



Identifying the Correlates of Individual, Peer and Systemic Advocacy Among Parents of Children with Disabilities Who are Interested in Civic Engagement

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Abstract

Parent advocacy is often critical for families of individuals with disabilities. Prior research has suggested that parent advocacy occurs across three levels: individual, peer, and systemic. Yet, little empirical research has identified the correlates of advocacy for each level. For this study, we examined the survey responses of 246 parents of individuals with disabilities who were interested in participating in a legislative advocacy program. Analyses included hierarchical regressions to identify the correlates of individual, peer, and systemic advocacy. Parents of children with autism were significantly more likely to engage in individual advocacy. Parents who identified as Black (versus other racial groups) advocated significantly more on a systemic level. Further, malleable factors such as empowerment and motivation correlated positively with advocacy. Implications for research and practice are discussed.

Keywords Families · Advocacy · Disabilities · Empowerment

Advocacy is often critical for individuals with disabilities to access needed services across the lifespan. Indeed, from birth through old age, parents report having to advocate for their children with disabilities (Carlson & Wilt, 2020; Schraml-Block & Ostrosky, 2022). When parents advocate, there are benefits to the family (e.g.,

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improved empowerment and optimism, Burke et al., 2019) and to the individual with a disability (e.g., improved access to services, better educational programming, Taylor et al., 2017). However, there can also be negative patterns with advocacy. Indeed, parents report that greater advocacy is associated with greater maternal stress (Burke & Hodapp, 2014) and lower family quality of life (Wang et al., 2004). It may be that the greater stress and lower family quality of life is indirectly related to advocacy and more directly related to the poor receipt of services which causes parents to advocate. Nonetheless, parents overwhelmingly report that advocacy is key to raising their children with disabilities (Burke, 2012).

There are many different types of advocacy. In a study of 382 parents of individuals with disabilities from five states and Washington, D.C., Li and colleagues (in press) characterized advocacy in three ways: individual advocacy (i.e., advocacy for one's own child), peer advocacy (i.e., advocating for other families) and systemic advocacy (i.e., advocacy for all children with disabilities). Each type of advocacy loaded onto its own factor suggesting that each type reflects a unique form of advocacy. To date, few studies have examined the correlates of each type of advocacy. Instead, most studies aggregate all advocacy activities into one variable (e.g., Burke et al., 2019; Pearson & Meadan, 2021). By identifying the correlates of each type of advocacy, we may be able to recognize who is likely to conduct each type of advocacy and who is prone to little advocacy. Such information can help inform strengths to leverage and individuals to target for an advocacy intervention. Thus, the purpose of this study was to identify the correlates of individual, peer, and systemic advocacy among parents of individuals with disabilities.

Perhaps the most widely researched type of advocacy is individual advocacy. By conducting individual advocacy, the person with a disability may receive more appropriate services or be educated in the least restrictive environment (Burke et al., 2019); thus, there are important implications of individual advocacy for the person with a disability. Prior research has identified that parent and child characteristics may correlate with individual advocacy. Given the often-high advocacy expectation for families of children with disabilities (Rossetti et al., 2021), individual advocacy may require greater capital (e.g., income, formal education). Further, in light of the cultural mismatch in advocacy strategies (e.g., in some cultures, it may be considered disrespectful to disagree with a professional), there may be more systemic barriers barring families of color from engaging in advocacy (Harry & Ocasio-Stoutenburg, 2021). When considering child characteristics, in a national sample of parents of children with disabilities, older child age and the presence of autism related to significantly greater individual advocacy (Burke & Hodapp, 2016). Other characteristics such as special education knowledge, motivation to impact change, and family empowerment may also contribute to greater individual advocacy (Goldman et al., 2019).

Peer advocacy is common in the disability community wherein parents may naturally function as navigators or advocates for other families. The implications of peer advocacy is that it may help families receive more appropriate services for their children; the families who advocate for other families may feel more empowered themselves (Goldman et al., 2019). Families of color may especially participate in peer advocacy, leveraging their social capital (e.g., Magaña

et al., 2017) and transcending socioeconomic and educational backgrounds. With respect to child characteristics, families of children with more significant support needs may be less likely to participate in peer advocacy given the often-exorbitant demands on their time (Smith et al., 2014). Finally, when families are knowledgeable, empowered, and motivated, they often report wanting to engage in peer advocacy to “pay it forward” for other families (Goldman et al., 2019).

Systemic advocacy may benefit all individuals with disabilities by creating sweeping changes to legislation or policy. Of the limited extant research, it seems that there may be some correlates of systemic advocacy. For example, the parents who conducted systemic advocacy in some studies were characterized as well-educated, more likely to be White, and have higher income (Trainor, 2010; Wright & Taylor, 2014). However, few extant studies have specifically examined whether certain parent characteristics relate to systemic advocacy. In relation to child characteristics, it seems that parents of older (versus younger) children may be more likely to engage in systemic advocacy (Rossetti et al., 2021). Further, perhaps because of the large lobbying efforts of autism organizations, systemic advocacy may be more common among parents of children with autism (Callaghan & Sylvester, 2021). Alternatively, it may be that the extent of support needs (in relation to adaptive and/or maladaptive behavior) may relate to greater systemic advocacy—given the spectrum of autism, it is important to more carefully parcel out the correlates which may contribute to systemic advocacy. Finally, extant research has suggested that greater special education knowledge and empowerment may lead to more systemic advocacy (Smith-Young et al., 2022).

By understanding who is most likely to engage in each type of advocacy, we can determine who needs to be targeted for intervention because they are prone to low levels of advocacy. We can also discern facilitators to certain levels of advocacy—facilitators can be targeted in interventions to improve advocacy. Thus, for this study, we had three research questions: (1) What are the correlates of individual advocacy?; (2) What are the correlates of peer advocacy?; and (3) What are the correlates of systemic advocacy? Based on extant literature, we hypothesized that participants with more formal education and/or higher incomes would demonstrate higher levels of all advocacy activities because of their access to education and/or financial capital (Taylor et al., 2019). Because of the systemic barriers facing families of color (Harry & Ocasio-Stoutenburg, 2021), we hypothesized that parents of color would be significantly less likely to engage in all advocacy activities. According to Balcazar’s taxonomy of advocacy (1996), we hypothesized that peer and systemic advocacy activities would correlate positively with child age. Because of greater needs for services, we hypothesized that parents of children with autism, with fewer functional abilities, and/or greater maladaptive behaviors would be significantly more likely to engage in individual advocacy (Burke & Hodapp, 2016). We hypothesized that systemic advocacy may occur more in certain states given the state’s opportunities for parent engagement. Finally, we hypothesized that parents with greater special education knowledge, empowerment, motivation to impact change, and civic activity would be significantly more likely to engage in advocacy (Goldman et al., 2019).

Method

Participants

A total of 246 participants who were parents of individuals with disabilities were included in this study. The majority of participants were female and averaged 46.42 years of age ($SD=8.75$), with a range from 17 to 71 years. Over half of the participants were White. Regarding the children with disabilities, they were predominantly male and averaged 15.10 years of age ($SD=5.44$, range = 2–27 years). See Table 1.

Recruitment

Data were collected as part of a multi-state project to investigate the impact of a legislative advocacy program among parents of individuals with disabilities. Participants were recruited from five states in the U.S. (Illinois, Louisiana, Maine, New Mexico, and South Carolina) and Washington, D.C. The Parent Training and Information Centers (PTIs) located in each of the sites assisted with recruitment. To be included in the study, participants needed to complete the survey in English, have a school-aged child with a disability (ranging in age from 0–27), and indicate a willingness to participate in a civic engagement program. The legislative advocacy program was six hours in length; for more information about the program, see Rivera, 2020. Approval from the University Institutional Review Board was obtained for all study procedures and written consent was obtained from all participants.

Compliance with Ethical Standards

We received Institutional Review Board approval for this project. We have no conflicts of interest. All research involving human subject participants provided informed consent to be included in this study.

Procedures

Interested individuals completed the screening form (via RedCap) to determine whether they met the inclusionary criteria. If the individual met the inclusionary criteria, they were sent to the online consent form. After providing consent, the participant completed the survey. Participants could have assistance with completing the survey.

Measures

Dependent Variable: Parent Advocacy Activities

The Advocacy Activities Scale (Li et al., in press) was developed based on established measures about parental advocacy for special education rights (e.g., Burke et al., 2016) and the literature about advocacy for individuals with disabilities (e.g.,

Table 1 Participant demographic

Characteristic	% (n)
Relationship	
Mother	76.4% (188)
Father	14.2% (35)
Legal guardian	4.1% (10)
Other	4.1% (10)
Marital status: married	63.8% (157)
Race/Ethnicity*	
White	54.9% (135)
Black/African American	34.1% (84)
Hispanic/Latino	10.6% (26)
Asian/Pacific Islander	0.8% (2)
Indigenous	2.8% (7)
Other	1.6% (4)
Educational background	
High school diploma or less	11.0% (27)
Some college	23.2% (57)
College degree	34.1% (84)
Graduate degree	31.3% (77)
Annual household income	
Less than \$15,000	10.2% (25)
Between \$15–29,999	12.6% (31)
Between \$30–49,999	18.3% (45)
Between \$50–69,999	18.3% (45)
Between \$70–99,999	15.9% (39)
More than \$100,000	23.6% (58)
Site	
Illinois	18.7% (46)
Louisiana	10.2% (25)
Maine	12.6% (31)
New Mexico	17.1% (42)
South Carolina	25.2% (62)
Washington, D.C	15.0% (37)
Child with disability gender (Male)	66.3% (163)
Disability*	
Autism	48.0% (118)
Attention deficit/Hyperactivity disorder	35.0% (86)
Speech or language impairment	26.8% (19)
Learning disability	23.2% (57)
Emotional/Behavioral disorder	21.1% (52)
Intellectual disability	21.1% (52)

* Percentages do not add up to 100% as multiple responses could be checked

Balcazar et al., 1996). Comprised of 15 items (individual advocacy=7 items, peer advocacy=3 items, systemic advocacy=5 items), there is a 5-point Likert scale ranging from (1) *not at all* to (5) *very often* gauging the frequency of each advocacy activity. The summed score for each subscale was used to measure the level of involvement in parental advocacy, with higher scores equating to more involvement. Individual advocacy items included: “Called agencies to ask about services” and “Attended trainings about services and/or rights”. Peer advocacy items included: “Reviewed the records of another family to help them advocate” and “Helped another family communication with agencies and professionals”. Systemic advocacy items included: “Visiting the office or held meetings with legislators about disability issues” and “Wrote letters to legislators about disability issues”. Reliability was high for all three subscales: individual advocacy ($\alpha=0.88$), peer advocacy ($\alpha=0.83$), and systemic advocacy ($\alpha=0.90$).

Independent Variable: Site

We asked one question: “What site will you attend the training at?”. Responses included: Washington, D.C., Illinois, New Mexico, Maine, Louisiana, and South Carolina.

Independent Variable: Parent Educational Background

We asked one question about parent educational background: “Please choose your appropriate educational background”. Response options included: (1) *some high school*, (2) *high school diploma*, (3) *some college*, (4) *college degree*, and (5) *graduate degree*.

Independent Variable: Annual Household Income

We asked one question about the annual household income of the family. Response options included: (1) *less than \$15,000*, (2) *\$15–29,999*, (3) *\$30–49,999*, (4) *\$50–69,999*, (5) *\$70–99,999*, and (6) *more than \$100,000*.

Independent Variable: Racial Background

We asked participants to indicate their race and/or ethnicity. Options included: *White*, *Black/African American*, *Hispanic/Latino*, *Asian-American*, *Indigenous American*, and/or *other*. Participants could indicate more than one race and/or ethnicity.

Independent Variable: Child Age

We asked participants to provide their child’s age in years.

Independent Variable: Presence of Autism

One question was asked to determine whether the participant had a child with autism: “Do you have a child with autism?” Response options were: (0) *no* and (1) *yes*.

Independent Variable: Functional Abilities

We asked 15 items about functional abilities as measured by the Activities of Daily Living (ADL; Seltzer & Li, 1996). Participants were asked, “Can your child with a disability perform the following activities with total help, some help, or without help?” Items included: housework, laundry, and prepare meals. For each item there were three responses: (1) *with no help*, (2) *with some help*, and (3) *with total help*. Higher scores indicate fewer functional abilities. In this study, the Cronbach’s alpha was .91.

Independent Variable: Maladaptive Behavior

We used the 8-item Scales of Independent Behavior—Revised (SIB-R; Bruininks et al., 1996), which provides three subscales: internalizing behaviors (e.g., hurtful to self, repetitive, withdrawal), externalizing behaviors (e.g., hurtful to others, destructive to property, disruptive), and asocial behaviors (e.g., socially offensive, uncooperative), with higher scores inferring more serious maladaptive behaviors. Items include questions about frequency and severity. For this sample, Cronbach’s was 0.92.

Independent Variable: Special Education Knowledge

We asked 10 multiple choice questions about parent special education knowledge of IDEA (Burke et al., 2016). Each question had four response options; only one response option was correct. A sample item was “At what level does the federal government currently fund IDEA?”.

Independent Variable: Family Empowerment

Family empowerment was measured using the Family subscale of the Family Empowerment Scale (FES; Koren et al., 1992). Items are rated on a 5-point Likert scale from (1) *not at all true* to (5) *very true*. A sample item was “When problems arise with my child, I handle them pretty well.” Item scores are summed to form an overall score, with higher scores indicating greater empowerment. For this sample, Cronbach’s alpha was 0.92.

Independent Variable: Public Service Motivation

We used the 14-items Public Service Motivation Scale (Perry, 1996) to measure the willingness of the participant to provide services to others. A sample item

was “I am prepared to make enormous sacrifices for the good of society” For each item, there was a 5-point Likert scale ranging from (1) *disagree* to (5) *agree*. For this study, Cronbach’s alpha was 0.92.

Independent Variable: Civic Activity

We used a subscale of the Broad Civic Engagement Scale (Jackson-Elmoore, 2006) to examine civic activity of the participants. A sample item was “Have you volunteered or done any voluntary community service for no pay?” Response options included: (1) *Yes, I have in the last 12 months*, (2) *Yes, once a month or more* or (3) *Not within the last 12 months*. For this study, Cronbach’s alpha was 0.56.

Analyses

First, we conducted preliminary analyses to familiarize ourselves with the data. Specifically, we conducted descriptive statistics; see Table 2. We also reviewed the distributions of the scaled variables finding that the scales were normally distributed. We proceeded with parametric statistics. We conducted correlations among the independent variables (see Table 3) and a Variable Inflation Factor (which was below 2.5); thus, multicollinearity was not a concern (Tabachnik & Fidell, 2007). We then conducted individual hierarchical linear regressions with multiple imputation for each of the dependent variables (individual, peer, and systemic advocacy). The first model included site location variables to examine the influence of location. To examine the parent characteristics, the second model included parent demographic variables: education, income, and race. Given its more distal relation to advocacy, the third model included variables related to the child with disabilities: age, presence of autism, functional abilities, and maladaptive behavior. Because our main interest was to examine malleable variables, the fourth model included malleable characteristics: special education knowledge, family empowerment, motivation, and civic activity. Change in the amount of variance in individual and systemic advocacy accounted for at each step of the regression model was examined.

Table 2 Descriptives and correlations of the dependent variables

Variable	1	2	3	\bar{X}	<i>SD</i>
Individual advocacy	--	--	--	26.54	6.08
Peer advocacy	.527**	--	--	7.95	3.69
Systemic advocacy	.268**	.618**	--	10.07	5.73

* $p < .05$. ** $p < .01$. *** $p < .001$

Table 3 Multicollinearity among the independent variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. Site	--	--	--	--	--	--	--	--	--	--	--	--
2. Education	.095	--	--	--	--	--	--	--	--	--	--	--
3. Income	.210**	.464**	--	--	--	--	--	--	--	--	--	--
4. Race	-.204**	-.112	.185**	--	--	--	--	--	--	--	--	--
5. Child age	.037	.071	.044	-.104	--	--	--	--	--	--	--	--
6. Presence of autism	.125	.008	.044	-.091	-.062	--	--	--	--	--	--	--
7. Functional abilities	.082	-.042	-.091	.024	-.419**	.198**	--	--	--	--	--	--
8. Maladaptive behaviors	-.042	.175*	.132	.041	.169*	-.239**	-.227**	--	--	--	--	--
9. Knowledge	.218**	.215**	.247**	-.139*	.178**	.080	-.011	.110	--	--	--	--
10. Empowerment	.085	-.005	.026	-.065	.127	.063	.073	.045	.190**	--	--	--
11. Motivation	.447	.049	-.008	-.055	.054	-.018	-.019	-.031	.145*	.452**	--	--
12. Civic Activity	-.021	-.149*	-.162*	-.091	.052	.166*	-.027	-.122	.070	-.119	-.166*	--

* $p < .05$. ** $p < .01$. *** $p \leq .001$

Results

Correlates of Individual Advocacy

Site location factors did not account for a significant amount of variance of individual advocacy ($F(6, 239)=0.62, p=0.67$). After adding the second model (parent factors), the regression model did not explain more of the variance and was not significant, $F(17, 222)=0.88, p=0.60$. With the third model (child factors), the regression model explained significantly more variance ($\Delta R^2=1.9\%$, $F(4, 218)=3.07, p<0.05$). Specifically, participants of children with autism were significantly more likely to advocate for their child ($p<0.01$). Including the fourth model (malleable factors) significantly increased the variance accounted for by 19.7%, $F(4, 214)=15.07, p<0.001$. Participants who were more empowered advocated significantly more for their children ($p<0.001$). Participant motivation positively and significantly correlated with individual advocacy ($p<0.05$). Participants civic activity significantly and positively correlated with individual advocacy ($p<0.001$). Additionally, participants with children who had fewer maladaptive behaviors now demonstrated significantly greater individual advocacy ($p<0.05$). In total, the final model explained 21.6% of the variance ($F(31, 214)=3.62; p<0.001$) for individual advocacy. See Table 4.

Correlates of Peer Advocacy

Site location factors accounted for 5.3% of the variance of peer advocacy ($F(6, 239)=3.17, p<0.05$). When the second model (parent factors) was added, the regression model explained more of the variance ($\Delta R^2=3.9\%$), but this change was not significant, $F(17, 222)=1.56, p=0.08$. With the third model (child factors), the regression model explained more of the variance ($\Delta R^2=0.6\%$), but this change was not significant, $F(4, 218)=1.47, p=0.21$. Including the fourth model (malleable factors) significantly increased the variance accounted for by 8.6%, $F(4, 214)=9.35, p<0.001$. Specifically, participants who were more empowered advocated significantly more for other's children ($p<0.05$). Further, civic activities correlated positively with peer advocacy ($p<0.001$). In total, the final model explained 18.4% of the variance ($F(31, 214)=2.70; p<0.001$) for peer advocacy. See Table 5.

Correlates of Systemic Advocacy

Site location factors accounted for 14.0% of the variance of systemic advocacy ($F(6, 239)=6.69, p<0.001$). In particular, participants from Maine, New Mexico, and South Carolina were shown to advocate significantly less on a systemic level ($p<0.05$). With the inclusion of the second model (parent factors), the regression model explained significantly more variance ($\Delta R^2=6.2\%$, $F(17, 222)=2.11, p<0.01$). Specifically, participants who identified as Black/African American advocated significantly more for systemic change ($p<0.001$). After adding child

Table 4 Results of hierarchical regression analyses on individual advocacy

Independent variables	Model 1			Model 2			Model 3			Model 4		
	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>
Site												
Illinois	-.116	-.172	.864	-.066	-.095	.925	-.129	-.186	.853	-.552	-.878	.382
Louisiana	.071	.103	.918	-.043	-.061	.952	-.084	-.118	.906	-.637	-.975	.331
Maine	-.275	-.401	.689	-.307	-.436	.664	-.414	-.591	.556	-.913	-.1425	.157
New Mexico	-.189	-.276	.783	-.291	-.411	.682	-.323	-.461	.646	-.725	-.1129	.261
South Carolina	-.135	-.202	.840	-.134	-.194	.846	-.187	-.273	.785	-.649	-.1026	.307
Washington, D.C	-.386	-.565	.573	-.397	-.571	.569	-.400	-.582	.562	-.762	-.1194	.235
Parent factors												
Education				2.366	1.848	.066	2.344	1.852	.065	1.353	1.170	.244
Income				-1.137	-1.459	.146	-1.136	-1.473	.142	-0.739	-1.048	.296
Race (White)				.373	1.338	.183	.313	1.106	.270	.155	.606	.545
Race (Black)				.381	1.290	.199	.354	1.186	.238	.225	.822	.412
Race (Hispanic)				.356	1.314	.190	.250	.901	.369	.180	.725	.469
Race (Asian)				.420	.539	.590	.483	.622	.534	.336	.477	.634
Race (Indigenous)				.528	1.150	.251	.456	1.001	.318	.534	1.285	.201
Race (Other)				.738	1.174	.242	.586	.922	.358	.380	.663	.509
Child factors												
Age							-.049	-.346	.730	.004	.030	.976
Presence of autism							.041	2.661	**	.026	1.880	.062
Functional abilities							.094	1.158	.249	.012	.169	.866
Maladaptive behaviors							-.114	-1.376	.172	-.135	-1.907	*
Malleable factors												
Knowledge										.056	.733	.465

Table 4 (continued)

Independent variables	Model 1		Model 2		Model 3		Model 4		
	β	t	β	t	β	t	β	t	
Empowerment							.302	3.650	***
Motivation							.165	2.235	*
Civic activity							.170	2.343	***
F		.62						1.08	3.62
$Adj R^2$.000						.019	.216
ΔR^2		-						.019	.197

* $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$

Table 5 Results of hierarchical regression analyses on peer advocacy

Independent variables	Model 1			Model 2			Model 3			Model 4		
	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>
Site												
Illinois	.280	.482	.630	.307	.524	.601	.280	.475	.635	.081	.142	.887
Louisiana	.119	.198	.843	-.032	-.053	.957	-.054	-.089	.929	-.160	-.267	.790
Maine	-.640	-1.088	.277	-.554	-.930	.353	-.602	-1.000	.319	-.781	-1.335	.183
New Mexico	-.274	-.470	.639	-.359	-.601	.548	-.362	-.603	.547	-.475	-.811	.419
South Carolina	-.115	-.199	.842	-.156	-.269	.788	-.167	-.284	.777	-.314	-.547	.585
Washington, D.C	-.023	-.039	.969	-.196	-.338	.736	-.185	-.317	.752	-.237	-.415	.679
Parent factors												
Education				2.266	1.741	.084	2.257	1.743	.083	1.248	.954	.342
Income				-1.081	-1.170	.246	-1.067	-1.158	.251	-.703	-.766	.447
Race (White)				.069	.260	.795	.032	.118	.906	-.028	-.107	.915
Race (Black)				.519	1.860	.065	.504	1.780	.077	.378	1.394	.165
Race (Hispanic)				.547	2.105	*	.477	1.782	.077	.479	1.844	.067
Race (Asian)				.287	.391	.697	.359	.480	.632	.483	.669	.504
Race (Indigenous)				.593	1.431	.154	.543	1.305	.193	.538	1.350	.179
Race (Other)				.499	.812	.418	.389	.629	.530	.382	.631	.529
Child factors												
Age							-.064	-.468	.641	.027	.198	.844
Presence of autism							.023	1.572	.118	.020	1.372	.172
Functional abilities							.045	.600	.549	-.018	-.245	.807
Maladaptive behaviors							-.105	-1.275	.206	-.121	-1.519	.133
Malleable factors												
Knowledge										.057	.773	.441

Table 5 (continued)

Independent variables	Model 1		Model 2		Model 3		Model 4	
	β	t	p	β	t	β	t	p
Empowerment						.161	2.000	*
Motivation						-.026	-.320	.750
Civic activity						.275	3.533	***
F		3.17		2.12			1.76	2.70
$Adj R^2$.053		.092			.098	.184
ΔR^2		-		.039			.006	.086

* $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$

variables in the third model, an additional 2.2% of the variance in systemic advocacy was accounted for, an R^2 change that was significant, $F(4, 218) = 3.19, p < 0.05$. Including the fourth model (malleable factors) significantly increased the variance accounted for by 9.4%, $F(4, 214) = 7.85, p < 0.001$. Specifically, civic activities significantly and positively correlated with greater systemic advocacy ($p < 0.001$). The final model for systemic advocacy explained 31.8% of the variance ($F(31, 214) = 3.77; p < 0.001$). See Table 6.

Discussion

Parents often advocate for their children with disabilities across the lifespan; such advocacy includes individual, peer, and systemic advocacy. However, little is known about the correlates of specific types of advocacy. This study provides a launching point to identifying parent, child, and malleable correlates of each type of advocacy. Our study had four main findings. First, the correlates of advocacy activities differ depending on whether the advocacy occurs at the individual, peer, or systemic levels. This finding suggests that measures of advocacy activities should be de-aggregated as each type of advocacy is its own unique construct. Unfortunately, most extant literature combines all types of advocacy activities into a single scale (e.g., Burke et al., 2016). Thus, future research should consider using subscales of advocacy activities.

Second, unlike peer and systemic advocacy, child and malleable factors significantly correlated with individual advocacy. Combined child and malleable factors explained 21.6% of the variance. Unlike prior research which has focused on child and parent predictors of individual advocacy (Burke & Hodapp, 2016), this finding suggests that individual advocacy is driven by myriad factors. Further, this finding extends the literature by identifying several malleable factors explaining individual advocacy including: empowerment, motivation, and civic activity. The malleable factors of empowerment and motivation align with the intervention literature about advocacy, suggesting that when advocacy programs target empowerment and/or engage individuals who are motivated to impact change, there are significant increases in advocacy (Goldman et al., 2019).

Third, we know very little about the correlates of peer advocacy. Compared to individual and systemic advocacy, the model for peer advocacy explained only 18.4% of the variance; the only significant variables were empowerment and civic activity. The low variance explained by the majority of factors in relation to peer advocacy is problematic. Many advocacy programs rely on a cohort model emphasizing the importance of peer support and advocacy (e.g., Pearson et al., 2020; Magaña et al., 2017; Burke et al., 2016). Increasingly, navigator programs are being funded wherein navigators—often parents of children with disabilities themselves—provide peer support and advocacy to other families of children with disabilities (Burke et al., 2023). Given the surge in peer support programs, it seems crucial to understand the correlates explaining peer advocacy so such programs can be effective and provide needed supports to families.

Table 6 Results of hierarchical regression analyses on systemic advocacy

Independent variables	Model 1			Model 2			Model 3			Model 4		
	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>
Site												
Illinois	-.505	-.774	.441	-.398	-.611	.543	-.288	-.447	.656	-.436	-.709	.480
Louisiana	-.930	-1.420	.158	-1.089	-1.664	.099	-.953	-1.455	.149	-.971	-1.524	.131
Maine	-1.468	-2.256	*	-1.263	-1.956	.053	-1.148	-1.795	.075	-1.224	-1.988	*
New Mexico	-1.524	-2.374	*	-1.399	-2.169	*	-1.260	-1.965	.052	-1.264	-2.048	*
South Carolina	-1.298	-2.016	*	-1.252	-1.942	.055	-1.103	-1.731	.087	-1.141	-1.856	.067
Washington, D.C	-.763	-1.168	.245	-.910	-1.411	.162	-.810	-1.265	.209	-.761	-1.225	.224
Parent factors												
Education				2.484	2.195	*	2.600	2.320	*	1.511	1.397	.164
Income				-.496	-.720	.472	-.469	-.686	.493	-.040	-.060	.953
Race (White)				.301	1.217	.225	.279	1.126	.262	.261	1.114	.267
Race (Black)				.815	3.077	**	.805	3.082	**	.704	2.881	**
Race (Hispanic)				.312	1.291	.198	.317	1.282	.202	.322	1.389	.166
Race (Asian)				.276	.399	.690	.378	.548	.584	.448	.688	.492
Race (Indigenous)				.445	1.145	.254	.391	1.013	.312	.423	1.161	.247
Race (Other)				.473	.808	.421	.382	.652	.515	.501	.896	.372
Child factors												
Age							-.308	-2.434	*	-.190	-1.526	.129
Presence of autism							.016	1.100	.273	.016	1.140	.256
Functional abilities							.012	.162	.872	-.036	-.487	.627
Maladaptive behaviors							-.099	-1.328	.187	-.098	-1.266	.210
Malleable factors												
Knowledge										-.006	-.094	.926

Table 6 (continued)

Independent variables	Model 1		Model 2		Model 3		Model 4		
	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>	β	<i>t</i>	<i>p</i>
Empowerment							.088	1.210	.229
Motivation							.056	.788	.432
Civic activity							.301	4.293	***
<i>F</i>			6.69			2.81			2.60
<i>Adj R</i> ²			.140			.202			.224
ΔR^2			-			.062			.022

* $p \leq .05$. ** $p \leq .01$. *** $p \leq .001$

Fourth, Black parents were significantly more likely to engage in systemic advocacy. This finding is new to the literature as historically families of color, including Black families, face exacerbated and unique barriers to advocacy (Pearson & Meadan, 2018). However, this finding must be considered in the national racial reckoning, advent of Black Lives Matter, and broad attention to systemic racism (Harry & Ocasio-Stoutenberg, 2021). It may be that the culmination of multiple events that specifically impact Black families instigated systemic advocacy among Black individuals. Further, this finding aligns with research by Ocasio-Stoutenburg and Harry (2021) which situates parent advocacy within the broader context facing families of color. More research is needed to understand the complex interplay between race and systemic advocacy.

Further, research is needed to understand how policymakers and systems are responding to the greater systemic advocacy from Black individuals. It is important to hear from Black families to make systemic change and improve equity. However, the next step is to understand whether individuals in positions of power (e.g., lawmakers) are listening, responding, and addressing their concerns. In prior research about systemic advocacy of families of children with disabilities, parents reported advocating to their legislators with mixed responses—sometimes with no response from the legislators (Burke & Sandman, 2017). However, few Black families were included in that sample. Future research may include a case study of Black families who are advocating for a specific cause to holistically understand their advocacy effort and examine the responses of lawmakers.

Limitations

The findings of this study should be considered in light of its limitations. This study reflects a convenience sample of parents who registered for a civic engagement program. Thus, the findings may not be generalizable to the broader population. Notably, compared to the racial/ethnicity makeup of each state's population in this study, the racial and ethnic composition of our sample under-represents White individuals (55% in our sample versus 59% for the states), over-represents Black individuals (34% in our sample versus 20% in the states), under-represents Latino individuals (11% in our sample and 14% in the states), and under-represents Asian individuals (0.8% in our sample and 2.7% in the states). Future research is needed with a generalizable population that includes parents who may not be interested in a civic engagement program. Related to the sample, it may be that other participant characteristics influence advocacy (e.g., whether a parent is a foster parent or familial kin); unfortunately, we did not ask participants about their parenting status. Also, this study reflects cross-sectional data. Direction of effects cannot be assumed. This study also reflects participant self-report; the observation of advocacy activities (versus self-report of advocacy activities) may have different correlates.

Directions for Future Research

Although each of the models explained 18–31% of the variance in advocacy activities, there are more factors which could explain the remaining variance. For example,

recent research suggests that the profession of the parent (e.g., whether the parent is a special education teacher) could provide additional capital facilitating advocacy activities (Taylor et al., 2019). In examining the advocacy expectation, Rossetti et al. (2021) found that Yosso's community cultural framework (2005) can be applied to parent advocacy. Specifically, aspirational capital (e.g., expectations for one's child), resistance capital (e.g., willingness to challenge authority), linguistic capital (e.g., ability to speak multiple languages), social capital (e.g., one's social connections), familial capital (e.g., one's family network), and navigational capital (e.g., the ability to navigate complex systems) contribute to parent advocacy. In future research, such additional variables should be included in models to determine their effect in predicting advocacy activities at the individual, peer, and systemic levels.

There is also a need to examine advocacy activities over time. Proposed by Balcazar et al. (1996), the taxonomy of advocacy is linear, beginning with individual advocacy while one's child is young and then escalating to peer and systemic advocacy as the child ages. This study along with other cross-sectional research (e.g., Schraml-Block & Ostrosky, 2022; Li et al., in press) suggests advocacy activities are not linear. Longitudinal research can help discern how advocacy occurs and whether it changes over time. Further, longitudinal research with a diverse sample can help determine whether advocacy changes over time and, if so, when, for whom, and under what circumstances.

Implications for Policy and Practice

Policymakers may more closely examine states such as New Mexico and Maine wherein parents were significantly more likely to engage in systemic advocacy. It may be that policymakers have structures in place (e.g., Disability Day on the Hill) that provide a forum for parent advocacy. Conversely, it may be that there are more systemic issues impacting individuals with disabilities in those states which have prompted parent advocacy. Policymakers may closely examine the reasons for systemic advocacy and ensure there are ways to provide parents with opportunities to voice their concerns.

There are also several implications for practice. Increasingly, advocacy programs are becoming more common (Goldman et al., 2020). Such programs may struggle to identify the mechanism of action through which advocacy increases. This study suggests that, depending on the intended type of advocacy activity (i.e., individual, peer, or systemic), an advocacy program may identify a different mechanism. For example, if trying to increase individual advocacy, an advocacy program may target empowerment and motivation during the advocacy program. However, more research is needed to determine directionality between the potential mechanisms and each advocacy activity.

Practitioners may also consider the relation between civic engagement and advocacy. If conducting an advocacy program focused on systemic advocacy, practitioners may target civic engagement which may also help facilitate systemic advocacy. This finding further underscores the importance of not treating all advocacy activities as the same given their different correlates.

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Declarations

Conflicts of Interest There are no conflicts of interest.

Ethical Approval This study was approved by the University Institutional Review Board and was performed by the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments or comparable ethical standards.

Informed Consent All participants provided informed consent.

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References

- Balcazar, F. E., Keys, C. B., Bertram, J. F., & Rizzo, T. (1996). Advocate development in the field of developmental disabilities: A data-based conceptual model. *Mental Retardation-Washington*, *34*, 341–351.
- Bruininks, R. H., Woodcock, R. W., Weatherman, R. F., & Hill, B. K. (1996). Scales of Independent Behavior-Revised (SIB-Royal). Riverside.
- Burke, M. M. (2012). Examining family involvement in regular and special education: Lessons to be learned from both sides. *International Review of Research in Developmental Disabilities*, *43*, 187–218.
- Burke, M. M., Goldman, S. E., Hart, M., & Hodapp, R. M. (2016). Evaluating the efficacy of a special education advocacy training program. *Journal of Policy and Practice in Intellectual Disabilities*, *13*, 269–276.
- Burke, M. M., & Fulton, K. (2023). Developing the service inventory: A system to gauge the effect of advocacy on service access. *Behavior and Social Issues*, *32*, 474–481.
- Burke, M. M., & Hodapp, R. M. (2014). Relating stress of mothers of children with developmental disabilities to family-school partnerships. *Intellectual and Developmental Disabilities*, *52*, 13–23.
- Burke, M. M., & Hodapp, R. M. (2016). The nature, correlates, and conditions of advocacy in special education. *Exceptionality*, *24*, 137–150.
- Burke, M. M., Rios, K., & Lee, C. (2019). A pilot evaluation of an advocacy program on knowledge, empowerment, family-school partnership and parent well-being. *Journal of Intellectual Disability Research*, *63*, 969–980.
- Burke, M. M., & Sandman, L. (2017). The effectiveness of a parent advocacy training upon legislative advocacy. *Journal of Policy and Practice in Intellectual Disabilities*, *14*, 138–145.
- Callaghan, T., & Sylvester, S. (2021). Private citizens as policy entrepreneurs: Evidence from autism mandates and parental political mobilization. *Policy Studies Journal*, *49*, 123–145.
- Carlson, S. R., & Wilt, C. L. (2020). Learning about and qualifying for Home and Community-Based Services waivers: Families' perspectives and experiences. *Journal of Vocational Rehabilitation*, *53*, 17–28.

- Goldman, S. E., Burke, M. M., Casale, E., Fuller, M., & Hodapp, R. M. (2020). Families requesting advocates for children with disabilities: The who, what, when, where, why and how of special education advocacy. *Intellectual and Developmental Disabilities, 58*, 158–169.
- Goldman, S. E., Burke, M. M., & Mello, M. (2019). The perceptions and goals of special education advocacy trainees. *Journal of Developmental and Physical Disabilities, 31*, 377–397.
- Harry, B., & Ocasio-Stoutenburg, L. (2021). Parent advocacy for lives that matter. *Research and Practice for Persons with Severe Disabilities, 46*, 184–1998.
- Jackson-Elmoore, C. (2006). Influencing state policy: Information, access, and timing. *American Journal of Health Education, 37*, 159–169.
- Koren, P. E., Dechillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities: A brief questionnaire. *Rehabilitation Psychology, 37*, 305–321.
- Magaña, S., Lopez, K., & Machalicek, W. (2017). Parents taking action: A psycho-educational intervention for Latino parents of children with autism spectrum disorder. *Family Process, 56*, 59–74.
- Ocasio-Stoutenburg, L., & Harry, B. (2021). *Case studies in building equity through family advocacy in special education*. Teachers College.
- Pearson, J. N., & Meadan, H. (2018). African American parents' perceptions of diagnosis and services for children with autism. *Education and Training in Autism and Developmental Disabilities, 53*, 17–32.
- Pearson, J. N., & Meadan, H. (2021). FACES: An advocacy intervention for African American parents of children with autism. *Intellectual and Developmental Disabilities, 59*, 155–171.
- Pearson, J. N., Traficante, A. L., Denny, L. M., Malone, K., & Codd, E. (2020). Meeting FACES: Preliminary findings from a community workshop for minority parents of children with autism in Central North Carolina. *Journal of Autism and Developmental Disorders, 50*(1), 1–11.
- Perry, J. L. (1996). Measuring public service motivation: An assessment of construct reliability and validity. *Journal of Public Administration Research and Theory, 6*, 5–22.
- Rivera, J. (2020). Legislative advocacy among parents of children with disabilities: Nature, strategies, and barriers. *Journal of Special Education, 54*, 169–179.
- Rossetti, Z., Burke, M. M., Hughes, O., Schraml-Block, K., Rivera, J. I., Rios, K., Aleman-Tovar, J., & Lee, J. D. (2021). Parent perceptions of the advocacy expectation in special education. *Exceptional Children, 87*, 438–457.
- Schraml-Block, K., & Ostrosky, M. M. (2022). The meaning and nature of parental advocacy in the early years. *Exceptionality, 30*, 157–172.
- Seltzer, M. M., & Li, L. W. (1996). The transitions of caregiving: Subjective and objective definitions. *The Gerontologist, 36*, 614–626.
- Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2014). The family context of autism spectrum disorders: Influence on the behavioral phenotype and quality of life. *Child and Adolescent Psychiatric Clinics, 23*, 143–155.
- Smith-Young, J., Chafe, R., Audas, R., & Gustafson, D. L. (2022). “I know how to advocate”: Parents' experiences in advocating for children and youth diagnosed with autism spectrum disorder. *Health Services Insights, 15*, 23–39.
- Tabachnik, B. G., & Fidell, S. L. (2007). *Discriminant analysis: Using multivariate statistics*. Pearson.
- Taylor, J. L., Hodapp, R. M., Burke, M. M., Rabideau, C., & Waitz-Kudla, S. N. (2017). Training parents of youth with autism spectrum disorders to advocate for adult disability services: Results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders, 47*, 846–857.
- Taylor, S., Wright, A. C., Pothier, H., Hill, C., & Rosenberg, M. (2019). It's like I have an advantage in all this: Experiences of advocacy by parents of children with disabilities from professional backgrounds. *Journal of Sociology and Social Welfare, 46*, 159–172.
- Trainor, A. A. (2010). Diverse approaches to parent advocacy during special education home-school interactions: Identification and use of cultural and social capital. *Remedial and Special Education, 31*, 34–47.
- Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*, 144–155.
- Wright, A. C., & Taylor, S. (2014). Advocacy by parents of young children with special needs: Activities, processes, and perceived effectiveness. *Journal of Social Service Research, 40*, 591–605.
- Yosso, T. J. (2005). Whose culture has capital? A critical race theory discussion of community cultural wealth. *Race Ethnicity and Education, 8*(1), 69–91.

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