

# Brief Report: The Feasibility and Effectiveness of an Advocacy Program for Latino Families of Children with Autism Spectrum Disorder

Meghan M. Burke<sup>1</sup> · Sandra Magaña<sup>2</sup> · Marlene Garcia<sup>2</sup> · Maria P. Mello<sup>3</sup>

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**Abstract** Latino, Spanish-speaking families of children with autism spectrum disorder (ASD) face unique barriers in special education advocacy. Although advocacy programs are becoming more common in the United States, none of these programs target Latino families. This is a pilot study to examine the feasibility and effectiveness of an advocacy program for Latino families of children with ASD. Using a quasi-experimental design, 40 Latino family members of children with ASD participated in this study. Results demonstrated consistent attendance, low attrition, and high participant satisfaction. Intervention (versus control) group participants demonstrated significantly increased empowerment and special education knowledge, and stronger family–school partnerships. Findings provide preliminary support for advocacy programs for Latino families of children with ASD.

**Keywords** Advocacy · Empowerment · Family–School Partnership · Family · Services

## Introduction

Recognizing the importance of parent involvement, the Individuals with Disabilities Education Act (IDEA) embeds many rights for parents such as requiring their

consent for evaluations, placement, and special education services. However, parents often struggle to advocate for their children. Latino families of children with autism spectrum disorder (ASD) especially face obstacles in advocacy. For example, special education documents are only made available in English making it difficult for Spanish-speaking parents to advocate (Shapiro et al. 2004). Also, because of the jargon in IDEA, most interpreters do not effectively communicate everything that is said at individualized education program (IEP) meetings thereby relegating Spanish-speaking families to listening roles (Hughes et al. 2002). Furthermore, Latino (versus White) families are more likely to lack information about ASD and relevant services (Mercadante et al. 2009).

Advocacy programs tailored for Latino families may enable families to collaborate with the school and advocate for their children with ASD to receive appropriate services. Given the needs of parents of children with disabilities, special education advocacy programs are becoming increasingly common across the United States (Burke 2013). The purpose of this pilot study was to test the feasibility and effectiveness of the Latino Parent Leadership Support Project (LPLSP, Puente and Castillo 2015)—a 36-h, advocacy training for Spanish-speaking families of children with ASD. Feasibility was operationalized as organizational support (i.e., resources); recruitment and completion rate (i.e., attendance, and attrition); and satisfaction with the intervention (i.e., formative and summative evaluation) (Goddard and Harding 2003). The secondary aim of this study was to determine the effectiveness of the LPLSP on the empowerment, special education knowledge, family–school partnership, number of services, and parent–school communication of Latino families of children with ASD.

✉ Meghan M. Burke  
meghanbm@illinois.edu

<sup>1</sup> Department of Special Education, University of Illinois at Urbana-Champaign, 288 Education Building, 1310 S. 6th Street, Champaign, IL 61820, USA

<sup>2</sup> Department of Disability and Human Development, University of Illinois at Chicago, Chicago, IL, USA

<sup>3</sup> Department of Special Education, Vanderbilt University, Nashville, TN, USA

## Methods

### Research Design

A quasi-experimental control design, including quota sampling, was used. By using quota sampling, we explained to participants that placement in the intervention or waitlist control group was based on a “first come, first serve” basis relative to the number of slots available. Due to past experiences of discrimination, Latino individuals may distrust researchers (Magaña 2000). By being transparent about the sampling process, we tried to overcome such distrust. The first 24 participants who completed the pre-survey were enrolled in the intervention group; the remaining 16 participants completed the pre-survey and were enrolled in the control group.

### Participants

Overall, 40 participants were recruited. From the intervention group, there was little attrition ( $n = 4$ ). The four participants who withdrew from the LPLSP only attended the first session; they reported scheduling conflicts and expressed interest in attending a later training. Regarding the waitlist control group, we could not successfully contact four participants and, consequently, the four participants did not complete the post-survey. See Fig. 1. **Inclusionary criteria required that the participants be: (1) Latino, Spanish-speaking (but can also speak English); (2) older than 18 years of age; (3) willing to participate in the 36-h LPLSP; and (4) a family member of an individual with ASD.** The ASD diagnosis was confirmed by the Social Communication Questionnaire (SCQ; Berument et al. 1999). On average, participants ranged from 25 to 72 years of age. The children of the participants ranged from 3 to 19 years of age. There were no significant demographic or pre-survey differences between the intervention and control groups. See Table 1.

### Recruitment

To recruit participants, we collaborated with community-based organizations (CBOs), which served Latino families of children with ASD. By collaborating with CBOs, we ensured that the LPLSP and associated research was relevant to the participants (Magaña 2000). We collaborated with Parent Training and Information Center (PTI) and a support group, which served 450 Latino parents of children with ASD. Both CBOs distributed information about the LPLSP. Also, we distributed information to churches, clinics, and Spanish media outlets (i.e., newspapers, radio stations). This study was approved by the Institutional Review Board.

### LPLSP

The LPLSP was conducted by an attorney and an advocate who worked at a PTI; both individuals were parents of children with ASD, were Latina, and spoke Spanish. The individuals used their knowledge and curricular materials, examined the materials of the Volunteer Advocacy Project (an advocacy training for English-speaking families, Burke 2013), and an empowerment framework (Gutierrez 1990) to develop the LPLSP. The LPLSP curriculum was then reviewed by parents of individuals with ASD. The LPLSP entailed 36 h of instruction across nine sessions. The training and curricular materials were administered in Spanish. The measures were provided in Spanish by using the translation/back translation method (Brislin 1970) or existing Spanish versions of measures. Participants completed the pre/post measures of effectiveness prior to the first LPLSP session and at the end of the last LPLSP session, respectively.

### Treatment Fidelity

At each session, the research coordinator completed a treatment fidelity checklist. The first author also conducted treatment fidelity for 77.78 % ( $n = 7$ ) of the sessions. Inter-rater agreement was 95.45 %. Fidelity to the curriculum was 90.91 %.

### Measures of Feasibility

#### Attendance

Attendance was calculated for each participant as the total number of sessions attended.

#### Attrition

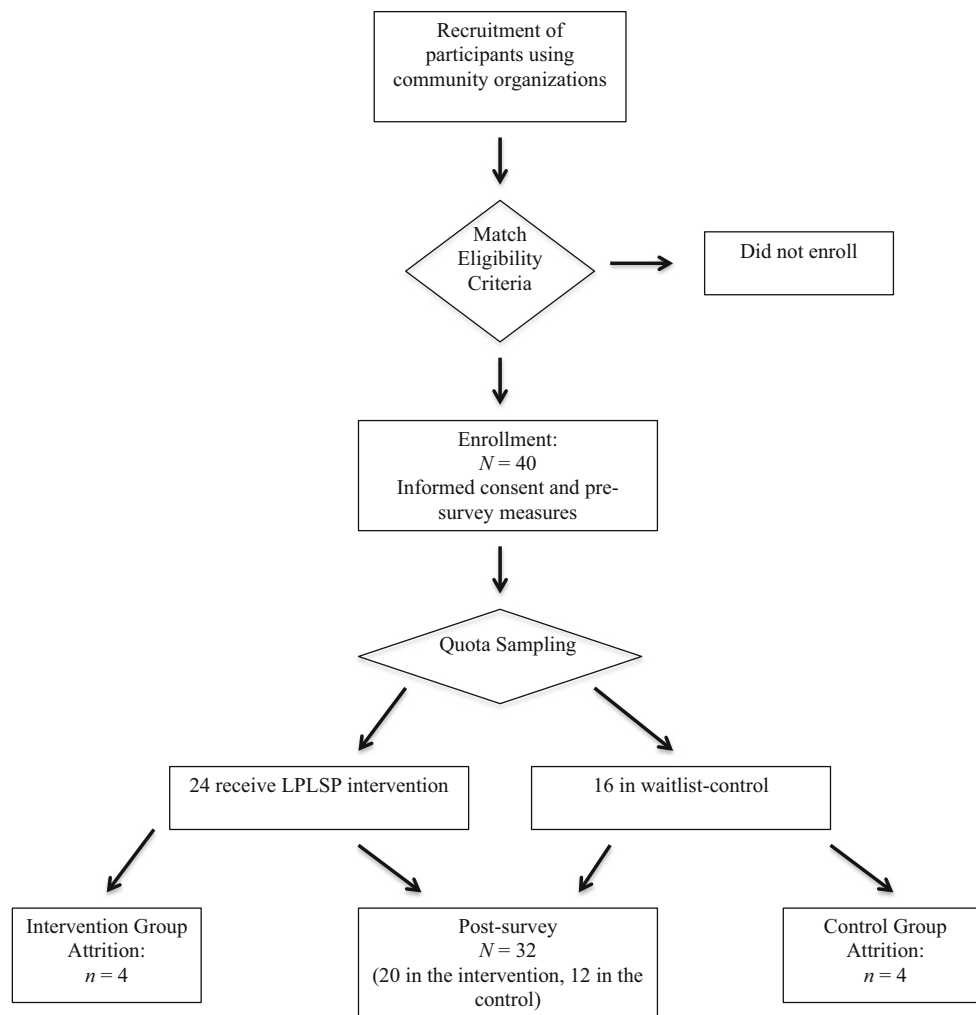
Attrition was calculated as the number of individuals who completed the LPLSP divided by the number of individuals who attended the first session of the LPLSP.

#### Participant Satisfaction: Formative Evaluation

The participants anonymously completed a formative evaluation at the end of each session. Comprised of four close-ended questions, the formative evaluation included “How satisfied were you with the presentation?”

#### Participant Satisfaction: Summative Evaluation

**The summative evaluation included questions such as “Did the LPLSP meet your expectations?” and “What kind of ongoing support would better enable you to advocate for**



**Fig. 1** Flowchart of study participants

families of children with disabilities?” Participants anonymously completed the summative evaluation at the last session.

## Measures of Effectiveness

### *Family–Professional Partnership Scale*

Using two subscales (Child-Focused and Family-Focused) with nine items apiece, the Family–Professional Partnership Scale measured the degree of partnership between a family and the school (Summers et al. 2005). For this study, Cronbach’s alpha was .92 and .95 for the Child-Focused and Family-Focused subscales, respectively. The Family–Professional Partnership Scale has been used and validated with Spanish-speaking families (Balcells-Balcells et al. 2011).

### *Special Education Knowledge Scale: Abbreviated*

Comprised of 10 multiple-choice questions about special education knowledge (Burke and Sandman, in press), each question was followed by four choices, one of which was correct. For this study, we created a cumulative variable ranging from 0 (i.e., no questions were answered correctly) to 10 (i.e., all questions were answered correctly); the Kuder–Richardson Coefficient was .68. This scale has been used with Spanish-speaking families (Burke and Sandman in press).

### *Family Empowerment Scale (FES)*

Including 34 items related to empowerment in three domains: Family, Service System, and Community/Political (Koren et al. 1992), the FES has been used with Spanish-speaking parents of children with disabilities

**Table 1** Participant demographics

Characteristic	Intervention	Control	$t/\chi^2$	$p$
Respondent type			1.96	.38
Mom	79.20 % (19)	93.75 % (15)		
Other	20.80 % (5)	6.25 % (1)		
Marital status			.464	.793
Married	58.30 % (14)	68.75 % (11)		
Not married	41.60 % (10)	31.25 % (5)		
Ethnicity			2.04	.36
South American	12.5 % (3)	6.25 % (1)		
Mexican	87.50 % (21)	87.5 % (14)		
Central American	—	6.25 % (1)		
Respondent age	41.67 (9.62)	44.67 (4.72)	−.12	.35
Education			.42	.81
Some high school	25.0 % (6)	31.25 % (5)		
High school graduate	41.70 % (10)	31.25 % (5)		
Some college	33.30 % (8)	37.50 % (6)		
Income			1.53	.68
Less than \$15,000	37.50 % (9)	25.0 % (4)		
\$15–29,999	29.20 % (7)	37.50 % (6)		
\$30–49,999	33.40 % (8)	37.50 % (6)		
Spanish proficiency*	10.25 (2.21)	9.82 (2.44)	−.52	.61
English proficiency**	5.33 (3.06)	6.73 (4.42)	1.08	.29
Years in the United States	14.96 (6.37)	18.81 (8.91)	1.45	.16
Child gender			.87	.35
Male	70.80 % (17)	87.50 % (14)		
Female	29.20 % (7)	12.50 % (2)		
Time in general education class			2.24	.69
0–20 %	37.50 % (9)	37.50 % (6)		
21–40 %	12.50 % (3)	—		
41–60 %	16.70 % (4)	18.75 % (3)		
61–80 %	20.80 % (5)	25.00 % (4)		
81–100 %	12.50 % (3)	18.75 % (3)		
Child age	8.13 (3.18)	7.84 (4.37)	−.22	.83

\* Range from 1 to 12, with 12 indicating excellent proficiency in Spanish

\*\* Range from 1 to 12, with 12 indicating excellent proficiency in English

(Canino et al. 2008). For this study, the FES had high reliability (Cronbach's alpha = .83, .80, and .82, for the Family, Service System, and Community/Political domains, respectively).

#### *Services Inventory*

Comprised of questions related to 13 related/supplementary services, participants were asked whether each service was received (Summers et al. 2007). Responses were dichotomous: “no” (0) or “yes” (1). We summed the number of services into a continuous variable ranging from 0 to 13. The Kuder–Richardson coefficient was .87.

#### *School Communication Scale*

Including seven items related to parent-school communication, we developed this scale based on extant literature; the scale was reviewed by Latino parents, and teachers and piloted with two Latino parents. Each question had a five point likert scale ranging from “not at all” (1) to “very often” (5). Cronbach's alpha was .87.

#### **Analyses of Feasibility**

For the quantitative formative and summative evaluation data, frequencies were conducted. For the open-ended

responses, we (i.e., the first and fourth authors) conducted constant comparative analysis (Glaser and Strauss 1989). Each piece of data was notated with a code. Then, codes were grouped into categories and categories were organized into themes.

### Analyses of Effectiveness

We conducted a power analysis and analyses of effectiveness. For the power analysis, we estimated the power of a Group x Time interaction using traditional assumptions (i.e., power = 80 %,  $p < .05$ ). The power analysis indicated that the needed sample size was 40 participants. Thus, this study was under-powered. Paired  $t$  tests and analysis of covariance (ANCOVAs) were conducted to determine the effect of the training. Paired  $t$ -tests were conducted to discern within group differences. In the ANCOVAs, pre-survey scores for the intervention and control group participants were controlled for. Notably, there were no significant differences between the intervention and control group with respect to demographic characteristics or pre-survey scores.

## Results

### Feasibility

#### *Organizational Support*

Storage and training space were made available by the University. If this training were to be conducted without a research component, the cost to conduct the LPLSP would be \$7838.

#### *Attendance and Attrition*

Attendance was high with 85 % ( $n = 17$ ) of participants attending 80 % or more of the training sessions. The attrition rate was low at 16.67 % ( $n = 4$ ).

#### *Satisfaction*

Across all of the individual sessions, at least 80 % of participants consistently reported being “very satisfied”. None of the participants reported being “unsatisfied” or “very unsatisfied”. Regarding the summative evaluation, 90 % ( $n = 18$ ) of participants reported that they were “very satisfied” and 10 % ( $n = 2$ ) were “satisfied” with the LSLSP.

In response to “Did the LPLSP meet your expectations?”, all participants reported that the LPLSP met their expectations. Participants reported that the LPLSP

provided them with valuable information as well as empowered them to advocate. Regarding information, one participant wrote, “Yes, I gained very valuable information.” Regarding empowerment, another participant wrote, “Yes, because I learned how to advocate for the rights that my son has.”

In response to “What kind of ongoing support would better enable you to advocate for families of children with disabilities?”, overwhelmingly, participants reported wanting “more training”. Indeed, 18 of the 20 participants reported wanting to attend the LPLSP again. Other participants reported wanting emotional support. One participant wrote, “I would like to have therapy as a family.” Another participant wrote “emotional help”.

### Effectiveness

For intervention participants, paired  $t$ -tests indicated significant within group differences with respect to: special education knowledge, empowerment, services, and the Family-Focused Subscale. See Table 2. The intervention (versus control) participants demonstrated significantly greater: special education knowledge,  $F(1, 29) = 32.89$ ,  $p < .001$ , partial  $\eta^2 = .53$ ; empowerment with respect to the: Family,  $F(1, 29) = 6.18$ ,  $p = .019$ , partial  $\eta^2 = .18$ ; Service System,  $F(1, 29) = 9.52$ ,  $p = .004$ , partial  $\eta^2 = .25$ ; and Political/Community,  $F(1, 29) = 6.50$ ,  $p = .016$ , partial  $\eta^2 = .18$ ; and Family-Focused subscale,  $F(1, 29) = 6.10$ ,  $p = .020$ , partial  $\eta^2 = .18$ . There were no significant differences regarding: communication, services, or the Child-Focused Subscale.

## Discussion

Although Latino families face unique barriers in advocacy, no programs have been directed toward meeting their needs. In this study, we examined the feasibility and effectiveness of an advocacy intervention (i.e., the LPLSP) for Latino families. We had two main findings.

First, the LPLSP was feasible for Latino families of children with ASD as demonstrated by high participant attendance and low attrition. Also, from the formative and summative evaluations, participants reported high levels of satisfaction. Second, intervention (versus control) group participants demonstrated significantly greater special education knowledge and empowerment. Results were consistent with the open-ended responses from the summative evaluation wherein participants also reported increased special education knowledge and empowerment. Such benefits may enable families to be better advocates for their children (Cohen 2013). Future research should include a randomized control trial of the effectiveness of

**Table 2** Pre/post survey differences

	Intervention					Control				
	Pre	Post	<i>t</i>	<i>p</i>	<i>d</i>	Pre	Post	<i>t</i>	<i>p</i>	<i>d</i>
Special education knowledge	2.35 (2.34)	5.35 (1.46)	−5.34	.001	1.24	1.92 (2.06)	1.42 (2.35)	.62	.55	.17
Empowerment: family	43.50 (5.92)	52.10 (5.78)	−6.23	.001	1.70	44.82 (7.41)	47.73 (8.31)	−1.31	.22	.39
Empowerment: services	41.05 (6.59)	52.25 (7.09)	−7.81	.001	1.55	42.67 (7.52)	46.00 (8.47)	−1.92	.08	.56
Empowerment: community	36.00 (6.22)	52.35 (5.10)	−9.16	.001	2.07	36.92 (5.55)	46.00 (8.47)	−4.34	.01	1.34
Number of services	4.40 (3.62)	6.25 (5.11)	−1.98	.06	.47	8.91 (4.70)	6.82 (6.03)	1.53	.16	.48
Family-focused subscale	31.00 (7.56)	35.75 (7.59)	−2.84	.01	.64	33.50 (7.97)	36.92 (7.53)	−1.02	.33	.33
Child-focused subscale	33.70 (6.91)	35.65 (6.55)	−1.45	.16	.32	36.36 (7.87)	41.91 (5.13)	−1.85	.10	.65
Communication with school	24.25 (6.36)	25.95 (6.64)	−1.08	.29	.24	24.08 (7.39)	25.58 (7.12)	−.63	.54	.18

the LPLSP as well as follow-up data to discern the maintenance of effects.

Notably, this study has some limitations. First, this was not a randomized control trial; as such, there may be undetected differences between the intervention and control groups. For example, more active participants could have registered first thereby biasing the intervention group. Notably, however, we found no significant differences between the intervention and control groups. Also, this study was underpowered to measure effectiveness. Second, all of the measures were self-report. With respect to the satisfaction questions, Latino individuals are more likely to respond positively (Davis et al. 2011).

In conclusion, this pilot study offers important implications about the feasibility and effectiveness of the LPLSP for Latino families of children with ASD. Related to advocacy, limited resources and supports exist for Latino families. The LPLSP may be one intervention which could assist Latino families in navigating the special education system and feeling empowered and knowledgeable to advocate for their children.

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**Author Contributions** Meghan M. Burke designed and directed this study and drafted the manuscript. Sandra Magaña consulted regarding the design and reviewed the manuscript. Marlene Garcia collected the data and reviewed the manuscript. Maria P. Mello analyzed the open-ended responses and reviewed the manuscript.

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#### Compliance with Ethical Standards

**Ethical Approval** All applicable international, national, and/or institutional guidelines for the care and use of animals were followed.

**Human and Animal Rights** All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and

with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

**Informed Consent** Informed consent was obtained from all individual participants in the study.

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