Recruiting Latino and Non-Latino Families in Pediatric Research: Considerations from a Study on Childhood Disability

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Objective To improve representation of minorities in research, we examined recruitment methods from our study of Latino and non-Latino families of children with Intellectual Disability (ID). Method We compared recruitment strategies that yielded the enrollment target of 200 matched Latino and non-Latino families of children with ID and controls. Active recruitment strategies involved direct contact with potential participants; passive strategies included disseminating study information. Results Effective outreach focused on community agencies where children had ongoing involvement and utilizing bilingual/bicultural staff. Latino families were significantly more likely to be recruited by an active strategy than non-Latino families. Active and passive strategies were both effective with non-Latino ID families. Asking research participants to inform other families about the study and sharing consent to contact lists with other investigators was productive with control families. Conclusions Bilingual staff and active recruitment through familiar community services were successful in recruiting Latino families for research.

Key words family; Latino; minority recruitment.

There is increased focus on expanding minority representation in clinical research to improve generalizability of results and to assist in reducing health-care disparities (USDHHS, 2002). Wendler et al. (2006) found that when they were invited to participate, minorities were as willing as non-Hispanic whites to consent to participate in health research. Therefore, it has been recommended that investigators make research projects more accessible to minorities and document and evaluate the effectiveness of strategies used for the recruitment and retention of minority participants (USDHHS, 2002; Wendler et al., 2006). There are two major types of recruitment strategies (Yancey, Ortega, & Kumanyika, 2006). Active strategies involve direct contact with potential participants, either in person or by telephone. Passive strategies involve distributing information about the study through posting flyers, mailings, and mass media including television, radio, internet, magazines, and newspapers.

Outreach to minority populations has been complicated by language, cultural, and socioeconomic differences, decreased access to health-care services, and lack of trust and experience with research projects (Yancey, Ortega, & Kumanyika, 2006). To increase recruitment of minority participants, recommended practices include improving communication about the study goals and benefits to potential participants and to clinical and community recruitment sources, developing specific goals and plans for minority recruitment, and reducing logistical barriers to
participation such as being flexible in scheduling appointments and assisting with transportation and childcare (USDHHS, 2002; Yancey et al., 2006). While these practices are applicable to recruitment of non-minorities as well, they address issues identified as hindrances to minority participation including the need to improve trust with researchers and to increase access to research projects (USDHHS, 2002).

Yancey et al. (2006) reviewed the recent literature on recruitment of minority adult research participants. However, little work has been published on the enrollment of minority children in research. Although Latinos are the largest and the youngest minority group in the United States (Pew Hispanic Center, 2009), Latino children have been underrepresented in pediatric research (Kelly, Ackerman, & Friedman Ross, 2005). Two recent studies described efforts to enroll Latino adolescents in clinical trials (Sweeney, Robins, Ruberu, & Jones, 2005; Villarruel, Jemmott, Jemmott, & Eakin, 2006). Both highlighted the importance of having bilingual study materials and research personnel and of establishing relationships with schools, parents, and Latino community leaders for the recruitment and retention of Latino families in clinical research. Both articles described their outreach efforts but did not report specific data such as the number of agencies involved, how they contacted potential participants, or how many families were screened and agreed to participate.

Similar to studies describing the recruitment of adults for clinical research, we documented our experiences recruiting families for a study about siblings of children with and without a disability. To address the paucity of information on minority recruitment in the pediatric literature, the aim of this study was to provide a comprehensive account of our recruitment and enrollment of Latino and non-Latino Caucasian children and families. Our project (Lobato et al., 2011) on cultural factors affecting families with children with disabilities provided a unique opportunity to evaluate the recruitment strategies used with four different populations. We examined the psychological functioning of Latino siblings of children with Intellectual Disability (ID). Most research on the impact of a child’s disability on well siblings has been based on families of European–American descent. The cultural context of sibling adaptation is seldom considered. To assess the influence of cultural and familial factors on siblings’ psychological functioning, we compared Latino (LID) and non-Latino (NLID) siblings of children with ID to matched Latino control (LC) and non-Latino control (NLC) siblings of typically developing children. There were multiple eligibility criteria and the project required participation of a parent and a well sibling from each family.

Details of the project including full demographic characteristics of the sample and primary findings are reported elsewhere (Lobato et al., 2011). The purpose of the current study was to report data on the screening and enrollment of participants and on the methods and sources of recruitment, and to compare the effectiveness of different strategies for the four groups (i.e., LID, NLID, LC, and NLC). Given our multiple eligibility criteria involving populations of different cultural and socioeconomic backgrounds, we planned to use a variety of recruitment methods simultaneously and anticipated the need to focus on active recruitment strategies in order to identify eligible participants for each of the four groups.

Further, we hypothesized that enrollment of Latino families would require increased use of active, as opposed to passive, strategies related to both socioeconomic and cultural reasons. Due to the likelihood of more language barriers and lower literacy levels among the Latino families (DeNavas-Walt, Proctor, & Smith, 2009), we expected that printed or computer-based recruitment materials would have less penetration in that community. Culturally, Latinos from diverse regions share a familistic and collective orientation, whereby individuals are socialized to be sensitive to and accommodate the feelings of others (Triandis, 1994). This collective orientation is reflected in the Latino cultural concept of personalismo, wherein great value is placed on interpersonal relationships and interactions (Antshel, 2002). Thus, we anticipated that Latino families would respond more favorably to recruitment strategies involving direct personal contact.

**Methods**

**Participants**

Our recruitment goal was 100 (50 LID and 50 NLID) siblings and parents of children with ID, and 100 (50 LC and 50 NLC) siblings and parents of typically developing children to serve as controls. All families had to meet the following inclusion criteria: (a) the participating parent was a primary caregiver of the children; (b) one child, the well sibling, was 8–15 years old; (c) one child, the index child, was 3–18 years old; and (d) the sibling and index child were biologically related and lived together. In the ID families, the index child had a documented diagnosis of developmental delay or ID made at least 6 months prior to the study. For the well sibling and for all of the children in the control group families, the children had no history of disability or illness requiring special education services, therapy, inpatient hospitalization, or emergency room visit over the past year. For a sibling to be considered of Latino descent, one or both parents had to self-identify as
being first- or second-generation Latino. For non-Latino siblings, parents had to self-identify as being non-Latino and Caucasian.

In the 200 families enrolled in the study, the well siblings (44% male) had a mean age of 11.73 years and 75.5% were older than the index child (mean age = 9.05 years). The Latino siblings were self-identified as Dominican (42%), Puerto Rican (14%), Central American (21%), or other Latino (23%) group. All non-Latino siblings self-identified as Caucasian. Participating parents had a mean age of 39.35 years. Latino families had an average family per capita income of $7,332.78 and 70% were two-parent households. Non-Latino families had an average family per capita income of $13,448.18 and 78% were two-parent households. For the 100 index children with ID, parents reported the following comorbid diagnoses in addition to the ID: chromosome disorder such as Down syndrome (40%), autism spectrum disorder (20%), neuromuscular disorder such as cerebral palsy (5%), or neurological disorder such as seizure disorder (4%).

We attempted to match the control families to the ID families based on the index child’s gender, the well sibling’s gender and birth order relative to the index child, and the families’ economic status. The study and all recruitment methods had the approval of the hospital Institutional Review Board. All participants provided written consent and assent before their participation in this study. The research protocol consisted of a 90-min parent interview and a 60-min sibling interview. Parents and siblings were interviewed separately and both interviews were completed in one visit.

Study recruitment was conducted primarily in Rhode Island and also in neighboring areas in Connecticut and Massachusetts. According to the U. S. Census Bureau (2006–2008 American Community Survey), about 11% of the Rhode Island population is Latino and the largest Latino subgroups are persons of Puerto Rican, Dominican, and Central American origin.

Recruitment Planning

The research team met weekly to organize and monitor recruitment activities and to track progress toward recruitment goals. The principal investigator and the two primary research assistants were bilingual, bicultural, and of Hispanic descent. We prioritized recruitment of ID families, and then recruited control families to match the ID families.

To reduce barriers to participation, the research team developed bilingual study and recruitment materials including flyers, media announcements, consent-to-contact forms, and postcards. Latino participants completed interviews in the language of their choice. Interviews were scheduled at a time and location convenient for the family including their home. Families who chose to be interviewed at the research office were compensated for transportation and parking. All families were compensated $100 for completing the study.

Recruitment Sites

The research team contacted personnel at multiple agencies who agreed to serve as sources of recruitment for participants and who signed letters of commitment to our project. We obtained Health Insurance Portability and Accountability Act (HIPAA) waivers when identifying potential participants from clinical centers affiliated with our center. Four cooperating community agencies brought our research assistants onto their administrative staff as volunteers. The research assistants completed required formal training to become volunteers at the agencies and in that capacity they contact families on behalf of the agency for recruitment into the research study.

For recruitment of families for all four groups, we contacted pediatric practices, schools, and community agencies serving children and families. To recruit ID families, we contacted pediatric specialists, hospital-based pediatric specialty and clinical programs, community agencies serving children with special needs, and community organizations for individuals with disabilities. To recruit Latino families, we targeted providers and agencies that predominantly served the Latino community, had bilingual staff, and were located in cities with a culturally diverse population. To recruit control families, we collaborated with investigators at the Bradley Hasbro Children’s Research Center to identify research projects where parents had signed consent to be contacted for future studies. To recruit participants with a range of economic status, we contacted agencies that served lower income families such as food pantries.

Active Recruitment Strategies

Active strategies involve direct communication with potential participants and require more time and effort.

Presentations and Events

The research team gave presentations, obtained consent to contact forms, and provided recruitment materials for distribution at three parent support groups and the parent advisory councils of three school departments. The research team attended three annual Back to School events for families sponsored by local public schools and obtained consent to contact forms from parents. We distributed recruitment materials and obtained consent to contact
forms at 14 community events including health fairs, resource fairs, and recreational events for the general public and for families with children with special needs.

**Telephone Contact**
Research assistants called families from four collaborating pediatric practices, and two hospital-based and three community-based programs for children with special needs. They also called families from consent to contact lists provided by five other research projects.

**Word of Mouth**
Research assistants informed families about the study through their personal contacts (e.g., church). Parents who completed the study were given postcards to distribute and were asked to let other families know about the project.

**Passive Recruitment Strategies**
We used passive strategies where recruitment materials were distributed to inform potential participants about our study. Interested families contacted the project by calling the research office, sending in prepaid postcards, or leaving consent to contact forms at recruitment sites to be collected by research staff.

**Information Dissemination**
Recruitment materials were placed in the waiting areas of 18 pediatrician offices and 5 pediatric specialty programs. The research team gave presentations and provided recruitment materials for distribution to families at one hospital-based and five community-based programs serving children with special needs, and two community organizations for individuals with disabilities. Research assistants gave recruitment materials to agencies to distribute to families. They gave materials to a variety of school programs including eight public schools, eight private schools, two charter schools, two schools for children with disabilities, two Head Start centers, and four daycare centers. One public school department sent a telephone message about the study to 600 families with a child with special needs. Recruitment materials were given to five agencies serving children with special needs and to eleven agencies for lower income families including eight food pantries, two public housing complexes, and one community center. Our recruitment materials were available at an additional seven community events for the public and for families with children with special needs.

**Mailing**
Study information was included in mailings sent out by one pediatrician, one research project, and four community organizations for children with special needs. A managed care health plan included study information in two editions of their bilingual newsletter.

**Website**
Study information was posted on the website or listserv of three community agencies for children with special needs, one website for the local Latino community, and two websites for the general public.

**Media**
The principal investigator wrote an article for a bilingual magazine for the Latino community and participated in two radio shows, one targeting the Latino community and one targeting families with children with special needs.

**Data Collection**
Research assistants documented all recruitment activities. For each agency, they documented the date and outcome of meetings and telephone calls with agency staff, the type of recruitment materials provided, the recruitment activities completed by or with the agency, and the research team’s presentations and attendance at agency events. They also kept a log documenting the referral source and the date received of all consent to contact forms and postcards.

There was a two-step process for determining study eligibility. In the first step, bilingual research assistants completed telephone screenings with parents and documented the recruitment source and the method of referral to the research project, family demographic information, and parents’ responses to our eligibility questionnaire. Families who were eligible based on the initial telephone screening and agreed to participate were seen for the study interview. In the second step, we verified that the family met all inclusion and exclusion criteria by obtaining additional information from parent interviews and from records requested with parental permission. We obtained teacher reports about siblings to verify that they did not have a disability requiring services, and we obtained medical or school records about the child with ID for documentation of their disability.

**Results**
Recruitment was completed over a 2.5-year period during which 400 families were screened and 200 eligible families were enrolled and completed the study. Enrollment of the LID families was completed in the first 21 months of the study. The majority (94%) of the NLID families were enrolled during the first 18 months and the remaining 6%
were recruited over the following 8 months. Enrollment of the LC families was completed during the first 2 years of the study and most (68%) were recruited during the second year. Half (48%) of the NLC families were enrolled during the first 2 years, and the remaining 52% were enrolled during the last 6 months of recruitment.

Chi-squared analyses were used to compare the four groups. Figure 1 shows the number of potential participants at each step of the screening, eligibility, and enrollment process. Based on the initial telephone screening, 241 (60%) of the 400 families screened were eligible for the study interview. Of the 241 families, the majority of eligible families from each of the four groups (87% LID, 84% NLID, 91% LC, and 91% NLC) agreed to participate and were interviewed. There were no significant group differences in agreement to participate. Based on additional information obtained after the interview, 12 families were determined to be ineligible. In the final sample, 200 eligible families completed the study, 29 eligible families declined to participate, and 171 families were ineligible.

Of the 171 families who were not eligible, the most frequent reasons for ineligibility were that the sibling had an illness or disability requiring services (38%), the children were not in the targeted age range (26%), and the families’ annual income did not meet study criteria for matching to other participants’ economic status (14%). All families ineligible based on income were non-Latino Caucasian families who reported higher annual incomes than most of the enrolled Latino participants.

Of the 400 families who were screened, there were 175 Latino families who self-identified as Dominican (42%), Puerto Rican (19%), Central American (17%), or other Latino (22%) group. The 202 families that self-identified as being Caucasian and non-Latino were designated as non-Latino. There were 23 families who reported being African American (39%) or another ethnicity (61%) that was not Latino or Caucasian, and were designated as Other Ethnicity and were ineligible.

The recruitment strategies used for the 400 families who were screened, listed by group, are presented in Table II. The LID families (80%) and the LC families (84%) were more likely to be recruited by one of the four active strategies (calling families from a patient list, calling families from a research list, the research team attending an event or presentation, word of mouth) in comparison to the NLID families (55%) and the NLC families (57%), $\chi^2 (3) = 28.97, p < .01$. In addition, the LID (2%) and the LC (1%) families were less likely to respond to mailings or website postings compared to the NLID (24%) and the NLC (23%) families, $\chi^2 (3) = 37.97, p < .01$. The NLC families were the most likely to be contacted from a research list in comparison to the NLID, LID, and LC families, $\chi^2 (3) = 24.37, p < .01$. The most frequent passive strategy for all families was seeing recruitment materials; most families recruited this way came across study information through schools (32%), pediatrician’s offices (20%), and hospital-based specialty programs (16%). Most families who were designed as Other Ethnicity responded to passive recruitment strategies.

![Figure 1. Screening, eligibility, and enrollment of participants.](image-url)
The recruitment sources for the 200 study participants are presented in Table I. Personal contacts were more productive recruitment sources for the LC and NLC families compared to the LID and NLID families, \( \chi^2 (3) = 21.67, p < .01 \). For both control groups, about half of the personal contact referrals were from previous study participants and half were from research assistants. The LC families were more likely to be recruited from schools compared to the other three groups, \( \chi^2 (3) = 14.29, p < .01 \). Most (86%) of the LC families’ school-based referrals were consent to contact forms that parents signed at Back to School events attended by the research team.

The recruitment strategies used for the 200 study participants are presented in Table II. The LID (74%), LC (88%), and NLC (68%) families were more likely to be contacted through active strategies compared to the NLID (54%) families, \( \chi^2 (3) = 14.47, p < .01 \). Active (54%) and passive (46%) strategies were both effective with NLID families. The NLID families were the most likely to respond to mailings about the study, and all of

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**Table I. Recruitment Source by Group**

<table>
<thead>
<tr>
<th>Group</th>
<th>Recruitment source</th>
<th>Pediatrician</th>
<th>Hospital specialty program</th>
<th>Community specialty program</th>
<th>Community agency</th>
<th>School</th>
<th>Other research project</th>
<th>Personal contact</th>
<th>Do not recall</th>
</tr>
</thead>
<tbody>
<tr>
<td>All families screened (N = 400)</td>
<td></td>
<td>25 (26.5)</td>
<td>27 (29)</td>
<td>10 (10.5)</td>
<td>9 (9.3)</td>
<td>10 (10.5)</td>
<td>2 (2)</td>
<td>11 (12)</td>
<td>0</td>
</tr>
<tr>
<td>LID (n = 94)</td>
<td></td>
<td>16 (20)</td>
<td>0</td>
<td>1 (1)</td>
<td>7 (9)</td>
<td>21 (26)</td>
<td>6 (7)</td>
<td>28 (33)</td>
<td>0</td>
</tr>
<tr>
<td>LC (n = 81)</td>
<td></td>
<td>10 (10.4)</td>
<td>34 (35.4)</td>
<td>35 (37)</td>
<td>8 (8)</td>
<td>1 (1)</td>
<td>1 (1)</td>
<td>6 (6.2)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>NLID (n = 96)</td>
<td></td>
<td>26 (24.5)</td>
<td>0</td>
<td>2 (2)</td>
<td>10 (9)</td>
<td>26 (24.5)</td>
<td>20 (19)</td>
<td>19 (18)</td>
<td>3 (3)</td>
</tr>
<tr>
<td>NLC (n = 106)</td>
<td></td>
<td>0</td>
<td>1 (12.5)</td>
<td>3 (37.5)</td>
<td>0</td>
<td>2 (25)</td>
<td>0</td>
<td>0</td>
<td>2 (25)</td>
</tr>
<tr>
<td>Other ethnicity</td>
<td></td>
<td>5 (33)</td>
<td>0</td>
<td>0</td>
<td>4 (27)</td>
<td>3 (20)</td>
<td>1 (7)</td>
<td>0</td>
<td>2 (13)</td>
</tr>
<tr>
<td>Control (n = 15)</td>
<td></td>
<td>0</td>
<td>1 (12.5)</td>
<td>3 (37.5)</td>
<td>0</td>
<td>2 (25)</td>
<td>0</td>
<td>0</td>
<td>2 (25)</td>
</tr>
</tbody>
</table>

*Group differences significant at \( p < .01 \) for all families screened.

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**Table II. Recruitment Method by Group**

<table>
<thead>
<tr>
<th>Group</th>
<th>RA called family from patient list</th>
<th>RA called family from research lista</th>
<th>Research team at event or presentation</th>
<th>Word of mouth</th>
<th>Mailinga</th>
<th>Websitea</th>
<th>Family saw recruitment material</th>
</tr>
</thead>
<tbody>
<tr>
<td>All families screened (N = 400)</td>
<td></td>
<td>52 (55)</td>
<td>2 (2)</td>
<td>10 (11)</td>
<td>11 (12)</td>
<td>2 (2)</td>
<td>0</td>
</tr>
<tr>
<td>LID (n = 94)</td>
<td></td>
<td>12 (15)</td>
<td>6 (7)</td>
<td>22 (27)</td>
<td>28 (33)</td>
<td>0</td>
<td>1 (1)</td>
</tr>
<tr>
<td>LC (n = 81)</td>
<td></td>
<td>41 (43)</td>
<td>1 (1)</td>
<td>5 (5)</td>
<td>6 (6)</td>
<td>23 (24)</td>
<td>1 (1)</td>
</tr>
<tr>
<td>NLID (n = 96)</td>
<td></td>
<td>9 (9)</td>
<td>18 (17)</td>
<td>14 (13)</td>
<td>19 (18)</td>
<td>11 (10)</td>
<td>14 (13)</td>
</tr>
<tr>
<td>NLC (n = 106)</td>
<td></td>
<td>0</td>
<td>1 (6.5)</td>
<td>3 (20)</td>
<td>0</td>
<td>3 (20)</td>
<td>1 (6.5)</td>
</tr>
<tr>
<td>Other ethnicity</td>
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<td>0</td>
<td>0</td>
<td>0</td>
<td>3 (37.5)</td>
<td>0</td>
<td>5 (62.5)</td>
</tr>
<tr>
<td>Control (n = 15)</td>
<td></td>
<td>0</td>
<td>1 (6.5)</td>
<td>3 (20)</td>
<td>0</td>
<td>3 (20)</td>
<td>1 (6.5)</td>
</tr>
<tr>
<td>Study participants (n = 200)</td>
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<td>0</td>
<td>3 (6)</td>
<td>7 (14)</td>
<td>2 (4)</td>
<td>0</td>
</tr>
<tr>
<td>LID (n = 50)</td>
<td></td>
<td>6 (12)</td>
<td>3 (6)</td>
<td>15 (30)</td>
<td>20 (40)</td>
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<td>0</td>
</tr>
<tr>
<td>LC (n = 50)</td>
<td></td>
<td>22 (44)</td>
<td>0</td>
<td>2 (4)</td>
<td>3 (6)</td>
<td>14 (28)</td>
<td>0</td>
</tr>
<tr>
<td>NLID (n = 50)</td>
<td></td>
<td>2 (4)</td>
<td>8 (16)</td>
<td>7 (14)</td>
<td>17 (34)</td>
<td>7 (14)</td>
<td>4 (8)</td>
</tr>
</tbody>
</table>

*Group differences significant at \( p < .01 \) for all families screened.
the mailings were from organizations for children with special needs. Website postings yielded the fewest eligible participants across groups.

Discussion

Although the importance of increasing minority representation in research is recognized, there have been few studies examining strategies for recruitment of minority children in clinical research. To address this gap in the literature, we examined the efficacy of recruitment methods for our study comparing Latino and non-Latino siblings of children with ID to Latino and non-Latino siblings of typically developing children. Once contacted, Latino and non-Latino families were equally willing to participate in the research project.

The primary recruitment challenge was having multiple study eligibility criteria and simultaneously enrolling for four different groups. Effective outreach efforts focused on recruitment sources where children and families had ongoing involvement, such as pediatricians and schools. Contacting families through familiar providers and agencies may have increased their willingness to respond to study recruitment.

The research team primarily used active recruitment strategies which were time- and labor-intensive, but were successful in identifying sufficient numbers of eligible participants. Having bilingual research staff and using active recruitment strategies were essential for outreach to Latino families. The majority of Latino ID and control families were contacted in person or by phone through formal relationships with health care and service providers and through informal relationships with people in their social network. The importance of interpersonal connections is consistent with the Latino cultural construct of personallismo and with our expectations that Latino families would respond to recruitment activities involving direct personal contact. Our results are consistent with previous studies that found direct contact to be effective in recruiting Latino adults in clinical research (Keyser et al., 2005; Larkey, Gonzalez, Mar, & Glantz, 2009; Rubin et al., 2002).

The passive strategies of mailings and website posting were not successful in reaching Latino families. Low literacy skills and less access to the internet may have been barriers for some Latino families, even when recruitment materials were available in Spanish (Fox & Livington, 2007). In general, website postings were a low-yield strategy for our study.

Targeted mailing was more effective for contacting NLID families. In addition, the majority of NLID families were recruited from programs and community organizations for children with special needs. The NLID participants tended to be higher income families who accessed specialty programs and were responsive to both active and passive strategies. We attempted to recruit families with a range of economic status and excluded a number of potential non-Latino families whose income level did not match the enrolled Latino families. We were able to match the four groups on characteristics of the siblings and the index children. However, many of the non-Latino families we contacted and enrolled were more affluent than the Latino families which reflected general socioeconomic characteristics of Latinos in the United States. Specifically, in comparison to non-Latino white households, Latino households have lower median incomes and lower rates of health insurance coverage (DeNavas-Walt, Proctor, & Smith, U.S. Census Bureau, 2009). Our finding that Latino and non-Latino families differed in economic status was consistent with many other studies and should be kept in mind for recruitment and research design of future studies.

Research participants were a resource for recruitment. Consent to contact lists from collaborators at a children’s research center were a referral source, particularly for NLC families. In addition, parents who completed our study responded to our request to inform other families about the project. It is a standard practice of our children’s research center to ask participants who complete any study to sign a consent to be contacted for future studies. In this way, past study participants serve as another recruitment source. Consistent with studies on adult research participants (Kennedy et al., 2005; Keyser et al., 2005), our results suggest that parents who previously participated in research studies were willing to take part in additional projects and to let others know about their experiences.

There are several limitations to the current study. The recruitment method and source were documented at the time of the telephone screening with participants. However, since multiple recruitment methods were used, families may have been informed about the study in more than one way. As there were overlapping recruitment strategies, we were not able to strictly test the efficacy of active versus passive strategies. In addition, active strategies were inherently more labor intensive than passive strategies which limit meaningful comparisons of the time and effort spent on the two types of recruitment strategies. Future studies can conduct planned comparisons of specific recruitment methods as part of their research design. However, more rigorous testing needs to be balanced with
flexibility in use of strategies in order to meet enrollment goals.

We did not document the cost of recruitment methods used, so information about the cost effectiveness of different strategies was not available. Our study had multiple eligibility criteria, required two family members to participate, had a focus on children with ID, and over-sampled Latino participants to ensure equal numbers in each group. Our results may not generalize to studies with fewer eligibility criteria, to the recruitment of populations with different ethnic backgrounds or with different diagnoses, or to recruitment conducted in other geographic areas. Finally, despite efforts to match on socioeconomic status, the groups differed in family income. Therefore, we cannot separate the effects of ethnicity and socioeconomic status on our results.

Despite the challenges of our eligibility constraints, our efforts were successful in meeting recruitment goals. A foundation of our success was drawing on relationships ranging from the individual level with word of mouth referrals to our project, to the institutional level with the research team establishing partnerships with agencies and other investigators. Our experiences demonstrated that a combination of recruitment strategies used with a variety of clinical and community programs and families were ultimately needed to identify and enroll eligible participants in our study. Based on our findings, the following strategies are recommended to improve recruitment of Latino and non-Latino children and families for clinical research:

- Employ bilingual research personnel and use bilingual study information for recruiting Latino participants.
- Allocate more time and resources for use of active strategies especially for recruiting Latino participants.
- Collaborate with health service providers, schools, and community agencies to recruit participants through ongoing agency activities (e.g., events, mailings).
- To recruit families with children with ID, collaborate with pediatric specialty providers and programs for children with special needs. To recruit Latino ID families, contact a wider range of sources such as pediatricians and schools in addition to specialty providers.
- Use word of mouth to recruit families through informal networks. Ask study participants to tell other families about the research project.
- Ask study participants to sign consent to contact forms.
- Network with other investigators to share contact lists.

Future studies can also track expenses, including staff time and materials, to evaluate the costs and yield associated with different strategies used to recruit participants from different minority populations.

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**References**


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