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Correlates of Individual and Systemic Advocacy Activities Among Siblings of Autistic Individuals

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Abstract:	While extensive research has focused on parent advocacy, the advocacy efforts of siblings of autistic individuals remain less studied. This study aims to identify the correlates of individual and systemic advocacy among siblings of autistic individuals. Using a national survey, 256 adult siblings of autistic individuals indicated their advocacy activities. Descriptive statistics and hierarchical regressions were used for analyses. Results indicated that while siblings often engaged in both individual and systemic advocacy, they present as distinct constructs with varying correlates. Older siblings, who engaged in future planning, and/or were knowledgeable about disability policy were more likely to conduct individual advocacy. Systemic advocacy was greater among siblings more connected to the disability community and had reciprocal exchanges of tangible support.

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Abstract

While extensive research has focused on parent advocacy, the advocacy efforts of siblings of autistic individuals remain less studied. This study aims to identify the correlates of individual and systemic advocacy among siblings of autistic individuals. Using a national survey, 256 adult siblings of autistic individuals indicated their advocacy activities. Descriptive statistics and hierarchical regressions were used for analyses. Results indicated that while siblings often engaged in both individual and systemic advocacy, they present as distinct constructs with varying correlates. Older siblings, who engaged in future planning, and/or were knowledgeable about disability policy were more likely to conduct individual advocacy. Systemic advocacy was greater among siblings more connected to the disability community and had reciprocal exchanges of tangible support.

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Siblings of autistic individuals often have varying roles. For example, adult siblings of individuals with severe disabilities, including autism, may serve as caregivers, advocates, and companions (Rossetti & Hall, 2015). Siblings may also serve as legal guardians or conservators, fiscal agents, and emotional supports (Lee et al., 2018). Such roles are often shaped by factors such as the sibling relationship quality, parental expectations, and the level of support needs of the autistic individual. Much research attention has focused on sibling caregiving roles including providing emotional support, daily care, and/or advocacy to the adult with a disability (Lee & Burke, 2018). Caregiving roles can also be influenced by myriad factors such as age, relationship quality, and parental involvement.

Less studied is the role of advocacy among siblings of autistic individuals despite sibling relationships being the longest-lasting familial relationships (Cicirelli, 2013). This is especially crucial as advocacy facilitates access to services for autistic individuals throughout their lives. Extending from infancy to old age, parents consistently report the need to advocate on behalf of their autistic offspring (Pearson et al., 2020). Research has shown that parent advocacy yields benefit not only for the autistic individuals (e.g., improved service access and quality education programming, Pearson et al., 2020; Taylor et al., 2017), but also the parents as well (e.g., increased empowerment and optimism, Burke et al., 2019). As siblings often outlive their parents, they may eventually assume primary caregiving and advocacy responsibilities for their autistic brothers and sisters. This transition can be critical, as siblings may need to navigate complex service systems and ensure continuity of care for their autistic siblings. Furthermore, siblings may experience a sense of responsibility and obligation to advocate for their autistic siblings, driven by their lifelong bond and commitment to their well-being. When a sibling is autistic, the sibling relationship may also entail caregiving responsibilities (Long et al., 2023), underscoring the importance of exploring the role of advocacy among siblings of autistic individuals.

There are many ways to characterize advocacy. Schneider and Lester (2001) proposed two types of advocacy: *case* (i.e., individual advocacy wherein the advocacy is focused on one individual) and *cause* (i.e., systemic advocacy wherein the advocacy efforts are focused on change for a group of individuals with disabilities). In one of the few studies about sibling advocacy, Burke and colleagues (2015) found that siblings of individuals with disabilities, including autism, characterized their advocacy efforts as either case (i.e., helping their own autistic brother/sister) or cause advocacy (i.e., helping spark systemic change for all individuals with disabilities). However, the correlates of case and cause advocacy are unclear. Indeed, the extant literature often conflates all advocacy activities into a single construct rather than different types of advocacy (e.g., Burke et al., 2016; Pearson et al., 2020). The purpose of this study was to identify the correlates of individual and systemic advocacy among siblings of autistic individuals. By distinguishing the correlates of types (e.g., individual [case] versus systemic [cause]) of advocacy, we may be able to identify who is likely to conduct individual and systemic advocacy and what support may be required for each type of advocacy. For example, siblings often play important roles in the lives of autistic individuals, including as advocates (Burke et al., 2019). Given the increasing incidence of autism in the United States (Interagency Autism Coordinating Committee, 2020) and the likelihood that adult siblings may share similar responsibilities as parent caregivers (Orsmond & Seltzer, 2007), it is important to understand the extent of advocacy activities among siblings of autistic individuals.

Many factors may impact individual advocacy. Characteristics of the caregiver and/or person with a disability may impact advocacy. In a national sample of parents of children with disabilities, older child age demonstrated a statistically significant association with greater advocacy (Burke & Hodapp, 2016). Further, the extant of sibling involvement as a caregiver may also impact advocacy. Caregiving can take an incredible amount of time (Smith et al., 2010)—if time is allocated to caregiving, then there may be less time for advocacy. When individuals have larger caregiving networks, they may have more time to allocate to other tasks (e.g., advocacy). With respect to caregiving tasks and domains, it is possible that the more areas of caregiving in which a sibling engages, the more likely they are to conduct advocacy. In a national survey of adult siblings of individuals with intellectual and developmental disabilities (IDD), including autism, Burke and colleagues (2012) found that caregiving was a unitary construct where a sibling who provided one aspect of caregiving (e.g., financial assistance) likely provided all aspects of caregiving. To date, there has not been a systematic examination of how caregiver characteristics impact individual and systemic advocacy.

Disability involvement may also contribute to advocacy. For example, special education knowledge equips individuals with the understanding needed to navigate educational systems and advocate for appropriate services (Trainor, 2010). With respect to systemic advocacy, research suggests that parents who are knowledgeable about special education, active in the disability community, and have attended trainings about disability policy, may be more likely to advocate not only for their children, but also for policy changes (Burke et al., 2020). Research also suggests that future planning and disability connectedness could relate to advocacy. Siblings of adults with IDD, including autism, often report that future planning is needed to ensure that their brothers and sisters with disabilities receive appropriate services in the future (Lee et al., 2019b). However, there are many barriers to future planning (e.g., lack of communication with family members, refusal to discuss one's mortality, Burke et al., 2018) that may require advocacy to overcome. Regarding disability connectedness, some extant advocacy programs for siblings of adults with IDD, including autism, are offered in peer, cohort models to build connections to the disability community (e.g., Burke et al., 2019). However, none of the abovementioned studies have systematically explored future planning or disability connectedness in relation to case or cause advocacy.

The quality of parent-child relationships may impact advocacy. In a study of parent advocacy with transition-aged youth with autism, parents who reported closer relationships with their offspring were significantly more likely to advocate (Author, submitted). Moreover, reciprocity may also impact advocacy. In a study of sibling reciprocity among siblings of individuals with IDD (including autism), siblings whose relationships were more reciprocal reported greater levels of systemic advocacy (Kramer et al., 2013). Yet, different aspects of reciprocity (i.e., emotional versus tangible) have not been examined as potential correlates to sibling advocacy.

Given the aforementioned evidence regarding sibling advocacy for autistic individuals, it is important to characterize individual and systemic advocacy. To this end, there were three research questions for this study: among adult siblings of autistic individuals, (1) what is the nature of individual and systemic advocacy; (2) what are the correlates of individual advocacy; and (3) what are the correlates of systemic advocacy?

We had several hypotheses: 1. Because siblings often fulfill more caregiving responsibilities as they age (Long et al., 2023), we hypothesized that age would positively correlate with both individual and systemic advocacy. 2. We hypothesized that siblings with more caregiving supporters, who engaged in more caregiving tasks and domains themselves, and who felt competent in their caregiving roles, would be more likely to engage in individual advocacy specifically. Indeed, greater caregiving tasks and domains often lead to a deeper understanding of the needs of their brothers and sisters (Burke et al., 2019), resulting in a greater drive to advocate. Feeling competent in caregiving roles enhances confidence (O'Malley & Qualls, 2017), thus, increasing the likelihood of individual advocacy. 3. Furthermore, we hypothesized that siblings who engaged in more future planning, had greater knowledge, sibling training support, and connectedness to the disability community would be more likely to conduct both individual and systemic advocacy. Siblings with greater knowledge (e.g., attendance at trainings, involvement in future planning) are more likely to understand the systemic issues (Heller & Kramer, 2009) and may be more likely to conduct systemic advocacy. 4. Based on prior research (Kramer et al., 2013), we hypothesized that siblings who had more emotional and tangible reciprocity with their autistic brothers and sisters would be more likely to engage in both individual and systemic advocacy activities as advocacy is one aspect of reciprocity.

Method

Participants

Participants included 256 siblings of autistic individuals. To be eligible for this study, participants were required to meet the following criteria: be over 18 years of age, willing to complete a web-based survey, and have a sibling (i.e., brother or sister) with autism. On average, participants were 32.93 years of age (*SD* = 10.98, range 20 to 73). The sample included participants from 39 states and Washington D.C.; no responses were received from residents of Alabama, Arizona, Delaware, Hawaii, Iowa, Mississippi, Montana, North Dakota, Rhode Island, Vermont, and West Virginia. Most participants were female (87.9%, *n* = 229), single (61.7%, *n* =

158), employed (83.2%, *n* = 213), identified as the primary caregiver of their sibling with autism (57%, *n* = 146), had children (27.7%, *n* = 71), cared for their parents (14.9%, *n* = 38), and were older than their sibling with autism (92.2%, *n* = 236). On average, the autistic siblings were 25.03 years of age (*SD* = 12.19, range 6 to 65). The full breakdown of participants' racial backgrounds and other demographic characteristics are presented in Table 1.

Recruitment

To recruit a diverse national sample, information about the survey was disseminated through several platforms. E-mails and recruitment flyers were distributed to the Sibling Leadership Network and its statewide chapters as well as local and state disability organizations. Additionally, since the number of organizations focused on siblings of individuals with disabilities are limited, 22 state and local chapters of The Arc, 67 University Centers for Excellence in Developmental Disabilities, and 7,843 agencies listed in the Yellow Pages for Kids with Disabilities were contacted. Specifically, agencies included: service providers (*n* = 3,025), advocacy and legal agencies (*n* = 1,725), schools and educational agencies (*n* = 1,386), nonprofit disability agencies (*n* = 1,271), and parent support groups (*n* = 436); also, efforts were made to recruit especially from organizations that serve racially and ethnically diverse communities. No compensation was provided for completing the survey.

Procedures

We developed the Adult Sibling Survey using multiple sources. First, we reviewed the literature about siblings of individuals with disabilities, including autism, to inform the survey measures (e.g., Lee et al., 2019a; Kramer et al., 2013; Burke et al., 2012). Then, we received feedback from three professors with research expertise about siblings of individuals with disabilities, five professionals in the autism field, and ten siblings of individuals with disabilities, including autism. Upon receiving their feedback, we revised the survey. We piloted the survey with five siblings of individuals with disabilities, including autism. Revisions were minimal (e.g., adding branching logic and correcting typos). For example, we revised a multiple-choice question to a ranked order question and added a response option with respect to family size.

All recruitment and study procedures were approved by the University Institutional Review Board. The survey was put onto a secure survey platform, Qualtrics. The survey was available from September 2018 to May 2019. There was a total of 250 questions. With branching logic, the survey took 20 to 25 minutes, on average, to complete. Although there was a paper and pencil option for the survey, all surveys were completed electronically. To access the survey, respondents were asked to click on the respective website link provided in the recruitment information which redirected them to a page with the study details and consent form before proceeding with the survey upon agreement of consent. Responses were stored on the Qualtrics survey platform.

Measures

Dependent variable: Individual Advocacy (Author, in press). The individual advocacy subscale of the Advocacy Activities Scale consisted of six items. While this subscale was initially developed for parent advocacy for their child with a disability, the items were adapted to represent advocacy for a sibling with a disability. Sample items included whether the respondent had ever: “searched the internet to find agencies and/or services to meet their sibling’s needs”. Questions were answered on a 5-point Likert scale: (1) *not at all* to (5) *very often*. A cumulative variable was used, ranging from 6 to 30. Prior studies have reported high reliability for this scale (e.g., Cronbach’s alpha = .88, Author, in press). For this sample, Cronbach’s alpha was .91.

Dependent variable: Systemic Advocacy (Author, in press). The systemic advocacy subscale of the Advocacy Activities Scale consisted of five items. This subscale was initially developed for parent advocacy for systemic changes in the disability field. The items were adapted to represent systemic advocacy as a sibling of an individual with a disability. Sample items included whether the respondent had ever: “visited the office or held meetings with legislators about disability issues?”. Questions were answered on a 5-point Likert scale: (1) *not at all* to (5) *very often*. A cumulative variable was used, ranging from 5 to 25. Prior studies have reported high reliability for this scale (e.g., Cronbach’s alpha = .90, Author, in press). For this sample, Cronbach’s alpha was .84.

Independent variable: Sibling Caregiver Age. Participants answered the year of their birth. Responses were then used to calculate the participant’s age (in years).

Independent variable: Caregiver Supporter Network. We created one item to determine the size of the sibling’s support network. Participants were asked “Who besides you is involved in caregiving or helping your brother/sister?”. Choices included: father/mother, other sibling, relatives, friends, community (church or neighbors), paid worker, or other. The types of supporters were chosen based on extant research about natural supports for siblings of adults with IDD (Sanderson et al., 2020). Similar to other research about families of adults with disabilities (e.g., Sanderson et al., in press), responses were summed into the total number of supporters.

Independent variable: Caregiving Tasks (Penrod et al., 1995). Participants were asked whether individuals (i.e., parents, other siblings, relatives, friends, community members, paid helpers, and others) help with direct assistance, financial assistance, or decision-making for their autistic siblings. Response options were binary: (0) *Not at all* or (1) *Some*. Items were summed up with higher numbers indicating receiving greater caregiving support from others. In a prior study, the Cronbach's alpha was .80 (Williams & Dilworth-Anderson, 2002). For this sample, the Cronbach's alpha was .63.

Independent variable: Caregiving Domains (Horowitz, 1985). Participants were asked "In which domains do you provide caregiving for your brother/sister with a disability?" for eleven domains of caregiving (e.g., transportation, household help). Response options were rated on a 5-point Likert scale ranging from (1) *never* to (5) *frequently*. A summed variable ranging from 11 to 55 was used for this study. Prior studies have reported high reliability for this scale (e.g., α = .94, Burke, Lee, & Arnold, 2019). For this sample, the Cronbach's alpha was .96.

Independent variable: Caregiving Problematic Issues (Perkins & Haley, 2010). Participants were asked eight questions about potential problems in caregiving for their autistic brother/sisters. Problems included "lack of adequate help from others". Each item was rated on a four-point Likert scale. The original study (Perkins & Haley, 2010) that used this scale reported high reliability (Cronbach's alpha was .86). In this study, the Cronbach's alpha was .90.

Independent variable: Caregiving Competence (O'Malley & Qualls, 2017). This is a subscale of the Caregiver Reaction Scale which appraises feelings of confidence and caregiving skills and ability. Items are scored using a 4-point Likert-type scale from (1) *not at all* to (4) *completely*. Higher scores indicate greater positive experiences. Prior studies have reported high reliability for this scale (e.g., Cronbach's alpha = .88, O'Malley & Qualls, 2022). For this sample, the Cronbach's alpha was .90.

Independent variable: Receipt of Sibling Supports. We created a measure describing the receipt of sibling support and training. This measure was created by two researchers, both of whom identified as siblings of adults with IDD; the measure was reviewed by 20 faculty members and siblings of adults with IDD, including autism. There were 10 supports: sibling support group, Partners in Policymaking (or similar leadership training), internet support group, future planning training, printed materials about caregiving, a peer mentor, training about adult disability services, training about person-centered planning, and trainings about other disability topics. Each item was dichotomous: (0) *no* or (1) *yes*. For this study, the items were summed into a composite variable. The Kuder-Richardson coefficient was .76.

Independent variable: Future Planning (Heller & Kramer, 2009). This scale consisted of eleven future planning activities such as: creating a letter of intent and locating an attorney. Response options were dichotomous: (0) *no* or (1) *yes*. A summed variable ranging from 0 to 11 was used for this study. In a prior study about siblings of individuals with disabilities, this scale had strong internal consistency (Kuder–Richardson coefficient = .86; Burke & Heller, 2016). For this sample, the Kuder–Richardson coefficient was .88.

Independent variable: Future Planning Barriers. Based on extant research about future planning for adults with IDD (Arnold et al., 2012), participants were asked whether they encountered ten barriers to future planning: lack of information; difficulty trusting the service delivery system; difficulty finding appropriate services; emotional barriers fighting the system for services; emotional barriers involved in thinking about mortality; procrastination; financial costs; disagreement with a family member about the future; family refusal; and other. Items were dichotomous (i.e., participants reported either [0] *this was not a barrier* or [1] *this was a barrier*). Items were summed up for this study. The Kuder-Richardson coefficient was .88.

Independent variable: Knowledge of Disability Policy (Author, submitted). Based on research with siblings about relevant disability policies (Burke et al., 2019), we created a measure to gauge their knowledge of six family support and disability policies (e.g., Home and

Community-Based Services; the Affordable Care Act). Responses were marked on a 4-point Likert scale ranging from (0) *I have not heard of it* to (3) *I am well-informed about this policy*. Responses were aggregated into a total score with higher scores indicating greater policy knowledge. In this study, reliability was also high (Cronbach's alpha = .81).

Independent variable: Disability Connectedness (Goscicki et al., in press). This measure included 10 items which asked participants about their degree of insiderness in the disability community. Items included "To what extent have you devoted time to disability-related groups, causes or activities?" and "To what extent do you have friends or socialize with parents of individuals with disabilities or individuals with disabilities themselves?". Response options ranged from (1) *not at all* to (5) *very much so*. In the original study establishing the reliability of the measure, there was high reliability (Cronbach's alpha = .88, Goscicki et al., in press). In this study, reliability was also high (Cronbach's alpha = .95).

Independent variable: Emotional Reciprocity (Perkins & Haley, 2013). Reflecting six items with a 5-point Likert scale (ranging from (1) *none* to (5) *a great deal*), the emotional reciprocity scale gauges the extent of emotional support given and received. Items included "How much companionship do you give your sibling?" and "How much companionship do you receive from your sibling?". Originally, the scale is scored from -12 to +12 with 0 reflecting balanced reciprocity. For ease of interpretation, the scale was transformed to range from 0 to 24 with 12 reflecting balanced reciprocity. In the original study of emotional reciprocity, the Cronbach's alpha was .75 (Perkins & Haley, 2013). In this study, the Cronbach's alpha was .89.

Independent variable: Tangible Reciprocity (Perkins & Haley, 2013). There were six items with each item having a five-point Likert scale ranging from (1) *none* to (5) *a great deal*, the tangible reciprocity scale gauges the extent of tangible support given and received. Sample items included "How much help do you give your sibling with cleaning tasks around the home?" and "How much help do you receive from your sibling with cleaning tasks around the home?". Originally, the scale is scored from -12 to +12 with 0 reflecting balanced reciprocity. For ease of interpretation, the scale was transformed for this study to range from 0 to 24 with 12 reflecting balanced reciprocity. In the original study of tangible reciprocity, the Cronbach's alpha was .93 (Perkins & Haley, 2013). In this study, the Cronbach's alpha was .74.

Analyses

All statistical analyses were conducted using the *R* statistical software. We used descriptive statistics (e.g., frequencies, means, standard deviations, and ranges) to examine the nature of individual and systemic advocacy. Two methods were used to identify multicollinearity between the independent variables: correlations above .65 (Burns & Grove, 2005) and Variance Inflation Factor (VIF) above 2.5 (Tabachnik & Fidell, 2007). None of the correlations were found to be high (i.e., r's $\leq .65$), and the VIFs were all below 2.5. Thus, multicollinearity was not a concern (see Table 2). To answer the latter two research questions, we conducted regression analyses. Specifically, hierarchical regressions were chosen to discern the variables in terms of characteristics of the sibling, aspects of caregiving, disability involvement factors, and sibling reciprocity which correlate with individual and systemic advocacy. The first block included one sibling demographic variable: age. The second block included sibling caregiving variables: caregiving tasks, caregiving domains, caregiving problematic issues, and caregiving competence. The third block included variables related to disability involvement by the sibling: receipt of sibling supports, future planning, disability advocacy, knowledge of disability policy, and disability connectedness. The fourth block included sibling reciprocity variables: emotional and tangible reciprocity. Change in the amount of variance in individual and systemic advocacy accounted for at each step of the regression model was examined. Given the number of variables in each regression model, we used Bonferroni correction when interpreting the significance of findings ($p < .01$).

Results

Nature of Individual and Systemic Advocacy

Using descriptive statistics, on average, individual advocacy scores were 14.40 (SD = 6.93), with scores ranging between 6 to 30. For systemic advocacy, participants averaged 7.97 (SD = 4.36; range = 5 to 25). The distribution of individual advocacy scores was positively skewed. The distribution of participants' systemic advocacy scores was also positively skewed. See Figure 1 for details.

Correlates of Individual Advocacy

The result of the hierarchal regression analysis for individual advocacy is presented in Table 3. The first block of variables accounted for 4.1% of the variance of case advocacy (F = 12.00, $p < .001$). Specifically, older participants were significantly more likely to advocate for their autistic sibling than younger participants ($p < .001$). With the second block, the regression model explained more of the variance (ΔR^2 = 15.7%), and was a significant increase, F (6, 248) = 9.28, $p < .001$. The number of caregiving problematic issues correlated positively with individual advocacy ($p < .001$). Including the third block increased the variance accounted for by 25.1%, an R^2 change that was significant, F (4, 244) = 29.15, $p < .001$. Future planning activities correlated positively with individual advocacy ($p < .001$). Participants who had greater future planning barriers advocated significantly more for their autistic siblings ($p < .001$). Participants who were more familiar with disability policy advocated significantly more for their autistic siblings ($p < .001$). Additionally, one variable from the second block in turn also significantly contributed to individual advocacy. The number of caregiving tasks that others (not the sibling without a disability) engaged in correlated positively with individual advocacy ($p < .01$). After adding sibling reciprocity variables in the fourth block, the regression model explained more of the variance ($\Delta R^2 = .8\%$), but this was not a significant increase, F (2, 242) = 2.83, $p = .06$. In total, the final regression model explained 45.7% of the variance ($F = 17.48$; $p < .001$) for individual advocacy.

Correlates of Systemic Advocacy

The result of the hierarchal regression analysis for systemic advocacy is presented in Table 4. The first block of variables accounted for 0.7% of the variance of systemic advocacy and was not significant ($F = 2.67$, $p = .10$). After adding sibling caregiving variables in the second block, an additional 7.3% of the variance in systemic advocacy was accounted for, an R^2 change that was significant, F (5, 248) = 4.05, $p < .001$. Caregiving problematic issues correlated positively with systemic advocacy ($p < .01$). Participants who felt more competent with their caregiving ability conducted more systemic advocacy ($p < .01$). Including the third block increased the variance accounted for by 37.3%, an R^2 change that was significant, F (4, 244) = 42.69, $p < .001$. Participants who were more connected with the disability community also conducted more systemic advocacy ($p < .001$). With the fourth block, an additional 0.7% of the variance in systemic advocacy was accounted for, an R^2 change that was significant, F (2, 242) = 6.64, $p = .002$. Specifically, participants had more reciprocal exchanges of tangible support reported greater systemic advocacy ($p < .01$). Additionally, one variable from the second block now also significantly contributed to systemic advocacy. Specifically, the number of caregiving tasks that others engaged in correlated positively with systemic advocacy ($p < .01$). The final regression model for systemic advocacy explained 47.0% of the variance ($F = 18.42$; $p < .001$).

Discussion

Siblings have the longest lasting familial relationship (Cicirelli, 2013). When a disability is present, sibling relationships may take on non-normative roles including caregiving and advocacy. Yet, little research has examined the nature of individual and systemic advocacy among siblings of autistic individuals. Using a national sample, this study was one of the first to examine correlates for different types of advocacy. We had three main findings. First, siblings conduct both individual and systemic advocacy. Some prior research has suggested that advocacy is conducted by siblings (e.g., Burke et al., 2015; Kramer et al., 2013). This study confirms that individual and systemic advocacy are conducted by siblings of autistic individuals, although to varying degree, with individual advocacy more prevalent in comparison to systemic advocacy. Further, this study suggests that advocacy may not be normally distributed among siblings; thus, advocacy may be especially important to many siblings of autistic individuals. In this way, this study extends the literature by suggesting that advocacy is important not only to parents (Burke, 2012) but also to other family members, such as siblings of autistic individuals.

With respect to correlates of advocacy, disability involvement matters for individual and systemic advocacy but in different ways. Altogether, this finding suggests the importance of disability involvement among siblings of autistic individuals. On one hand, this finding is not surprising. The more involved an individual is, the more likely they may be to engage in advocacy. However, in the context of siblings, this finding is more nuanced. Extant research has consistently found that siblings report struggling to be involved in the disability community. Specifically, siblings report struggling to: access trainings and workshops (Arnold et al., 2012), engage in future planning (Burke et al., 2018), learn about adult disability services (Hodapp et al., 2017), and engage in the disability community (Hodapp et al., 2017). This study underscores the importance of disability involvement and reinforces the need to mitigate barriers to involvement among siblings.

The significant finding on the different aspects of disability involvement also suggests that factors are distinct and nuanced. Future planning (including barriers) and knowledge of disability policy significantly and positively correlate with individual advocacy whereas disability connectedness significantly and positively correlates with systemic advocacy. From this finding, one can deduce several implications. For example, individual and systemic advocacy are unique constructs with different correlates. Relatedly, to improve individual or systemic advocacy, different correlates should be targeted. If a program is trying to improve individual advocacy, the program may target future planning (e.g., Future is Now, Heller & Caldwell, 2006). Conversely, if a program is trying to improve systemic advocacy, connecting siblings with the disability community through group or cohort training models may be more effective (e.g., Partners in Policymaking, Balcazar et al., 1995).

Limitations

The findings of this study should be considered in light of its limitations. This study reflects a convenience sample of siblings who completed a web-based survey. Thus, the findings may not be generalizable to the broader population of siblings of autistic individuals. Notably, our sample predominantly consisted of female participants (87.9%), which may limit the generalizability of the results to male siblings. Additionally, the racial and ethnic composition of our sample may not accurately represent the diversity of siblings across the United States. Moreover, since the data analyzed for this study were collected prior to some recent and notable global events (e.g., COVID-19 pandemic), responses collected at that time may not fully reflect the current experiences and perspectives of siblings of individuals with autism. Therefore, our findings should be interpreted within the context of the time period (i.e., 2018-2019) in which the data were collected, and further investigation into the current state of sibling advocacy efforts and relationships may be warranted. The reliance on self-reported data could have introduced bias, as participants may overestimate or underestimate their advocacy activities. Given the nature of the measures (i.e., response type and/or options for caregiving domains/tasks), there may be other dimensions of caregiving that could also be important to consider but were not assessed via the scales used in this study. The observation of advocacy activities, rather than self-report, may have different correlates and should be considered in future studies. Further, this study reflects cross-sectional data, so the direction of effects cannot be assumed.

Future Directions for Research

Although our models explained a significant portion of the variance in advocacy activities, there are additional factors that could account for the remaining variance. To that end, future research may consider applying Bronfenbrenner's ecological systems theory (1979) to identify the multiple micro, meso, and macro layers that may influence advocacy. Our study focused on the micro (e.g., age) and meso (e.g., reciprocity) layers. However, more research is needed regarding factors for each of these layers. For example, regarding micro layers, the intensity of support needs and maladaptive behaviors of the autistic individual may impact sibling advocacy.

For the meso layers, research that evaluates the quality of the sibling relationship (not just reciprocity) could shed light on other factors that influence advocacy. Taking this one step further, it could be helpful to gather data not only from the sibling without a disability but also their autistic sibling about the quality of the sibling relationship. To this end, future research should consider the self-determination of the autistic sibling and the role of supported decision-making in the sibling relationship. It could be that the self-determination of the autistic sibling is supported by advocacy within a supported decision-making framework.

Regarding the macro layers, research suggests that the availability of community support programs and sibling support groups could further facilitate advocacy activities among siblings of autistic individuals (Hodapp et al., 2017). Exploring the role of social capital, such as the presence of a strong social network and community connections, could provide insights into additional resources that support advocacy efforts. Such research could include going beyond a count of the number of supports to characterize the extent of support provided by each network member.

Additionally, it is important to examine advocacy activities over time. Other cross-sectional research suggests that advocacy activities might not follow a linear trajectory (Li et al., in press). Specifically, in the context of parents of transition-aged youth with autism, parents may begin by conducting individual advocacy and then, over time, conduct systemic advocacy. It is important to conduct longitudinal research with siblings to determine if and how advocacy evolves over time. Longitudinal research can help determine the timing, conditions, and circumstances under which advocacy activities change. Such an approach will provide a clearer understanding of the advocacy dynamics. The results of such research could characterize the extent to which siblings provide free labor to their brothers and sisters with autism. Such information should inform systems and policy changes to mitigate the expectation that siblings are obligated to serve as advocates.

Implications for Practice and Policy

The findings of this study have important implications for practice. Training programs for siblings to enhance their special education knowledge and advocacy skills are essential. Such programs can empower siblings to navigate complex systems and advocate effectively for their brothers and sisters with autism. Developing support networks to provide resources and emotional support for sibling caregivers can also enhance their advocacy efforts. In particular, it may be beneficial for community organizations to develop support programs for sibling caregivers. For example, organizations can establish support groups specifically for siblings, providing a safe space for them to share their experiences, receive emotional support, and connect with others in similar circumstances.

Policy changes recognizing and supporting the advocacy roles of siblings of individuals with autism are critical. These changes could include providing resources, training, and financial support to sibling caregivers, thereby acknowledging their contributions and alleviating some of their burdens. Understanding the distinct factors influencing individual and systemic advocacy can inform targeted interventions and support systems, ultimately improving outcomes for individuals with autism and their families.

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Table 1

Participants Demographics

Characteristic	*%* or *M* (*n* or *SD*)
Age	
Respondent	32.93 (10.98)
Sibling with Autism	25.03 (12.19)
Gender	
Respondent (Female)	87.9% (225)
Sibling with Autism (Male)	71.9% (184)
Respondent Marital Status	
Single	61.7% (158)
Race*	
White	85.2% (218)
Hispanic/Latino	8.6% (22)
Black/African American	5.1% (13)
Asian/Pacific Islander	3.9% (10)
Respondent Educational Background	
Some high school	1.6% (4)
High school graduate	5.1% (13)
Some college	23.4% (60)
College graduate	31.3% (80)
Some graduate school	12.9% (33)
Graduate school graduate	25.8% (66)
Respondent Household Income	
Less than $20,000	14.8% (38)
Between $20-40,000	16.0% (41)
Between $40-60,000	15.2% (39)
Between $60-80,000	19.9% (51)
Between $80-100,000	14.1% (36)
More than $100,000	19.9% (51)

Note: * Percentages do not add up to 100% as participants could choose to check multiple responses

Table 2

Multicollinearity Among the Independent Variables

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Respondent Age	--	--	--	--	--	--	--	--	--	--	--	--	--
2. Caregiver Supporters	-.05	--	--	--	--	--	--	--	--	--	--	--	--
3. Caregiving Tasks	-.05	.59**	--	--	--	--	--	--	--	--	--	--	--
4. Caregiving Domains	-.03	.11	.09	--	--	--	--	--	--	--	--	--	--
5. Caregiving Problematic Issues	.03	-.06	-.03	.41**	--	--	--	--	--	--	--	--	--
6. Caregiving Competence	.02	.18**	.17**	.29**	-.14*	--	--	--	--	--	--	--	--
7. Receipt of Sibling Supports	.05	.13*	.16*	.10	.24**	-.03	--	--	--	--	--	--	--
8. Future Planning	-.01	.14	.23*	.05	.00	.17	.23*	--	--	--	--	--	--
9. Future Planning Barrier	.06	-.01	.09	.16*	.36**	-.13	.33**	.00	--	--	--	--	--
10. Knowledge of Disability Policy	.25**	.19*	.06	.08	.04	.16*	-.01	.03	-.01	--	--	--	--
11. Disability Connectedness	.12	.16*	.06	.14*	.14*	.18*	.02	.12	.13	.56**	--	--	--
12. Emotional Reciprocity	-.07	-.07	-.15*	.28**	.26**	-.08	.12	.18	.09	-.01	-.05	--	--
13. Tangible Reciprocity	-.02	-.15	-.16	.58**	.32**	.07	.11	-.21	-.01	.24*	.07	.42**	--

Note: * $p < .05$. ** $p < .01$.

Table 3

Results of Hierarchical Regression Analyses on Individual Advocacy

Independent Variables	Model 1			Model 2			Model 3			Model 4		
	β	*t*	*p*	*β*	*t*	*p*	*β*	*t*	*p*	*β*	*t*	*p*
Demographic Factors												
Respondent Age	.019	3.464	<.001***	.019	3.675	<.001***	.010	2.303	.022	.013	2.823	.005**
Caregiving Factors												
Caregiver Supporter				.030	.384	.703	-.153	-2.168	.031	-.176	-2.488	.014
Caregiving Tasks				.025	.318	.748	.165	2.217	.028	.211	2.751	.006**
Caregiving Domains				.172	2.566	.012	.151	2.701	.007**	.150	2.644	.009**
Caregiving Problematic Issues				.252	3.815	<.001***	.152	2.647	.008**	.142	2.451	.015
Caregiving Competence				.145	2.292	.020	.103	1.913	.057	.111	2.063	.040
Disability Involvement Factors												
Receipt of Sibling Supports							.021	.413	.680	.013	.257	.798
Future Planning							.166	3.290	<.001***	.144	2.815	.005**
Future Planning Barrier							.244	4.572	<.001***	.235	4.426	<.001***
Knowledge of Disability Policy							.391	6.378	<.001***	.378	6.147	<.001***
Disability Connectedness							.113	1.934	.050	.111	1.892	.050
Reciprocity												
Emotional										.068	1.274	.204
Tangible										-.090	-1.841	.067
F			12.00			9.986			19.850			17.48
R^2			.041			.197			.449			.457
ΔR^2			-			.156			.252			.008

Note: ** $p \le .01$. *** $p \le .001$.

Table 4

Results of Hierarchical Regression Analyses on Systemic Advocacy

Independent Variables	Model 1			Model 2			Model 3			Model 4		
	β	t	p	β	t	p	β	t	p	β	t	p
Demographic Factors												
Respondent Age	.009	1.642	.102	.009	1.542	.124	.004	.811	.418	.007	1.698	.091
Caregiving Factors												
Caregiver Supporter				.125	1.485	.140	-.097	-1.371	.172	-.131	-1.879	.061
Caregiving Tasks				-.062	-.739	.471	.139	1.862	.064	.209	2.769	.006**
Caregiving Domains				-.087	-1.210	.232	-.089	-1.582	.115	-.093	-1.653	.099
Caregiving Problematic Issues				.219	3.085	.002**	.130	2.268	.024	.113	1.976	.049
Caregiving Competence				.201	2.966	.003**	.075	1.381	.169	.087	1.639	.102
Disability Involvement Factors												
Receipt of Sibling Supports							.118	2.325	.021	.105	2.123	.035
Future Planning							.090	1.776	.077	.056	1.101	.272
Future Planning Barrier							-.041	-.758	.449	-.054	-1.034	.302
Knowledge of Disability Policy							.138	2.248	.026	.117	1.926	.050
Disability Connectedness							.560	9.597	<.001***	.560	9.684	<.001***
Reciprocity												
Emotional										.114	2.166	.031
Tangible										-.129	-2.660	.008**
F			2.695			3.815			19.660			18.420
R^2			.007			.071			.446			.470
ΔR^2			-			.064			.375			.024

Note: ** $p \leq .01$. *** $p \leq .001$.

Figure 1

Distribution of Advocacy Activities