), the three a priori codes that comprise this theme, as well as the most frequent subjects discussed by the parents under each code.

The second theme, practice of community leadership, was comprised of a total of seven codes. Two a priori codes answered the first research question about the process through which the parents' became involved in community activities and their reasons for becoming involved in

TABLE I

CODES AND MOST FREQUENT SUBJECTS FOR THEME 1: CONCEPTUALIZATION OF

COMMUNITY LEADERSHIP

Codes and Most Frequent Subjects	Frequency of Subjects Discussed[a]
Definition of a community leader: Someone who helps	63%

Role(s) of a community leader:
    Accessing information
    Helping
	58%
	47%

Skills of a community leader: Intrinsic characteristics	68%

[a] Frequencies do not equal 100% because the parents discussed more than one subject for each code.

community activities. Five emergent codes, which revealed information on the key elements that influenced the parents' community involvement (connections with other parents, balancing personal and community interests, experiences as immigrants, empowerment, and self-efficacy), answered the second research question. The first four emergent codes were considered a good representation of the factors that influenced the parents' leadership development because they were the ones they discussed most frequently. Moreover, the fact that these codes were emergent meant that they were grounded in the parents' experiences, and therefore, are readily applicable and meaningfully relevant to them (Lincoln & Guba, 1985). Although self-efficacy was not among the most frequently discussed codes, it was included because it was initially proposed as an exploratory factor related to the parents' leadership development. I further analyzed each of these seven codes for a deeper understanding of the parents' experience of community leadership. For example, among the reasons the parents' identified for becoming involved were: awareness of community needs, and support and information for self and/or child (among others). Table II presents an overview of the practice of community leadership, the two a priori codes and five emergent codes that comprise this theme, as well the most frequent subjects discussed by the parents under each code.

A bilingual undergraduate research assistant was trained to independently conduct analysis of codes as well. To familiarize her with the process of identifying and labeling information, she was given the list of eighty-nine codes and instructed to code three entire interviews (because most of them were in Spanish, two of the interviews she coded were in Spanish, and the third in English). After each interview, we discussed decisions about coding,

TABLE II

CODES AND MOST FREQUENT SUBJECTS FOR THEME 2: PRACTICE OF

COMMUNITY LEADERSHIP

Codes and Most Frequent Subjects	Frequency of Subjects Discussed
Process of becoming involved:	
Dissatisfaction with services	74%
Reasons for becoming involved:	47%
Communal nature (more involved parents)	
Individual nature (less involved parents)	53%
Key elements influencing parent involvement	
Connections with other parents:	
Exchange information	100%
Mutual support	89%
Helping each other	89%
Understanding	89%
Encouraged involvement	79%
Balancing personal/community interests:	
Lack of time	89%
Family commitments	68%
Experiences as immigrants:	
Language (not speaking English)	100%
Lack of information	100%
Lack of access to resources/services	84%
Self-efficacy:	
Proverb (*Querer es poder*)	68%
Statements of self-confidence	42%
Empowerment:	
Actions	74%
Conceptually	63%

as well as agreements and disagreements. Disagreements were usually due to the research assistant's misunderstanding of the definition of a code, or not coding information at all (indicating that she thought it was not relevant). For the most part we were able to resolve disagreements, and the few times that an agreement could not be reached, I made the final coding decision. Twenty-five percent of the content from each interview (there were a total of sixty questions, each interview was divided into four parts of fifteen questions each) was randomly selected to be checked for intra-coder reliability (comparing it to my coding of each interview in phase one). Intra-coder reliability was checked by dividing the number of agreements by the total number of agreements plus disagreements multiplied by 100 (Miles & Huberman, 1984). This formula yielded an intra-coder reliability score of 85% at training.

At phase two of data analysis the research assistant independently analyzed each of the ten codes within the two major themes, and again we met to compare coding, discuss decisions about coding, and determine where there were agreements and disagreements. Twenty-five percent of the content from each code (first, second, third, or fourth part of the codes, based on number of pages) was randomly selected to be checked for intra-coder reliability. Intra-coder reliability was checked by dividing the number of agreements by the total number of agreements plus disagreements multiplied by 100 (Miles & Huberman, 1984). This formula yielded an intra-coder reliability score of 88%. To assess the stability of the coding system over time, I reanalyzed twenty-five percent of the codes one month after the completion of the analysis process (Foster- Fishman & Keys, 1997). Using the Miles and Huberman (1984) formula resulted in a stability code of 98%.

In addition to conducting reliability and stability checks, throughout the data analysis process I have had several discussions with two colleagues (a community psychology graduate student knowledgeable about research methods, and a social science researcher with expertise in qualitative methods), who were not otherwise involved in this study, about the procedures followed to analyze the interviews. The purpose of these analytic discussions was to explore "aspects of the inquiry that might otherwise remain only implicit within the inquirer's mind" (Lincoln & Guba, p. 308). These discussions have been useful in helping me clarify my understanding of the interviews, select analytic approaches that would be appropriate for this study, and choose writing styles that would make the data analysis more comprehensible.

4. **Post-analysis member checking.** Through my prolonged engagement with the parents, I had opportunities to engage with them in informal discussions during the process of data analysis. The purpose of these discussions was to keep the parents abreast of the status of the interviews, and to obtain their feedback on the approach used to analyze the interviews and the interpretations that resulted. In general, the parents agreed with the data analytic approach and expressed optimism about the findings. When all analyses had been completed and preliminary conclusions had been reached, I conducted a formal member check with the parents. I personally invited all parents who participated in the interviews to attend a meeting in which we discussed the findings of the interviews and the preliminary conclusions. At this meeting, the parents also had the opportunity to provide feedback about the appropriateness of the analytic approach, whether the preliminary conclusions truly represented their experiences, and to express their opinions about the process of conducting this study.

A total of twenty-one people attended the meeting: six parents, accompanied by eleven relatives, and four of their children with disabilities. The meeting began with a presentation about the reasons for conducting the study, its purpose, demographic information, findings, and preliminary conclusions. The parents were informed that they may ask questions during or after the presentation—whichever they preferred, however, they reserved their questions for the end of the presentation. Overall, the parents commented that they thought the analytic approach was appropriate because the findings did represent their reality. Furthermore, they felt the preliminary conclusions were analogous to their multiple realities because they were congruent with their day-to-day experiences. In addition to providing these comments, the parents also requested more detailed information about the findings presented, and inquired about other aspects of the interview that were not the focus of the present study. After addressing these questions, the parents were informed that when this manuscript is finalized, a community report will be prepared and delivered to them. Before concluding this meeting, the parents were asked to share their opinions about the process of conducting this study. In general, the parents felt it was a good experience because professionals and service providers rarely take interest in their feelings, opinions, and experiences. Moreover, two parents indicated that the interview was an opportunity for emotional relief. Lastly, one parent stated that the process of participating in this study has been like watching a movie that leaves them with personal satisfaction from looking back at their accomplishments, and seeing that people believe in each other and the possibility of social change.

G.   Trustworthiness of the Data

According to Lincoln and Guba (1985), the present study meets the criteria for credibility

(internal validity) by virtue of my prolonged engagement with the organizations, and persistent

observations throughout the process of conducting the interviews; peer debriefing through

analytic discussions with two disinterested peers (a community psychology graduate student, and

a social researcher); and member checks, including the piloting process. In terms of

dependability (reliability), the consistency of the findings has been ascertained through intra-

coder reliability and stability of the codes over time.

III. RESULTS AND DISCUSSION

A combination of inductive and deductive analysis was used as an approach to understand the leadership development of immigrant Latino parents of children with disabilities. The inductive part of the analysis revealed the parents' conceptualization of community leadership, and answered the exploratory research questions of how and why the parents' become involved in community activities. The deductive part of the analysis showed that connections with other parents, balancing personal and community interests, being an immigrant, and empowerment were the elements most frequently identified by the parents' as key to their leadership development. Self-efficacy was not among the most frequently identified factors, possibly because it is a concept that refers to a person's perception of themselves, not their actions. Therefore, the information about self-efficacy provided by the parents consisted of demonstrations of intellectual grasp of self-efficacy (sense of self-efficacy). Information about empowerment, on the other hand, consisted of information about the parents theoretical understanding of this concept as well as the empowering actions in which they have engaged (pragmatic grasp). Despite its low frequency, a discussion of self-efficacy is included because it was initially proposed as an exploratory factor relevant to the parents' leadership development. In presenting the findings, distinctions between more active and less active parents will be noted and discussed.

41

A.   Theme 1: Conceptualization of Community Leadership

Before attempting to answer the research questions posed by the present study, it is important to understand how the parents conceptualize community leadership.   Understanding the parents' conceptualization of community leadership serves as context for the interpretation of this study's findings. Therefore, in an effort to gain insight into the parents' conceptualization of community leadership, a priori information on the parents' definition of a community leader, the roles of a community leader, and the skills a community leader should have was examined.

In general, "someone who helps" was the most common way in which parents (63%) defined a community leader. Specifically, they described someone who makes a conscious effort to help and helps unconditionally; provides physical, financial, and emotional help; finds information and resources and shares it with others; helps whoever is in need; and helps others grow/develop into leaders. One parent indicated:

> "Un lider comunitario es una persona que ayuda a las demas personas, no importando si es mexicano, o si es puertorriqueño, si es moreno, si es blanco ... lo debe hacer del corazon ... deja de compartir con la familia para poder ayudar a la comunidad ... aun estando enfermo ... con cualquier cosa, fisica, emocional, o enconomicamente ... dar para recibir nada a cambio ..." (A leader is a person who helps others, not caring if they are Mexican, Puerto Rican, if they are Black, if they are White ... s/he should do it from the heart ... stop sharing with their family to be able to help the community ... even when sick ... with anything, physically, emotionally, or economically ... give to receive nothing in return ...)[2].

Given this definition, it seems that the parents define a leader by the roles s/he plays in the community. Additional analyses revealed that the most commonly identified roles of a community leader were associated with information (58%; i.e., looking for information,

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[2] Throughout the results/discussion section, quotes will be presented to illustrate the findings. Three consecutive periods will be used to indicate places where the parent paused or provided information that was irrelevant to the purpose of the quote.

acquiring knowledge, becoming informed/knowledgeable; and sharing information/knowledge).

Although the parents were not explicit about the kinds of information to which they referred,

throughout the interview they raised concerns about the lack of information about services,

resources, and/or benefits. Other prominent roles identified by the parents (47%) were related to

help: finding ways to help the community; looking and asking for things for those in need;

helping community/everyone in need; helping others develop into leaders. As two parents

stated:

> "Estar informado, el trabajo de [un lider] es estar informado para quien lo necesite. Y siempre dispuesto ... a compartir y ayudar" (To be informed, the job of [a leader] is to be informed for whoever needs it. And always willing ... to share and help).

> "La primera funcion es ayudar, no importa a quien. No importa si esa persona le cae mal o no le cae mal, si esa persona tiene una necesidad, lo va a ayudar si es un buen lider ...no hacerle las cosas a las personas, tratar que esas personas tambien salgan adelante por si mismas y se den cuenta de las necesidades para que ellos mismos puedan ser tambien unos buenos lideres ..." (The first function is to help, not caring who. Not caring if they like that person or not, if that person has a need, s/he will help if s/he is a good leader ... not do things for others, try that those people also forge ahead on their own and become aware of the needs so that they can also be good leaders).

There was no one particular skill that the parents commonly identified as essential for

leaders to carry out their roles of helping in every way possible, and becoming/being informed

and sharing that information. However, the majority of the traits identified are best described

collectively as intrinsic characteristics (68%; i.e., respect, sincerity, sensibility, humbleness,

patience, knowing how to treat people, human quality, great heart, serving spirit, and kindness).

One parent indicated:

> "Bueno, definitivamente debe ser una persona con un gran corazon, espiritu de servicio a la gente ... saber hablar con la gente sencillamente ... ser accessible a personas que no

son de cultura mas alta, menos cultura ... contacto directo con la gente, con los problemas de la gente individual" (Well, definitely it should be a person with a great heart, spirit for serving the people ... know how to talk with people simply ... be accessible to people who are not from higher education, lower education ... direct contact with the people, with people's problems).

In accord with Kelly's (1992) conceptualization of community leadership , these inherent characteristics are fundamental to the personal, communal, ideological, and spiritual connections that unite the parents, which in turn comprise the foundation for their understanding of community leadership.

The parents' definition of a community leader, as well as their perspectives on the roles of a community leader and the skills a leader should have, suggest that in their experience community leadership is about doing for each other. In the context of their lives, the most prominent ways in which the parents do for each other is by helping and sharing information, sometimes through personal sacrifices, and with a serving spirit and human qualities. This conceptualization of leadership as a collective process that engages different people with varied skills, is similar to the one Kelly (in press) derived from his work with African American community leaders. Also, in accord with the writings of Clark (1994) and Hernandez (1998), the parents cooperate with each other in efforts to address shared concerns and reach a common end. It is by working together that immigrant Latino parents of children with disabilities develop into leaders in the context of oppressive conditions (Kieffer, 1984). One parent used the tree metaphor (Tandon, Azelton, & Kelly, in press) to illustrate the collective nature of community leadership:

"... si tenemsos mas [lideres] podemos dividir responsabilidades ... entre mas lideres haigan, mas ramas va a tener el arbol y mas fruto va a ver" (... if we have more [leaders] we can divide responsibilities ... the more there are, the more branches the tree will have and the more fruit there will be).

Given this perception of community leadership, it makes sense that the parents view leadership as a continuum. In their view, all parents are connected to each other to some extent. Hence, a parent with few connections is simply a less active leader, not a non-leader. As exemplified by one parent:

"Yo digo que hay dos tipos de lideres, el lider, el que decide, el que va al frente, y el lider que lo sigue. No puedo decir que no sean lideres porque tambien opinan y tambien hacen [cosas], pero simpre necesitan de una persona mas. Ese es un lider que todavia le falta convertirse en si mismo, y eso se logra a traves del tiempo, de la auto-estima, de la confianza" (I say there are two types of leaders, the leader who decides, that one in the forefront, and the leader that follows her/him. I can't say that they are not leaders because they also have an opinion and they also do [things], but they always need another person. That is a leader that still has to become her/himself, and this is accomplished through time, self-esteem, and confidence).

Experiencing leadership within their community as a continuum of involvement means that leaders vary in their level of activity. Thus, the fact that some parents are less involved than others does not imply that they are not leaders. Being less involved simply means that the extent to which these parents do for others and others do for them is not as great as those parents who are more involved.

B.   Theme 2: Practice of Community Leadership

For this group of immigrant Latino parents of children with disabilities, community leadership in theory is a collective process of doing for each other. It is also important to examine how leadership is practiced in this community. For these parents leadership takes place

through community involvement; this is the context in which they establish the connections that are the basis of leadership within their community. Thus, the parents' community involvement is the source for understanding their leadership development. Specifically, I sought to ascertain how the parents became involved in community organizations, their reasons for becoming involved, and how self-efficacy and empowerment influence their leadership development. Connections between parents, how the parents attend to personal and community interests, and their experiences as immigrant Latinos also emerged as key elements to the parents' leadership development.

1. Process of Becoming Involved in Community Advocacy Activities

Most of the parents (74%) became involved in their community activities primarily as a consequence of their dissatisfaction with the services they were receiving from already established community agencies and service providers. The parents described these services as being culturally inappropriate (i.e., lack of awareness of cultural factors that impact the disability experience, linguistic discrepancies) and not specific to their child's disability, leading them to feel discriminated by and distrustful of the institutions intended to assist them. There was also lack of information/knowledge about these services. As a consequence of these conditions, the parents' needs were not met, and they decided to become involved and organized to address their own needs. One parent articulated:

> "... hay organizaciones de los Americanos, gueros o Blancos ... ¿y nosotros los Latinos porque no? ... ¿Como podemos conseguir, o como podemos hacer que nos oigan? Bueno, uniendonos. Entonces ... yo fui uno de los fundadores con otro padre ... de un grupo [de apoyo] pequeño ... como grupo de apoyo teniamos que depender de otras organizaciones que no nos daban los servicios necesarios que nosotros andabamos

*buscando ... Nosotros teniamos que agarrar luz propia ... nos fueron obligando a ya no
ser un grupo de apoyo sino a ser una organizacion ... la necesidad nos obligo ...
Entonces cuando no les dan el servicio, ¿que es lo que tiene uno que hacer? Hacer una
organizacion"* (... there are organizations for Americans, Whites ... and why not one for
Latinos? ... How can we get [things], or how can we be heard? Well, uniting. So then ...
I was one of the founders, with another parent ... of a small support group ... as a support
group we had to depend on other organizations that were not giving us the necessary
services that we were looking for ... We had to grab our own light ... we were being
forced to no longer be a support group, but be an organization ... the need forced us ... so
when you don't get a service, what do you have to do? Create an organization).

This group of immigrant Latino parents of children with disabilities became involved in

community activities in response to the failure of service agencies to meet their needs. These

findings are consistent with previous research conducted with mainstream parents of children

with disabilities (Grosser & Vine, 1991; Zirpoli, Wieck, & McBride, 1989). The inability of

larger organizations to provide appropriate services to the parents and their families led them to

take joint action to change this situation. The question remains, however, as to what is the

source of the parents' courage to organize and challenge more than just the social service system,

considering that most of them were undocumented and did not speak English. One possible

explanation is that the parents remained committed to the common belief among immigrants that

economic and social advancement is attainable in "the land of opportunities." One parent

expressed her/his optimism by stating:

*"... en nuestros paises se nos ha hecho dificil ... entonces cuando llegamos a este pais
tratamos de aprovechar las oportunidades que brinda este pais ... este pais ayuda
mucho a sobresalir si uno lo quiere, dan oportunidades, entonces nosotros las
aprovehchamos ... aunque nosotros siempre buscamos mas, porque tiene que haber ..."*
(in our countries it has been difficult for us ... so when we come to this country we try to
take advantage of the opportunities this country has to offer ... this country helps you
excel if you want to, opportunities are given, so we take advantage of them ... even
though we are always looking for more, because there has to be [more] ...).

Kieffer (1984) offered an alternative explanation. According to the leaders who participated in his study, their empowerment was provoked by a personally experienced sense of outrage or confrontation. In their case, these experiences mobilized the leaders into a process of developing participatory skills and political understanding. This argument appears to hold true for the parents in the present study, as the threat to their families' quality of life motivated them to reach out to other parents, and initiate a process of collaboration to achieve common goals (Miller & Keys, 1996). In the words of one of the parents, among the determining factors that lead her/him to become involved in community activities was:

> *"... simplemente pensar y reflexionar en que si yo tengo una necesidad, los demas tambien la deben tener, reflexionar mas que nada en eso ... si todos juntamos todas nuestras necesidades podemos hacer algo para poder salir adelante, es mas que nada eso"* (... simply thinking and reflecting that if I have a need, others probably have it too, reflecting on that more than anything ... if we all join all of our needs we can do something to be able to forge ahead, it's that, more than anything).

The parents' interdependence on each other and the community is unmistakable when evaluating their reasons for becoming involved in community activities.

2. <u>Reasons for Becoming Involved in Community Advocacy Activities</u>

There were clear distinctions between those parents who belonged to the board of directors of their respective organization and those who did not. For the most part, parents who were board members (100%) reported reasons of a communal/collective nature, such as awareness of community needs, help each other, for those with less opportunities, and because of injustices in the community. One parent captured this phenomenon when s/he reported:

> *" ... no debemos ser egoistas ni individualistas, ni quedarnos con todo en nuestros adentros. Yo considero que hay que aprender para compartir y ayudar a quien lo*

necesita" (… we should not be selfish nor individualistic, nor keep everything inside. I
think that we have to learn to share and help whoever needs it).

In general, parents who were not on the board (100%) of their respective organization
reported reasons for becoming involved that were of an individualistic nature, such as for my
child, for myself, as a distraction, and for support and information for self and/or child. As stated
by a parent:

> *"En primera yo he asistido a todas esas organizaciones … por mi … es para un
> desahogo … compartir algo de mis sentimientos …"* (First of all, I have attended all of
> those organizations … for me … it's for an emotional relief … share something of my
> feelings).

The only explicit distinction found between more active parents and less active parents
was in the reasons they identified for becoming involved in community activities. The more
active parents presented more communal reasons, which can be succinctly described as an
awareness of the community's needs and concerns, and a desire to work collectively to address
them. The less active parents offered more individualistic reasons, such as acquiring support and
assistance for themselves and/or their children. This difference between the more active and less
active parents is not surprising when taking into account the existing knowledge about
community leaders as the ones who usually initiate the community's organization (Balcazar,
Keys, Bertram, & Rizzo, 1996; Balcazar, Keys, Kaplan, & Suarez-Balcazar, in press; Balcazar,
Keys, & Suarez-Balcazar, in press; Hernandez, 1998), and those who are conscious of the
broader, social implications of their individual situations (Cruze, 1988; Gutierrez & Ortega,
1991; Hernandez, 1998; Kieffer, 1984). However, it is important to acknowledge that the parents

in the present study do not conceptualize community leadership as a dichotomy, but on a continuum. Therefore, it is essential that we give proper attention to other possible explanations for the dissimilarity between more active and less active leaders.

Although the more active leaders are the ones responsible for organizing the community, and recognize their problems as larger social issues, there were other differences between them and the less active parents. All of the parents on the board of Organization A are married, live with their spouses, and have older children who assist in the care of their child with a disability. As a consequence, the support of their families is more accessible to them when compared to those parents from Organization A who are not on the board. All of the parents on the board of Organization B were born in the US and are English-speaking, whereas the parents who are not on the board of Organization B were not born in the US and did not speak English. Therefore, board members of Organization B possibly did not deal with linguistic and cultural adjustment issues to the extent that non-board members did. Both the more active parents and the less active parents are aware of the dissimilarities between them:

> "... si ellos no tienen la oportunidad de salir a buscar [informacion], nosostros lo hacemos para que ellos se informen ... si yo tengo mas recursos, yo puedo ayudar a mas personas ... por ejemplo algunos padres dicen que no tienen dinero para el pasaje, yo los he ayudadado dandosle dinero ..." (if they don't have the opportunity to go out and look [for information], we do it so that they can be informed ... if I have more resources, I can help more people ... for example, some parents say that they don't have money for the fare, I have helped them by giving them money).

> "Nosotros cuando tenemos problemas de cuidado de niños, nos llevamos a nuestros hijos y [la organizacion] nos proporciona ayuda en ese sentido ..." (When we have problems with child care, we bring our children and the organization provides us with help in that sense ...).

"I would be helping the other Latina parents because with the language barriers that they have, they weren't getting the information that they needed" (interview conducted in English).

"Ella es una persona ... que no es inmigrante sino que viene de personas inmigrantes ... que tiene control sobre el idioma, ella ha aprendido las leyes ... tener a una persona como ella, pues uno se siente como un poco mas seguro ..." (She is someone ... who is not an immigrant, she comes from people who are immigrants ... she has control over the language, she has learned the laws ... having someone like her, well you feel like a little more secure).

While their similar experiences with poor services engendered the parents' union, at the same time their differences strengthened their bonds. It seems that the parents' consciousness of their individual needs and strengths, and how they can complement other parents' needs and strengths, elucidates the importance of forging links with other parents.

3. Key Elements that Influenced Involvement in Community Advocacy Activities

Five codes were considered representative of the key elements that influenced the parents' leadership development: connections with other parents, personal and community interests, experiences as immigrants, sense of self-efficacy, and empowerment. All five codes were chosen based on the fact that they were emergent, and selection of the first four was also based on the relative frequency with which they were discussed by the parents. The percentage of parents that identified each of them as important was 100%. The frequency with which these themes emerged throughout the interviews was compared to other emergent codes. The total frequency for all emergent codes was 1308, of which connections with other parents accounted for 210 (16%), personal and community interests accounted for 136 (10%), experiences as immigrants accounted for 122 (9%), empowerment accounted for 94 (7%). After empowerment

there was a drop-off in frequencies that ranged from approximately 40 (3%) to 1 (.08%), and the codes within this range of frequencies were not discussed by all parents. Self-efficacy was discussed once by all the parents and accounted for 20 (2%) of the frequencies.

Connections with other parents, as well as personal and community interests, experiences as immigrants, and empowerment were the elements most frequently identified by the parents as key to their leadership development. Thus, they accounted for a major part of the interview information analyzed. Self-efficacy was not among the most frequently identified factors, possibly because it is a concept that refers to a person's perception of themselves, not their actions. Therefore, the information about self-efficacy provided by the parents consisted of demonstrations of their sense of self-efficacy (intellectual grasp). Information about empowerment, on the other hand, consisted of information about the parents theoretical understanding of this concept as well as the empowering actions in which they have engaged (pragmatic grasp). Despite its low frequency, a discussion of self-efficacy is included because it was initially proposed as an exploratory factor relevant to the parents' leadership development. It should be noted that these five factors (connections with other parents, balancing personal and community interests, being an immigrant, and empowerment, and self-efficacy) are emergent themes, which means they are grounded in the parents' experiences. Therefore, they are applicable and meaningfully relevant to the leadership development of this group of immigrant Latino parents of children with disabilities (Lincoln & Guba, 1985).

a. **Connections with other parents.** The most prominent reason for the establishment

of connection with other parents, or the most common benefit obtained through these

connections, was the sharing or exchanging of information/knowledge (100%)—usually about

rights, benefits, and organizations. These connections were also a source of mutual support

(89%), both emotional and more logistical (e.g.—transportation, child care). Helping each other

was also among the most mentioned reasons for or benefits of connections with other parents

(89%), but the parents were not explicit about the kinds of help to which they referred. Another

reason for/benefit of connecting with other parents was sharing experiences for emotional relief,

motivation, and advice; to find out about new ideas and learn tactics; and to realize that they are

not alone and that their individual situation might not be as bad as that of another parent (89%).

Lastly, by connecting with each other the parents became more involved in their communities, as

most reported that other parents invited them or encouraged them to participate (79%). One

parent stated:

> " ... la union y el esfuerzo de todos ... union, esfuerzo colectivo hace que se den los
> cambios, porque cuando se distancia uno del otro no se logra nada ... podemos llegar a
> lograr bastantes cosas juntos" (... unity and everyone's efforts ... unity, and collective
> effort is what leads to changes, because when we distance ourselves from each other
> nothing is accomplished ... we can accomplish many things together).

By connecting with each other, immigrant Latino parents of children with disabilities

share information/knowledge, provide mutual support, help each other, share experiences, and

encourage each other to become involved in community activities. Previous research has

revealed similar findings (Gutierrrez & Ortega, 1991), indicating that Latinos in group settings

find mutual support, acceptance, and understanding by establishing contact with other members

of the group and sharing their experiences. Furthermore, the exchange of information emerges

again as an important topic for the parents. Information is a salient concern among immigrant

families because the lack of knowledge about their rights, combined with language barriers, may

result in their withdrawal from or rejection of services (Lequerica, 1993). As demonstrated

earlier, and in agreement with other researchers (Rosenberg, 1984), the parents organized as a

consequence of withdrawing from inappropriate services, and the sense of marginalization

incited by the service providers. Moreover, the parents' awareness of the needs of others and

their collective efforts to address these concerns strengthened existent bonds. In addition,

forging links with other parents is a preventive method intended to keep new parents of children

with disabilities from having similar experiences. As one parent explained:

> "... como sabemos que hay otros padres con la misma necesidad u otros que estan
> empezando, entonces nosotros queremos ser un ejemplo para los que estan comenzando
> ... estamos tratando que otros padres se ahorren ... todo lo que nosotros ya pasamos"
> (... because we know there are other parents with the same need or others who are
> starting out, then we want to be an example for those who are just beginning ... we are
> trying to save other parents ... from everything we already went through).

Immigrant Latino parents collaborate with each other to achieve mutual benefits. In this manner,

parents are addressing personal and community needs. As beneficial as these collective efforts

are, balancing personal and community interests is a dilemma the parents must confront

constantly.

b. **Balancing personal and community interests.** Overall, the parents struggled

mostly with lack of time (89%) and family commitments (68%). The majority of the parents

reported that their level of involvement in the community depended on the amount of time they

had available, given their job schedules and limited free time to share with their family, as well

as the community organization. Nevertheless, even those with more time available indicated that

balancing their commitment to the community with their family responsibilities was an on-going

concern for them. The way in which the following parent described how s/he handled this

dilemma is representative of how most parents described their experience:

> *"It is hard [to become and stay committed to these organizations and with my community activities], yes, because you have family of your own. Your first priority are your children and it's kind of hard down the road, you know. Sometimes you say to yourself: well, should I keep on going? Who needs me more, my family or them? ... and I don't know, it's just that I have to cut myself in half and say: well, a little bit here and more with my family. But a little bit is still with the community"* (interview conducted in English).

A few of the parents chose to make personal/family sacrifices to dedicate more time to

their community activities (16%). Although they experienced guilt, and sometimes even family

conflict over this choice, they reconciled it by arguing that their efforts in the community

impacted many more people (including their own family) than if they chose to be less involved

in community activities. As illustrated by one parent:

> *"... Yo dedico todo el tiempo que mas puedo [a la organizacion] ... todo mi tiempo libre ... Yo descuido a mis hijos, a mi casa ... para que podamos hacer algo positivo para todos, no no mas para mi hijo sino para todos los niños y todas las personas que necesitan ... si ha bajado un poquito la comunicacion con mi hijo por lo mismo, que dedico tanto tiempo a [la organizacion]... ese tiempo yo estoy alla trabajando y haciendo todo esto para la comunidad ... que viene siendo la comunidad de mi hijo"* (I dedicate all of the time that I can [to the organization] ... all of my free time ... I neglect my children, my home ... so that we can do something positive for all, not just for

my child, but for all the children and all the people who are in need ... the communication with my child has decreased for that same reason, that I dedicate so much time to [the organization] ... that time I am there working and doing this for the community ... that ends up being my son's community).

On the other hand, some of the parents (11%) indicated that they were not more actively involved in the organization, and did not plan to become more involved, because they felt guilty if they did not spend time with their own child. For example, one parent reported:

"No creo que me interese [participar mas en la organizacion] por mi tiempo ... casi siempre me siento mal cuando no le dedico mi tiempo a mi hija" (I don't think I am interested [in participating more in the organization] because of my time ... I almost always feel bad when I don't dedicate my time to my daughter).

Those parents who discussed their struggle with balancing personal and community interests usually referred to not having enough time to do more for the community or not being able to do more than they already do because of their family responsibilities. Less active leaders usually mentioned lack of time and family commitments as the two main reasons for not becoming more actively involved in their respective organizations. This finding clarifies the earlier finding that less active leaders reported more individualistic reasons for becoming involved in community activities. Mlawer (1993) and Kieffer, (1984) support this view when they wrote that, unless parents meet their basic, survival needs it will be difficult for them to concentrate on issues that are directly related to their child's disability, especially advocating at a broader social level. Other researchers extend this argument by pointing out that not many people are willing and able to pay the personal price of being a community leader (Hernandez, 1988). Community leadership involves the ability to balance personal and community interests, which means being willing to voluntarily meet your needs and those of others, in the context of

limited resources (Hernandez, 1988; Selsky & Smith, 1994). According to Kelly (1992), to be

able to do this, leaders need determination, a sense of community, a vision, and spiritual basis for

their lives. The more active leaders in the present study certainly possess a strong sense of

community, and the findings presented attest to this. Nonetheless, some of the parents explicitly

expressed their sense of community and commitment by stating:

> "... una de las cosas mas difíciles es ser líder, porque uno representa a muchos y las
> demas personas siempre confian en uno, y el defraudar a las demas personas es como
> defraudarse a uno mismo" (... one of the most difficult things is to be a leader, because
> you represent many [people] and the other people always trust you, and to disappoint the
> others is like disappointing yourself).

> "... I have this need to be out there, for some reason (I don't know why)I have a need to
> be out, as I call it, with 'my gente' (my people with disabilities)" (interview conducted in
> English).

A strong sense of commitment facilitates the parents' ability to attend to both personal and

community interests. In addition to this sense of commitment, the parents also have a strong

sense of determination. Their determination becomes evident when we examine the challenges

the parents experience as immigrants and their inner strengths in coping with these difficulties.

c. **Experiences as immigrants.** Among the issues parents discussed about their

experiences as immigrants, the most salient was related to language (not speaking English) as a

reason for being less involved in community activities (100%). Lack of information/knowledge

was also identified as an issue associated with being an immigrant (100%). Specifically, the

parents felt this was a problem because most organizations do not have Spanish-speaking staff

members or the service-related information available in Spanish. Consequently, the parents have

poor knowledge of service systems and the services to which they are entitled as immigrants. A

third concern the parents discussed was the lack of opportunities or access to benefits, resources, and/or services (84%). The parents indicated that this problem was particularly due to ineligibility for or denial of services due to lack of legal documentation. Moreover, the parents felt that what little services were available to them were for the most part culturally inappropriate in that they were not provided in Spanish, and did not take into account cultural differences between Latino and mainstream US cultures.

Language is clearly a major concern for immigrant Latino parents of children with disabilities; not only is it a problem in and of itself, but also in relation to other difficulties faced by the parents. Not speaking English is a problem at an individual level because it limits what the parents are able to do for and by themselves. However, it is also a social level concern in that organizations and service systems are doing little to effectively address this issue (Laquerica, 1993; Zea et al., 1997). Poor access to services due to lack of information and/or undocumentation makes matters worse for immigrant Latino parents of children with disabilities. The parents' experiences as immigrants is one of their multiple realities, and it is the context in which they must advocate for the rights of their children with disabilities. It would seem logical to presuppose that this complicated situation would discourage the parents from taking action toward change. Yet, on the contrary, their awareness of their disadvantages is the driving force for their leadership development. As exemplified by one parent:

> " ... [siento] mas confianza por ser inmigrante,[porque] tiene uno que luchar ... y tiene uno que tener confianza en uno mismo ... tener esa fuerza de fe, de ir adelante, de luchar ... Es mas las ganas de buscar y seguir ... porque uno dice: pues soy inmigrante y a lo mejor por eso me van a negar esto o lo otro " ([I feel] more confidence because I am an

immigrant, [because] you have to struggle … and you have to have confidence in yourself … have strength from faith, to forge ahead and struggle … The desire to seek and move forward is greater … because you say: well, I'm an immigrant and most likely because of this they are going to deny me this or the other thing).

The parents' determination in the context of personal adversity, and their commitment to their community in a marginalized environment, call our attention to their inner or inherent strength. Indeed, the most appropriate way to capture this inner strength is through direct interaction and observation of the parents in action. As Glidewell et al. (1998) articulated, "it's inside them, they feel it" (p. 77). However, the parents' self-efficacy and empowerment (as assessed in the present study) provides a means to convey their courage, spirit, and hope as essential elements to their leadership development (Bolman & Deal, 1994).

d. Self-efficacy. Assessment of self-efficacy was based on emergent information the parents reported throughout the interviews that was indicative of the extent to which they felt confident in their ability to accomplish their advocacy goals. Using this approach, there were two main ways in which the parents expressed their self-efficacy. The most common way (68%) in which they did this was through a proverb (or a variation of it) that is frequently used in Latino culture to indicate that if you want something you can attain it—*Querer es poder*. A literal translation would be: to want is to be able. According to Harrap's Concise Spanish/English Dictionary (1991), a figurative translation would be: Where there is a will, there is a way. Variations of the proverb used by the parents include:

"*… todos podemos si queremos … yo he tratado de querer porque se que puedo …*"
(… we are all able if we want … I have tried to want because I know I am able …)

> " ... *si uno quiere, uno puede ... uno puede hacerlo si uno quiere ... uno puede hacer lo que uno quiere ...* " (... if you want, you are able ... you can do it if you want it ... you can do what you want ...).

> " ... *el que quiere puede ...* " (... s/he who wants is able ...).

The second way in which the parents (42%) showed their self-efficacy was simply by stating that they were confident or felt confidence that they would accomplish their advocacy goals, or by stating that they had to have confidence to reach their advocacy objectives. As two parents indicated:

> "... *siento poca desconfianza de que vayamos a lograr lo que nos hemos propuesto ...* " (I feel little distrust that we will accomplish our objectives).

> " ... *ser immigrante no es ninguna barrera, cuando una persona necesita o quiere algo, si fijas una meta no hay nada que te dentenga, menos el hecho de ser inmigrante*"
> (... being an inmigrant is not a barrier, when a person needs or wants something, if you set a goal there is nothing that stops you, much less the fact that you are an immigrant).

The parents' confidence in their ability to accomplish their goals influences their perseverance, and commitment to community involvement, in a social setting that is lacking resources. Self-efficacy is a strength the parents utilize as a tool to deal with the day-to-day challenges imposed on them by a disadvantaged environment (Bandura, 1995; Depp, 1993; Maddux, 1995). Through their collective efficacious efforts the parents also address their common concerns, demanding and taking control of situations that affect their quality of life, and taking action toward social change (Bandura, 1997). Thus, the parents' empowerment does appear to be embedded in their self-efficacy.

d. **Empowerment.** Similar to self-efficacy, assessment of the parents' empowerment was grounded on emergent information reported throughout the interviews that was evidence of the extent to which the parents felt they could take action to change things that influenced their lives. Using this approach, there were two primary ways in which the parents demonstrated their sense of empowerment: in theory and in practice. For the most part, the parents manifested their sense of empowerment in practice (74%), which means that in their narrative they described instances in which they took actions to change a situation to improve the quality of their life or their child's life, both at a social level and individual level. At a social level, the ways in which the parents showed empowerment through practice include organizing and becoming involved in community activities in response to limited opportunities and inappropriate services as immigrants and/or Latinos. Displays of empowerment through practice at an individual level include examples provided by the parents of their particular experiences: choosing to immigrate to find better opportunities for their child, challenging the education system by collecting signatures and writing letters to demand better services for their children; and researching information at libraries, churches, and other sources because doctors and other health professionals did not provide them with this information. Two parents articulated:

> " ... *[al formar la organizacion], nosotros como Latinos, nosotros sentimos que estamos contribuyendo a un cambio para muchos Latinos, por la sencilla razon de que nosotros nos vimos bien limitados en este pais"* (... [by forming the organization] we, as Latinos, we feel we are contributing to a change for many Latinos, for the simple reason that we felt very limited in this country).

> " ... *yo trataba de hablar siempre con los padres y decir: ¿porque no nos juntamos, porque no decimos esto? Inclusivo muchas veces nosostros hicimos cartas de cosas que*

queriamos para los niños en la escuela ... querian integrar a sus hijos oyentes en esa
escuela [de niños sordos, para que los hijos oyentes tambien aprendieran señas] ...
hicimos la carta, la firmamos, y fuimos y hablamos con el concilio y al final de cuentas
si logramos que aceptaran a los hermanos y a los primos en la escuela ..." (... I always
tried to talk with the parents and say: Why don't we get together, why don't we say this?
Many times we even wrote letters about things that we wanted for the children in the
school ... they wanted to integrate their hearing children into that school [for deaf
children, so that their hearing children can also learn sign language] ... we wrote the
letter, we signed it, and we went and talked with the council and after all we did get them
to accept the siblings and cousins in the school).

The way in which the parents demonstrated their empowerment conceptually was by

communicating their understanding that although they faced limitations, there were actions they

could take to change their situation (63%). The parents usually did this by conveying their

awareness that by organizing and through collective efforts they could make changes and obtain

better things; recognizing that most things will not be given to them, therefore, they must look

and ask for what they want or need; and acknowledging that although the system makes things

difficult for them, they can make them a little easier by taking action, such as becoming involved

in community activities. As illustrated by a couple of parents:

" ... *como personas que venimos de otro pais nos vamos a encontrar con una infinidad*
de problemas ... en nuestras manos esta un 75% [de responsabilidad para] que las cosas
se nos faciliten ... [no hay que ser] conformistas ..." (... as people that come from
another country, we are going to encounter an infinity of problems ... 75% [of the
responsibility to] facilitate things is in our hands ... [we shouldn't be] conformists ...).

"You have to make the board of education and the mental health system accountable ...
we tend to think that because we are Latinos that it is harder for us to obtain these things
[education and mental health services], and yes it is harder to get services, but it doesn't
mean you cannot get them if you go out there and advocate, and really say you want them
and want to do it, and you want to go out there and not give up ..." (interview conducted
in English).

The parents' intellectual and pragmatic grasp of the extent to which they felt they could take

action to change things that influenced their lives (empowerment), is indicative of their inner

strength. Their courage in challenging and demanding more from powerful systems and

institutions further supports their empowerment. Despite the inability of external forces to

effectively respond to the parents, they remain involved in their communities in the interest of

change. The parents' firm belief in and hope for change is inspired by their past

accomplishments. In the words of two of the parents:

> "... yo me siento capaz hasta el 100% para poder cambiar [las cosas para mejorar la vida de mi hija/o], hasta ahora lo he estado demonstrando, espero tener mas oportuntidades de lograr lo que yo quiero" (... I feel up to 100% capable of changing [things to improve my child's life], until now I have been demonstrating it, I hope to have more opportunities to accomplish what I want).

> "[I feel I can change things to improve my child's life] to a great extent ... because I have ... I have done it" (interview conducted in English).

The parents' accomplishments are a consequence of their inner strength and their collective

efforts. Their attainments, in turn, nurture their fighting spirit and motivate them to remain

involved in their communities. The parents benefit from their community involvement by

acquiring resources to reach their advocacy goals (Maton & Salem, 1995). Community

involvement also contributes to the development of the parents as community leaders and agents

of social change (Tandon et al., in press).

C.   Summary of Findings

Of the factors found to influence the parents' leadership development, the finding that

connections with other parents was the theme most frequently discussed was not unpredictable,

considering the parents' conception of community leadership as a process of doing for each

other. The reasons the parents gave for becoming involved in their community activities complement this finding, because even those reasons that were of an individualistic nature were based on these connections: the parents who reported them relied on other parents to provide them with a space for emotional relief, to motivate and advice, and work collectively to meet each others' needs. This line of reasoning is further supported when we take into account the process through which the parents became involved in their community activities—as a means to address unmet needs, their own and those of other parents like them. The task of addressing unmet needs is an immense one, especially in the context of the parents' multiple realities (e.g., being an immigrant, working-poor, parent of a child with a disability, not speaking English). Matters are more complex in this context because the parents must struggle with trying to share resources with other parents while their own resources are limited. This struggle is discernable in the parents' efforts to balance their personal commitments with their commitment to community activities. These difficulties notwithstanding, the parents continued to forge ahead, partly driven by what appears to be strong self-efficacy and empowerment.

Considering all the commonalities that bind the parents: common needs and concerns about their children with disabilities, almost all are first generation immigrants who do not speak English, and most live in similar socioeconomic situations, it seemed important to understand what distinguished parents who were more active in their community involvement and those who were less active.

D. Distinctions Between More Active and Less Active Parents

Differences between the more active parents and the less active parents were not easy to detect at first. With the exception of their reasons for becoming involved, there were not any other obvious differences between more active and less active parents in the experiences they reported and issues they identified. A closer look at the differences in reasons for becoming involved raised questions about why more active parents reported more communal reasons, what this communicated about their frame of mind, and how the more active parents displayed this mindset throughout the interview. Taking this approach, it became clear that the differences between the more active and less active parents was not in what they reported, but in how they reported their experiences. In other words, what distinguished more active from less active parents was the way in which they interpreted their experiences and the manner in which they expressed themselves about these experiences.

More active parents tended to describe their experiences as collective experiences, and use more collective terms to express themselves, such as plurals, including plural pronouns (i.e.,we, us). Even when asked about individual perspectives, they would usually end up speaking in collective terms. For example, in explaining her/his reasons for becoming involved in community activities, one parent stated:

> "... como uno de los fundadores (porque no quiero quitarles el merito a los demas
> padres que me han ayudado), sabemos que hay otros padres con la misma necesidad ..."
> (... as one of the founders {because I do not want to take credit from the other parents
> who have helped me}, we know that there are other parents with the same need).

Although it is true that this parent was one of many to share this view and this might explain why

s/he chooses to speak about it in collective terms, for this commonality in opinions to exist, each person has to independently have that point of view. Yet, s/he chooses to express her/his viewpoints as a collective experience, rather than an individual experience. These expressions might be interpreted as indications that the more active parents cannot or do not think independently—which is usually regarded as a drawback or weakness in mainstream US culture (Kerr & Meyerson, 1987; Zea et al., 1997). However, considering the value the parents attach to connecting with each other, and how meaningful interdependence is within the Latino culture (Zea et al, 1997; Zuniga, 1992), not thinking independently is not necessarily a weakness in the context of the parents' lives. Given what we have learned about the more active parents, a better interpretation would take into account their awareness that others have similar concerns, that these concerns have to do with the system's failure to respond to their needs, and that they can address these concerns through collective action (Gutierrez, 1995). Knowing this about the more active parents, a conclusion that is more likely to accurately capture how they are different from the less active parents, is that more active parents are possibly at a more advanced stage of critical consciousness.

Critical consciousness refers to the development of a critical understanding about the causes of social, political, and economic victimization and oppression, as well as engaging in collaborative action to bring about social change (Neuman, 1996; Smith & Alschuler, 1976). According to Freire (1973), consciousness is problem solving that occurs at least at three levels: (1) naming and defining the problem, (2) reflecting on or understanding the cause of the problem, and (3) taking action to solve the problem. Critical consciousness is a process of

consciousness raising in which individuals evolve from magical, to naïve, and finally to critical consciousness.

Individuals in the magical stage conform to oppressive situations in which they live, they adapt fatalistic ideas of what is traditionally appropriate and cannot be changed. Moreover, they attribute power to superior beings (i.e., gods, spiritual beings, elite class of society), passively allowing others to take control of their lives or waiting for some divine intervention. Those at the naïve stage over-simplify problems, because they ascribe the cause of them to individuals instead of the system itself. They believe that the system would function flawlessly if individuals were reformed. Because they do not see the system as a problem, they do not engage in real social action; they do see strength in numbers, but more as a psychological comfort rather than as a political or social effort.

Freire (1973) conceptualized the last stage, critical consciousness, as one that "is characterized by depth in the interpretation of problems; the substitution of causal principles for magical explanations;…by the attempt to avoid preconceived notions when analyzing problems;…by rejecting the passive position…" (p. 18). Critically conscious people perceive that the system needs to be altered because it is unjust and unequitable. In terms of problem solving, people will name, reflect on, and act on their problems according to the stage in which they find themselves—magically, in a naïve manner, or critically. If the more active parents are indeed at a critical stage of consciousness, then it makes sense that they use a collective frame of

reference to describe their individual experiences. That being the case, not thinking independently is not a drawback.

E.   Conclusions

The present study documents the leadership development of immigrant Latino parents of children with disabilities. The findings indicate that, connections with other parents of children with disabilities are the foundation of the parents' understanding and practice of community leadership. It is by means of these connections that they help each other and share information. Balancing personal and community interests is an important component of the parents' experience of community leadership, as they must conceptualize leadership and put it into practice in a context of scarce resources. Being an immigrant is a significant element of this context, because it puts the parents in a position in which they must struggle with inevitable issues, such as language barriers, cultural differences, and limitations due to lack of documentation. These concerns are unavoidable in the sense that even if the social service system was more responsive to the parents' needs, they will not do so by granting them documentation, and they cannot wipe away cultural and linguistic differences. While it is true that the issues related to being an immigrant cannot be totally resolved, the social service system should be held accountable to work together with the parents to ameliorate their situation. The parents' expressions about self-efficacy and demonstrations of empowerment, (theoretically and pragmatically), are evidence that they are aware of this and are taking action to improve their quality of life. Altogether, connections with other parents, balancing personal and community interests, being an immigrant, and self-efficacy and empowerment encompass the parents'

multiple realities. These parents comprise a special group of people who are parents of children with disabilities, first generation immigrants, working-poor, and have low educational levels. In addition, they are advocates, activists, organizers, and community leaders. What makes them special is their community involvement, because instead of perceiving their demographic characteristics as impediments to participation in the community, these are the forces that compel them to take collective action toward change.

F.   Implications

The findings of the present study highlight the need for the parents to be more informed about the culturally appropriate services, how to access these services, and strategies for navigating service systems as undocumented immigrants who do not speak English. This information may be disseminated by universities, local government, larger agencies, and other community institutions through the creation and implementation of advocate or leadership development programs for immigrant Latino parents of children with disabilities. These programs should be tailored according to the community's strengths and needs, and foster partnerships between community institutions that have more access to resources, and the parent organizations that might be able to benefit from these resources. On a broader level, although state and federal governments might not be able to provide undocumented parents with direct assistance, they may do so indirectly by providing financial and other kinds of incentives to these community institutions in the interest of promoting partnerships and the sharing of resources with parent organizations. Lastly, local, state, and federal institutions may assist the parents in less structured ways, such as using the media to keep parents abreast of any information relevant

to their needs. Of course, cultural appropriateness should remain foremost in how and which information to provide: information should be in Spanish and English media, and information about the language requirements to access services and eligibility for services based on immigration status, should be included.

G. Limitations

A notable limitation of the present study was the selection of parents who were not on the board of their respective organizations as representatives of less active parents. My original intent was to interview parents who were on both ends of the continuum of involvement, those who actively participated in the organizations' activities and were on the board of their organizations, and those who did not actively participate in the organizations' activities and were not on the board of their organizations. The executive leaders of the organizations were concerned about this inclusion criteria, because they felt that those parents who did not actively participate in the organization were unlikely to collaborate on this project. The alternative they suggested was to interview parents who were not on the board, but actively participated in the organizations' activities, as the less active parents. Although identifying them as the less active parents might be a misnomer, it was necessary to be flexible to accommodate the reality that these organizations do struggle with poor participation.

Another limitation of the present study involves self-efficacy and empowerment, and their application to the experiences of immigrant Latino parents of children with disabilities. Self-efficacy and empowerment are constructs of the US mainstream culture, and may not be

experienced or manifested in the same manner by people from other cultures, calling into question the appropriateness of their use in the present study. As already indicated, due to the dearth of literature on community leadership, specifically as it relates to immigrant Latinos, the use of self-efficacy and empowerment were proposed as exploratory factors. The decision to include these two constructs was based on my impressions, and those of other staff members of the ADA project, of the parents as self-efficacious and empowered people. Additionally, the literature has identified self-efficacy and empowerment as influential in community involvement (Bandura, 1995; Kieffer, 1984). Despite attempts on my part to make the questions on the interview about self-efficacy and empowerment congruent to the parents' experiences, and efforts to explain to them their meaning and relevance to the understanding of leadership development, the parents were confused by the questions and experienced difficulties responding to them. For this reason, I chose to use emergent information as a source of the assessment of self-efficacy and empowerment among the parents. In retrospect, I realize that I could have focused my efforts more on assessing their understanding of the ideas behind these two constructs, and gain insight into their interpretation of self-efficacy and empowerment in the context of their lives. This would have been an ambitious project, and one beyond the scope of the present study. Nevertheless, future research would make an excellent contribution to the study of self-efficacy and empowerment by investigating the meaning of self-efficacy and empowerment among immigrant Latinos and other groups of color, their perspectives on these constructs as understood in US mainstream culture, and initiating the development of conceptualizations that are culturally relevant to marginalized groups.

H.   Contributions

This study is distinctive in that it is the product of an intensive collaborative effort between the community of immigrant Latino parents of children with disabilities and the ADA project. Many of the parents who were members of the organizations from which participants were recruited have worked in the past on other projects sponsored by the leaders of the ADA project. This established relationship between the parents and the staff of the ADA project, facilitated my entrée to the community of immigrant Latino parents of children with disabilities, and my engagement with the organizations. I was successful at gaining access to the various physical and emotional spaces the parents occupy, and believe that this would not be possible without the procedures I followed in working with them. The quality of the bonds between the parents and I and the rest of the ADA staff, and the mutual trust and respect we share were essential elements to integrity the research process.

The present study also contributes to the advocacy and community leadership literature, supporting previous findings that demonstrated that leadership is a collective process that involves personal, communal, ideological and spiritual connections between people (Clark, 1994; Hernandez, 1998; Kelly, 1992; Kelly, in press). Viewing community leadership from this perspective of collectivity and relations between people, provides additional evidence that personal characteristics such as personality, formal training, and management skills are not the essence of the leadership process among ordinary citizens (Johnson & Johnshon, 1997). Thus, these characteristics should not be the focus of the study of community leadership development, much less when it involves disadvantaged groups. As prior research indicates (Bandura, 1995;

Grosser & Vine, 1991; Pizzo, 1983; Zirpoli, Wieck, & McBride, 1989), and confirmed by this study, the lack of external resources and inadequate response from the system makes marginalized groups dependent on internal resources and inner strengths. Therefore, it would be inappropriate for efforts to understand community leadership to emphasize characteristics that are not congruent with the realities of the communities involved.

Another unique contribution of this research project is to expand scientific knowledge about community leadership in its application to a new population (immigrant Latino parents of children with disabilities), the challenges they face, and the resources they use to overcome these obstacles. Specifically, the results are in disagreement with existent views of those who are poor, of low education status, and socialized to be powerless as passive, with limited sense of options, less likely to take the lead in decision making efforts, and/or surrendering or withdrawing in the face of adversity (Kieffer, 1984; Lequerica, 1993; Zuniga, 1992). On the contrary, the present study expands our knowledge about the leadership development of ordinary community members, and more specifically about the process of leadership development of immigrant Latino parents of children with disabilities as a means to counteract oppressing conditions. This is one of the ways in which this study contributes to the field of community psychology. Another contribution to the field is that by understanding the experiences of these parents, and the factors that influence their development into community leaders, we can understand what is needed to enhance existing community leadership efforts. This is an important way in which the community also benefits from this work. Hence, through this study we can focus our efforts to collaborate with the community of immigrant Latino parents of children with disabilities to

increase their representation in community leadership, and improve their capacity to access the

resources needed to meet their needs. For example, by learning about the social service and

legislative systems, and how they function, parents may develop the skills to effectively utilize

these systems (Zirpoli, Wieck, & McBride, 1989). In addition, a major contribution of this study

is the attention it draws to a group of people who despite oppressive conditions (e.g.,

socioeconomic, political, linguistic, and cultural) continue fighting for social justice and equality.

The parents and I hope that by acquainting others with their work they are able to establish

additional collaborative relationships from which they may obtain various forms of support for

their efforts.

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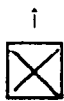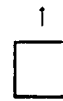| The sample sticker shown below will be affixed to all Level 1 documents	The sample sticker shown below will be affixed to all Level 2A documents	The sample sticker shown below will be affixed to all Level 2B documents
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