

Intellectual and Developmental Disabilities
Applicants to a Special Education Advocacy Training Program:
“Insiders” in the Disability Advocacy World
 --Manuscript Draft--

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Abstract

Although social groups have “insiders,” this construct has not been measured within the disability advocacy community. Examining 405 individuals who applied for an advocacy training program, this study examined the nature of insiderness within the disability advocacy community and ties to individual roles. Participants showed differences in mean ratings across 10 insider items. A principal components analysis revealed two distinct factors: Organizational Involvement and Social Connectedness. Non-school providers scored highest on Organizational Involvement; family members/self-advocates highest on Social Connectedness. Themes from open-ended responses supported the factors and showed differences in motivation and information sources across insiderness levels and roles. Qualitative analysis revealed two additional aspects of insiderness not addressed in the scale. Implications are discussed for future practice and research.

Keywords: Special education, advocacy, insider, parents, disability

Applicants to a Special Education Advocacy Training Program:**“Insiders” in the Disability Advocacy World**

Throughout our lives we try to connect to others, and these connections can occur in many ways. One such attempt relates to belonging to groups. Such groups might center around one’s interests, beliefs, or hobbies, but groups can also relate to one’s age (e.g., senior citizens), life stage (e.g., single parents of young children), or religious, political, ethnic, racial, or other characteristic. Despite the specifics, belonging to a group affords members certain benefits. By interacting with others around a common interest, activity or goal, group members often develop a sense of unity (Dion, 2000) and connection (Burke et al., 2020). If one engages in group activities intensively over a period of time, certain members might become group “insiders,” to different degrees sharing group-related social connections, possessing knowledge about both the group and its topic(s), and even using this knowledge to enact positive change within specific life spheres (Burke et al., 2020). In this study, we define an insider as a group member who, through their membership, holds useful, specialized information about the group and its mission and enjoys interpersonal connections with those in the group

The idea of group insiderness also connects to one’s sense of self. Social identity theory holds that, when individuals consider their group membership as central to their self-concept and feel strong emotional affiliations, social identities exert special influence (Tajfel, 1979). One’s self-esteem often grows with prolonged group membership, further sustaining the social identity (Jetten et al., 2015). Such group insiderness also likely influences individuals to act in line with the behaviors of other group members. Although the term “insider” is relatively new, these connections suggest that insiderness has parallels to the “in-group” term in social psychology (Tajfel, 1979). Specifically, both terms involve individuals psychologically identifying

themselves as members. However, we further distinguish insiders as being privy to useful knowledge specific to a cause. Insiders often participate in shared group activities and receive newsletters and other informational materials pertinent to the group. Such individuals also likely enjoy social benefits, networking and sharing interconnections around common activities. These shared connections might stem from the fact that social groups often possess specialized knowledge and vocabularies (Van Swol & Kane, 2019). Social relationships are also associated with improved health and psychological well-being (Cohen, 2004; Helliwell, 2003).

This concept of insiderness, and its advantages, likely translate to the world of disabilities and those involved in the disability-related groups (i.e., stakeholders, families, and individuals with disabilities themselves). One example of an organization in the disability community that builds insiderness concerns parent groups, sometimes referred to as mutual support groups. Such organizations are characterized by groups of parents of children with disabilities sharing similar experiences and challenges, meeting regularly to exchange information, and giving and receiving psychological support (Bray et al., 2017). Many parents of children with IDD join support groups to talk to and learn from other parents about how they approach daily challenges, including those related to poorer health (Miodrag et al., 2015), financial and psychological stress (Emerson, 2007), social isolation/marginalization (Doenyas, 2016), and challenging relationships with school professionals (Leiter & Krauss, 2004). Besides sharing daily challenges, many parents discuss challenges in advocating for disability service supports for their children (Solomon et al., 2001). Beyond helping with day-to-day coping, parent support groups may also foster three personal changes: overall identity, with the most involved members appreciating that they can be informed, independent actors; a sense of belonging, with new friendships and a space to share emotions without judgment; and feelings of personal change, with members feeling

more confident and accepting of their child's disability (Solomon et al., 2001). Thus, individuals belonging to disability-related groups, such as parent support groups, do so for both instrumental and affective support. Ultimately, becoming an insider in a specialized group that is part of the disability community can confer multiple benefits for those involved.

Although disability-related groups may benefit those members who are most active and involved, the more general issue of insider status has been infrequently examined within the disability advocacy world. Formal studies are limited because disability advocacy overall is underresearched (Burke et al., 2019); however, anecdotal examples abound of disability advocacy insiderness. Individuals in different roles may be deeply involved in disability advocacy causes and perceive themselves to be insiders (Hodapp et al., 2018). Historically, parents of children with intellectual and developmental disabilities (IDD) served critical roles in enacting change in the disability service system (Jones, 2004; Wehmeyer & Schalock, 2013). Further, certain groups of self-advocates with disabilities (e.g., autism) have a strong social identity based on specific group membership (O'Connor et al., 2018). Siblings of individuals with IDD, like parents, advocate for services and systemic change and also seek increased connections in the disability community (Burke et al., 2020).

Additionally, the concept of insiderness pervades many disability advocacy organizations and services. Disability advocacy organizations often overlap in both their general and board memberships, jointly sponsor events, and together inform legislatures or hold public activities to bring attention to disability-related causes (Burke et al., 2021). It would seem important to describe in greater depth the nature of the insiderness construct, to identify personal characteristics of those who become disability advocacy insiders, and the ways in which individuals reflect on their disability connections. Knowledge of disability advocacy insiderness

might shed light on how individuals feel most connected to others who provide disability services or advocate, including both families and individuals with disabilities. This information is important given that others (e.g., families) play key roles in shaping the trajectories of individuals with disabilities and have their own unique needs (Kim & Turnbull, 2004). Finally, knowledge of insiderness might have implications for how essential information is accessed.

To study one type of insiderness, we examined applicants to a program designed to teach participants about special education advocacy, the Volunteer Advocacy Project (VAP; Author, 2013). Upon graduating from the VAP, attendees become volunteer special education advocates who consult with families, attend IEP meetings, and in other ways help caregivers to advocate for special education services. Although completion of the VAP is associated with both greater involvement in the disability community (Authors, 2020) and stronger advocate identities among those with sustained advocacy (Authors, 2017a), it remains unclear to what extent those who would like to complete an advocacy training perceive themselves to be insiders before completing the training. By examining individuals who applied to an advocacy training over a multi-year period, we had a unique opportunity to examine insiderness for this particular group. As special education advocacy programs are becoming increasingly common (Goldman, 2020) it is appropriate to examine insiderness through the lens of an advocacy program. Using general demographic information as well as an insiderness questionnaire specifically designed for this study, our goals were threefold, to determine: (a) the nature of insiderness for VAP applicants; (b) whether levels of insiderness differed across individuals who held diverse roles (e.g., parents, individuals with disabilities, school and non-school service providers); and (c) whether themes of open-ended responses aligned with quantitative findings about insiderness for those with different roles who applied for the advocacy training program.

Method

Participants

Participants included 405 applicants to the VAP from the 2015-2019 cohort years (i.e., five cohorts). Participants were mostly White, female, and college-educated. Of these participants, 262 were parents or family members of an individual with a disability, 82 were non-school service providers (e.g., non-profit employee, therapist, university staff), 50 were school personnel (e.g., teacher, paraprofessional, administrator), 35 were university students, 32 self-reported another role and 17 were individuals with a disability (more than one role could be checked). See Table 1.

Procedures

Participants were recruited via social media and e-mail from one of the state's University Centers for Excellence in Developmental Disabilities (UCEDD), where the training was housed. We contacted numerous disability organizations (e.g., state and local chapters of the Arc; autism and Down syndrome associations) and agencies throughout the state, including the Parent Training and Information (PTI) center, as well as the state's other UCEDD. Organizations then shared VAP flyers and other information about the VAP to potential participants.

For each of the five cohort years, interested participants completed the online application via REDCap, a secure on-line platform (Harris et al., 2009), or had the option to request a paper application. The 6-page application took approximately 30 minutes to complete. Following Institutional Review Board approval, responses were stored in REDCap and afterwards transferred to SPSS for data analysis.

Application

The application was comprised of four sections: demographic information, logistical questions, the Insider Scale, and open-ended responses. The application also included a statement that responses would not affect the applicant's acceptance into the training and a place to provide consent to participate in research. To answer our research questions, we used information from three sections: (1) Insider Scale, (2) role, (3) open-ended responses.

Insider Scale

This scale was developed based on a literature review about insiderness (e.g., Balcazar et al., 1996) and preliminary findings related to advocate involvement and role identity (Authors, 2017a). The purpose of the measure was to examine the extent to which a respondent felt connected to the disability advocacy community. It was reviewed by experts in the disability field who held multiple roles in the disability community (e.g., parent, disability non-profit employee, disability organization board member). On a 5-point Likert-scale from (1) *Not at all* to (5) *Very much so*, ten questions asked the extent to which respondents perceived their insiderness (see Table 2).

Role

Applicants checked all roles that pertained to them. The roles included being an: Individual with a disability; Parent or family member of an individual with a disability; School personnel (e.g., teacher, paraprofessional, administrator); Non-school service provider (e.g., employee of a non-profit disability organization or state department on disabilities, therapist, university staff); University student (e.g., pre-service teacher); and Other. If participants selected "Other", they described the nature of that role via an open-ended response.

As we were interested in the extent to which one is an insider in the disability advocacy community related to one's particular role(s), we examined roles in three ways. First, we

considered roles in isolation—whether a person was an individual with a disability (yes-no); a family member (yes-no); a school professional (yes-no), etc. Next, we investigated the total numbers of roles self-selected by each participant (range = 1-6). Thus, a parent who was also a non-school provider held two roles (parent + non-school provider).

Finally, to make each respondent a member of a single role group and to create large-enough groups for analyses, we created a hierarchy of roles, with the hierarchy determined by the presumed importance of that role to insiderness. From highest to lowest, role categories were coded as: (1) Individual with a Disability, (2) Family Member, (3) School Service Provider, (4) Non-School Service Provider, (5) Student, and (6) Other. This hierarchy is loosely based on the social psychological principle of “construal theory.” According to Liberman and Trope (2008), humans think differently about roles or events that are “close” versus “far” from them, with this close-far distinction involving time, distance, and emotions. In this study, we considered being an individual with a disability or family member as more central than other roles, the roles of student or “other” less central. For these reasons, if a participant occupied more than a single role category, that respondent was placed into the “highest” role. It is also noteworthy that most participants ($n = 348$, or 85.9%) held only a single role, with the remaining 57 individuals (who held two or more roles) placed in the appropriate category based on our hierarchy. Of these 57 respondents, the most common multiple roles ($n = 27$) were parent and non-school provider (who we assigned to the “Family Member” category). See Table 1 for the numbers of respondents across these role categories.

The two categories “Family Member” and “Individual with a Disability” were combined for analyses to circumvent the practical issue of having so few individuals with disabilities in our training ($n = 17$) and because we considered the family’s and individuals’ perspectives to be

most closely in alignment compared to the other roles; the two groups also did not differ on any outcome measures. Similarly, the 35 university students and 32 “other role” individuals were also combined (again, both showed similar findings on our outcome measures and were considered similarly less central roles). Thus, we used four main role categories for analyses.

Open-Ended Responses

At the end of the VAP application, respondents answered seven open-ended questions. For this study, we examined only the three most central to insiderness including: their disability connections (“What is your personal connection to the disability field?”); their rationale for participating in the VAP (“What would you like to get out of participating in this project and how do you think you would apply the skills and knowledge you will have gained from this project?”); and how they learned about the VAP (“How did you learn about this Advocacy Project?”). For all questions, participants were allotted space to provide detailed open-ended responses with no character limit.

Analyses

We conducted three sets of analyses. First, to determine the nature of insiderness for this sample, we examined the scale itself. Comparing scaled items, we used a one-way repeated-measures ANOVA to determine whether items showed different mean values; post-hoc analyses identified which items were statistically higher and statistically lower relative to the Grand Mean (Silverstein, 1975). To reveal potential factors among items on the Insider Scale, we then conducted a principal components analysis with varimax rotation. Items loading (at .40 or greater) on individual factors were combined into factors; mean factor scores were derived by dividing the sum of all variables by the number of variables for each factor. Cronbach’s alphas were also computed. After completing the factor analysis, missing data were imputed for the

Insider Scale, with mean scores of all other factor items substituted for missing values. Only 5.3% ($n = 23$) of respondents missed any items and no respondent missed more than two of the 10 Insider Scale items.

Next, to compare insiderness across types of respondents, we examined the degree to which participants holding diverse role(s) differed in their degree of insiderness. We first examined roles separately, in isolation from one another. Using paired t-tests, we determined whether those holding (vs. not holding) specific roles differed in insider factors, for each of the roles separately. We then compared (using independent sample t-tests) whether those respondents holding any single role (e.g., non-school service provider) differed on insiderness factors from those holding two or more roles (e.g., parent + school provider). Finally, we used one-way ANOVAs to examine whether insiderness differed based on one's "highest" role category (i.e., Individual/Family Member; School Service Provider; Non-School Service Provider; Student-Other). In this way, we examined the effects of roles independently (e.g., respondent was or was not a parent, was or was not an individual with a disability) and by "highest" role, with every respondent assigned to one and only one role category.

Finally, we examined the nature of applicants' open-ended responses and the ties of such responses to role. Using the open-ended responses, we compared those with the highest and lowest insiderness scores by employing maximum variation sampling (Patton, 2002). This procedure involved two authors independently coding responses from 94 participants in the top and bottom 10% for each factor that emerged from the factor analysis. Using a qualitative analysis approach (Creswell, 2013), we assigned a descriptive code to each response and organized codes into themes. After preliminary coding, we compared our coding, discussing any disagreements. We then re-analyzed the data independently, allowing new codes to emerge.

After multiple iterations of this coding process, we agreed on the final themes. To promote trustworthiness, responses were triangulated across all questions.

Results

Characteristics of Insideress Scale

Scale items showed significant differences in mean ratings across these 10 Insider items, $F(9, 396) = 83.38, p < .001$. Items significantly higher than the Grand Mean included: Having friends or socializing with parents or individuals; Belonging to listservs, Facebook, chat rooms, or social media; and Receiving newsletters, e-mail alerts, or written information. On the other hand, items significantly lower than the Grand Mean included: Serving on boards, committees, or performing other leadership roles for one or more disability organizations; Belonging to local disability organizations (all p 's $< .001$ for greater or lower vs. Grand Mean, respectively; see Table 2).

To determine the nature of “insiderness” for this sample, we then performed a principal components analysis with varimax rotation. Two factors emerged, together accounting for 62.49% of the variance (see Table 2). The first factor (52.35%) related to Organizational Involvement ($\alpha = .88$) and was comprised of six items (i.e., serve on boards, committees, or performing other leadership roles for one or more disability organizations; know what is going on in terms of the area’s disability initiatives or activities; belong to local disability organizations; devote time to disability-related groups, causes, or activities; feel themselves to be an insider in the disability community in the local area; and see disability organizations as the main cause or activity they engaged in). A second factor, Social Connectedness ($\alpha = .76$), accounted for an additional 10.14% of the variance and was comprised of four items (i.e., have friends or socialize with parents of individuals with disabilities or individuals with disabilities

themselves; belong to listservs, Facebook, chat rooms, or other disability-related social media; have a mentor that they frequently ask advice from about disability issues; and receive newsletters, e-mail alerts, or other written information from one or more disability organizations). As one item (“Seeing disability organizations as the main cause or activity they engaged in”) loaded onto both factors about equally, we placed it on Factor 1 for conceptual reasons. Overall, participants showed greater mean scores for Social Connectedness than for Organizational Involvement, $t(404) = -19.11, p < .001$.

Connections of Participant Role to Insider Levels

We first considered each potential role independently to examine differences in Organizational Involvement and Social Connectedness based on each individual role(s) held by participants (see Table 3). For Organizational Involvement, higher mean scores were noted when participants were non-school service providers, $t(403) = -3.30, p < .01$ and was lower for university students, $t(403) = 3.42, p < .01$. For Social Connectedness, participants scored higher when they were parents/family members, $t(403) = -5.04, p < .001$ and non-school providers $t(403) = -2.85, p < .01$. In contrast, lower mean scores on Social Connectedness were noted for university students $t(403) = 3.09, p < .01$. Participants who engaged in multiple roles (vs. one role) reported higher levels of Organizational Involvement, $t(403) = -2.25, p < .05$ and of Social Connectedness, $t(403) = -2.30, p < .05$.

Placing each individual in their “highest” role category, significant differences also emerged across role categories for both Organizational Involvement, $F(3, 401) = 6.44, p < .001$ and Social Connectedness, $F(3, 401) = 19.38, p < .001$. Non-School Service Providers had the highest scores for Organizational Involvement ($M = 3.15; SD = .96$); for Social Connectedness, the highest scores were shown by the group of (combined) Individual/Family Members (M

=3.82; $SD = .92$). In contrast, Students and Others (combined) showed the lowest mean scores for both Organizational Involvement ($M = 2.25$; $SD = .95$) and Social Connectedness ($M = 2.67$; $SD = .98$).

Analyses of Open-Ended Responses vis-à-vis Insider Factors

Open-ended responses for joining disability advocacy organizations such as the VAP generally supported the two main Insider factors, as participants referenced both Organizational Involvement and Social Connections. Themes differed by role, and were related to participants' motivation to become an advocate and their sources of information about the training.

Advocacy Motivation and Experience

Participants who experienced the most Organizational Involvement often cited specific disability organizations as motivating their interest in becoming advocates. These participants also reported that their prior advocacy experiences motivated them to become advocates. A mother of a typically developing six-year-old described herself as a homemaker who worked part-time; as a teenager, she started working with children with disabilities. Citing such activities as Special Olympics, special needs dance teams, camps, and religious Sunday school, she explained, "Basically I am around special needs people about three days a week with all the involvement I have with several organizations." Parents of children with disabilities who were high in Organizational Involvement also referenced specific disability organizations. A mother of a Deaf child with healthcare needs worked at a state organization conducting support groups for families of children with disabilities. She explained, "I have been in countless IEPs, have gone to due process, my son is on the state Department of Health's Youth Advisory Council, I talk to families every day through my work and help them advocate for their children."

Further, parents highest in Organizational Involvement reported serving in leadership roles in disability organizations, with such roles often motivating them to become advocates. The program director of a statewide autism organization explained that, along with her colleagues, she was "...interested in completing this course [VAP] as a tool to better inform and educate our parents on their rights." Similarly, the executive director of a local Down syndrome awareness group, also the parent of a 14-year-old with Down syndrome, explained that she wanted to become an advocate because "I am always looking to gain more knowledge to help the students in our group." Other parents with high Organizational Involvement also cited leadership roles, such as forming a chapter of The Arc or being president of a disability organization.

In contrast, participants with low Organizational Involvement primarily attributed their motivation to become advocates to social connections, often including friendships with parents of children with disabilities. A self-employed mother of a child with ASD indicated she did not have prior experience with advocacy. She wanted to become an advocate because "I am part of a couple of social circles where kids are getting left behind or aren't getting the services that they need." Similarly, a mother with three daughters with disabilities explained, "On our special journey, I have met many families struggling to navigate the special education system, and I want to help them." Typically, these parents did not work in a disability-related field.

Non-family participants who scored low on Organizational Involvement were also often motivated by social reasons. A graduate student studying special education wrote about the child of her "closest friend from high school... [who] struggles with people misunderstanding or assuming things about" her child with Down syndrome. The participant explained, "I have a special place in my heart for children with disabilities and their families because so many of my family and friends have children with disabilities."

Sources of Information

Participants with high Organizational Involvement were more likely to cite disability organizations as their source of information. Some, who were also employed by disability organizations, heard about the advocacy program because it was recommended by their employer. A director of an autism non-profit stated, “I learned about the VAP when I began my position.”

In contrast, those with low Social Connectedness and/or Organizational Involvement were most likely to hear about the program from a social connection or internet search. A stay-at-home mom of a child with a learning disability explained, “My connection is wholly as a parent of a child with learning differences... This made me look online to see if there were any training programs available.” Even participants with low Social Connectedness often learned about the VAP through a social connection, such as friends or acquaintances. An accounts specialist with low Social Connectedness and low Organizational Involvement explained, “As far as a personal connection within my family, there is none.” She learned about the VAP from “an individual who has a friend who is involved and wanted to take the class. She mentioned the project and mentioned she believed I would be a good fit!”

Across both “low” and “high” groups on both factors, an often-cited source of information included the Facebook pages of disability organizations. Respondents in both groups also received information about the VAP from e-mail alerts and newsletters from disability organizations.

Additional Insideress Components

Two additional aspects of insideress emerged from the qualitative analysis.

Mentoring. Although the Insider Scale included one item about mentoring, that item considered the participant as the recipient—rather than provider—of mentoring. But especially among those with high Organizational Involvement or Social Connectedness, some respondents mentioned mentoring others as part of their own insiderness. A single mother of a son with ASD with high Social Connectedness explained, “People call me and ask me what they should do or who they should talk to because they know my history.” Another mother of a child with ASD, who scored high on both Social Connectedness and Organizational Involvement, reported “I have mentored parents for years.”

Parent of an Individual with a Disability. Many parent respondents wrote about their child with a disability motivating them to complete an advocacy program. A physician with high Social Connectedness and Organizational Involvement and a child with Down syndrome, explained, “I am passionate about ensuring my child and other children with special needs get the education they deserve.” Parents explained how having a child with a disability required them to become knowledgeable so they could advocate for their own child. The need for parent advocacy resulted in them becoming, to varying degrees, insiders in the disability world. A mother explained:

Both of my sons are dyslexic and my thirteen-year-old has ADHD as well. Thankfully, I identified their issue early, had the resources to get the best private testing possible, hire private experts, and work with the district to guarantee that their needs were met... I have also been involved in our district’s PAC [Parent Action Committee] as a resource for parents who are new to the learning difference world.

A mother similarly described her process of becoming an insider. She recently completed a bachelor's degree in Family Studies and was a graduate of *Partners in Policymaking* (a year-long program directed by The Arc):

I have four children and my life for the last 21 years has been raising them. The last 13 years have brought me a new way of parenting. I spent the first 4-5 years alone with a child I had no idea how to fight for... I want to support a more accessible community and a support system... But coming back out into the community is difficult...

Although not all parents had high Social Connectedness and Organizational Involvement, having a child with a disability seemed one aspect of insiderness not represented on the measure.

Discussion

Like any sub-group—even sub-culture—in our society, the disability advocacy community includes individuals who vary in the degree to which they perceive themselves to be insiders. To date, however, the disability advocacy world has been talked about but rarely examined, with even less attention paid to measuring and understanding the construct of insiderness. As such, this study is among the first to examine the concept of insiderness as it pertains to such stakeholders. This study has three main findings, each with important implications for practice, policy, and research.

Our first finding concerned the nature of insiderness for those interested in becoming special education advocates. Using our 10-item questionnaire, certain activities were more often engaged in by study participants. Especially highly rated were being friends with parents or individuals with disabilities; belonging to listservs, Facebook, and other social media; and receiving disability-related newsletters. In contrast, low ratings were noted for organizational activities—either serving in leadership capacities or even belonging to disability organizations.

But we also probed to examine how insider items interrelated, finding that insiderness was divided into two constructs: Organizational Involvement and Social Connectedness. Insiderness may be a more nuanced construct, with these individuals perceiving themselves a part of formal organizations or inter-personal networks.

This first finding, then, builds upon previous work suggesting that families of individuals with IDD seek out help for disability-related issues through formal (i.e., paid) and informal (i.e., natural) avenues (Gilson et al., 2017). These types of support can also interrelate; in one study, for example, individuals with intellectual and developmental disabilities listed paid professionals as informal supports (Sanderson et al., 2017). In the same manner, individuals' unique circumstances likely dictate the degree to which they perceive themselves an insider through organizational involvement, connecting with others, or both. The importance of such networking might explain why items related to social interactions were rated especially high. Some might join disability groups to network with others for psychological support and information (Jackson et al., 2018), which might lead to opportunities for finding valuable resources and navigating institutional barriers through others' experiences (Law et al., 2002), as well as stimulating individuals to reappraise or better cope with stress (Sloper, 1999).

A second finding concerned the ties of degree of insiderness—on both of our factors—when individuals held particular roles. We found that roles relate to insider scores, thereby building on previous research indicating that, following an advocacy training, parents report higher levels of involvement in the disability community compared to non-parent professionals (Authors, 2020). For Organizational Involvement, participants reported significantly higher scores when they were non-school service providers; for Social Connectedness, higher scores emerged for parents. On both factors, low scores were noted among university students. Degree

of disability insiderness also related to holding multiple roles. For example, non-school and school-providers who were also parents rated themselves higher on both insider factors, possibly leveraging their ties to disability organizations to help their own children.

Findings concerning those holding multiple roles might also relate to more general distinctions within the disability advocacy community. That community has, on occasion been conceptualized as two separate worlds, one relating to special education school services and the other to the non-school service system (Author, 2013). As services and initiatives often reach different audiences, parents might use this special education advocacy program to combine the two worlds, helping to remedy their disconnect with schools by seeking interactions with others in the wider, non-school service community (Authors, 2019a). Along the way, program attendees might avail themselves of information and assistance missing from schools by, for example, soliciting the services of advocates (Authors, 2019b).

Finally, open-ended responses indicated the ways in which insiderness relates to other issues for these participants. To illustrate, individuals with the greatest Organizational Involvement spoke of disability organizations as motivating their interest in becoming advocates; conversely, individuals with lower Organizational Involvement cited as their motivation to attend these trainings their social connections. Those highest and lowest on these two factors also identified different information sources about this special education training program. Ultimately, findings indicate that individuals seek out advocacy trainings to attain help for both their own families as well as to advocate for others.

Qualitative analyses also revealed important issues that were missing from our Insider Scale. While we did ask respondents whether they had a disability mentor, we did not inquire whether respondents themselves provided mentoring. Open-ended responses, however, revealed

that respondents were sometimes recipients of mentoring, sometimes providers of mentoring, and sometimes both. This interest in mentoring is consistent with earlier findings indicating that a large subset of participants in special education advocacy workshops are parents who want to help others (Authors, 2019a). Our Insider Scale also did not highlight parenting. Although studies have identified parents as the linchpin of services (Taylor, et al., 2017), few have explored the parental role as a special status within the disability advocacy community.

Implications for Research and Practice

Our findings have implications for research and for engaging various stakeholders in the disability advocacy community. First, findings from open-ended responses indicated that our Insider Scale should be updated to include items related to (a) being a mentor and (b) being the parent of a child with a disability. Research is needed to replicate and extend our findings, as well as to determine how the factors of insiderness apply to other sub-groups in the disability service community, including individuals who are not applying to an advocacy training.

Given that insiderness items divided into Organizational Involvement and Social Connectedness, researchers might consider examining how each factor corresponds with potential correlates such as disability knowledge, as well as respondent health and psychological well-being. Since individuals often join support groups to enhance coping (Nichols & Jenkinson, 2006), Social Connectedness (compared to Organizational Involvement) might more strongly correlate with psychological well-being and health.

Although focusing on the nature and correlates of insiderness, this study does not address issues of how one becomes a disability insider. Future research might examine movement along that continuum over time, possibly related to progression during this type of advocacy training program, possibly as a result of other life events. It may also be that individual training

attendees show different amounts of change with, for example, participants who begin this type of training series with greater advocacy experience having less opportunity for improvement (Authors, 2017b). Similarly, participants with greater levels of insiderness when they apply might show lesser increases in perceived insiderness following the training; such individuals might already consider themselves disability advocacy group members. Future research might also examine other correlates. Empowerment, for example, has been associated with change scores in knowledge, advocacy, involvement, and role identity following an advocacy program (Authors, 2020) and with insiderness following participation in a peer support program (Burke et al., 2020). Other constructs might also relate to changes in disability-insider scores.

These findings also have implications for recruitment. To date, it remains mostly unclear how “outsiders” come to learn about—and enter into—the disability advocacy community. From these findings, members wanting to join the disability advocacy community might first consider joining related platforms (e.g., Facebook groups) to connect to others “in the know.” Such platforms might also connect group members with established organizations; both disability organizations and members themselves often share organizational resources through social media (Hodapp et al., 2018). Intentional action is also needed to address barriers experienced by culturally and linguistically diverse (CLD) families to entering the disability advocacy community. Disability organizations need to better conduct outreach in local communities and develop leaders within those communities to more successfully connect with CLD families (Rossetti & Burke, 2019). In the disability advocacy community more specifically, CLD advocates highlight the need to go beyond the typical outreach systems and use more informal methods (Authors, 2018).

Moreover, individuals from culturally and linguistically diverse backgrounds might benefit from formal support groups (or other disability organizations) to counter their initial lack of disability connections (Mueller et al., 2009) that exist due to broader systemic issues. Although preliminary evidence suggests similar iterations of advocacy training programs are effective for CLD participants (e.g., Latinx caregivers; Burke et al., 2016), future studies should make an effort to recruit more diverse samples and examine whether findings replicate among such populations. Some CLD families have different values and experiences compared to those expressed by schools; these different values might impact their perceptions, even after special education advocacy trainings (Scott et al., 2021). Further, CLD families might experience systemic racial inequities in school that marginalize students and prompt parents to take advocacy roles (Scott et al., 2021).

In developing advocacy (or other disability) programs more generally, coordinators might endorse a multi-pronged recruitment approach. That approach might begin with the “usual suspects” of disability organizations, agencies, and parent groups. But additional recruitment might occur through more casual means (e.g., Facebook). Though providing a lower yield than outreach to disability groups, these mechanisms might widen the circle of individuals within the disability advocacy community, particularly given the need to connect with and support more diverse participants (Authors, 2016). In this vein, programs might allocate time during sessions for participants to network with one another, using ice-breakers and structured group activities to ensure that all participants can enjoy the benefits of disability advocacy-related workshops, programming, and interpersonal connections.

Limitations

In addition to featuring participants from only one Southeastern state, respondents were primarily well-educated White females. Our sample did not include many individuals with disabilities and was not diverse in terms of other characteristics such as socio-economics, race, and ethnicity. Due to limited diversity, there may be components of insiderness that were not addressed in our original measure and were not identified in this study. Further, our sample included only applicants to a special education advocacy training program. From this study, then, statements about disability advocacy insiderness must be limited to this one specific group; our results may not generalize to other groups. Given that the VAP program recruits participants from disability organizations and social media platforms, our sample itself might also be comprised of more insiders relative to the general disability advocacy community. Finally, respondents self-reported their insiderness, which might lend itself to bias.

Conclusion

Still, this study begins the process of understanding insiders within a particular sub-set of the disability advocacy community. Our findings showed differentiation between higher and lower items on the Insider Scale, the existence of two constructs of inter-personal and organizational connections, and how individuals' roles impact how they relate to the disability advocacy community and the types of activities they engage in. In addition, our findings highlight the importance of understanding insiders' perspectives and using them to inform future, high-quality research. Ultimately, we need to reach beyond insiders to all members of the disability community, so that all can capitalize on the benefits that group membership brings.

References

Author. (2013).

Authors. (2017a).

Authors. (2017b).

Authors. (2018).

Authors. (2019a)

Authors. (2019b).

Authors. (2020).

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*, *34*, 341–351.

Bray, C., Carter, B., Sanders, C., Blake, L., Keegan, K. (2017). Parent-to-parent peer support for parents of children with a disability: A mixed method study. *Patient Education and Counseling*, *100*(8), 1537–1543. <https://doi.org/10.1016/j.pec.2017.03.004>

Burke, M. M., Lee, C., Carlson, S. R., & Arnold, K. K. (2020). Exploring the preliminary outcomes of a sibling leadership program for adults siblings of individuals with intellectual and developmental disabilities. *International Journal of Developmental Disabilities*, *66*(1), 82-89. <https://doi.org/10.1080/20473869.2018.1519632>

Burke, M. M., Magaña, S., Garcia, M., & Mello, M. P. (2016). Brief Report: The feasibility and effectiveness of an advocacy program for Latino families of children with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *46*(7), 2532–2538. <https://doi.org/10.1007/s10803-016-2765-x>

- Burke, M. M., Rios, K., & Lee, C. E. (2019). Exploring the special education advocacy process according to families and advocates. *The Journal of Special Education, 53*(3), 131–141. <https://doi.org/10.1177/0022466918810204>
- Burke, M. M., Rossetti, Z., & Li, C. (2021). The efficacy and impact of a special education legislative advocacy program among parents of children with disabilities. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-021-05258-4>
- Cohen S. (2004). Social relationships and health. *The American Psychologist, 59*(8), 676–684. <https://doi.org/10.1037/0003-066X.59.8.676>
- Creswell, J. W. (2013). *Research design: Qualitative, quantitative, and mixed methods approaches*. Thousand Oaks, CA: SAGE Publications.
- Dion, K. (2000). Group Cohesion: From “field of forces” to multidimensional construct. *Group Dynamics, 4*(1), 7–26. <https://doi.org/10.1037/1089-2699.4.1.7>
- Doenyas, C. (2016). The social living complex: A new, all day, yearlong intervention model for individuals with autism spectrum disorder and their parents. *Journal of Autism and Developmental Disorders, 46*(9), 3037–3053. <https://doi.org/10.1007/s10803-016-2846-x>
- Emerson, E. (2007). Poverty and people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 107-113.
- Gilson, C. B., Bethune, L., Carter, E. W., & McMillan, E. (2017). Informing and equipping parents of people with intellectual and developmental disabilities. *Intellectual and Developmental Disabilities, 55*, 347-360. <http://doi.org/10.1352/1934-9556-55.5.347>
- Goldman, S. E. (2020). Special education advocacy for families of students with intellectual and developmental disabilities: Current trends and future directions. *International Review of Research in Developmental Disabilities, 58*, 1-50.

- Harris, P. A., Taylor, R., Thielke, R., Payne, J., Gonzalez, N., & Conde, J. G. (2009). Research electronic data capture (REDCap)—A meta-data-driven methodology and workflow process for providing translational research informatics support. *Journal of Biomedical Information, 42*, 377–381. <https://doi.org/10.1016/j.jbi.2008.08.010>
- Helliwell, J. (2003). How's life?: Combining individual and national variables to explain subjective well-being. *Economic Modelling, 20*, 331–360. [https://doi.org/10.1016/S0264-9993\(02\)00057-3](https://doi.org/10.1016/S0264-9993(02)00057-3)
- Hodapp, R.M., Rosemergy, J., Garcia, B.L., Meskis, S.A., Hart, M., & McMillan, E. (2018). Information-and-Referral services in IDD: Toward integrated and comprehensive services? *International Review of Research in Developmental Disabilities, 54*, 211-250. <https://doi.org/10.1016/bs.irrdd.2018.07.007>
- Jackson, S. (2018). Support group value and design for parents of children with severe or profound intellectual and developmental disabilities. *Journal of Autism and Developmental Disorders, 48*, 4207–4221. <https://doi.org/10.1007/s10803-018-3665-z>
- Jetten, J., Branscombe, N. R., Haslam, S. A., Haslam, C., Cruwys, T., Jones, J. M., Cui, L., Dingle, G., Liu, J., Murphy, S. C., Thai, A., Walter, Z., & Zhang, A. (2015). Having a lot of a good thing: Multiple important group memberships as a source of self-esteem. *PloS one, 10*(5), e0124609. <https://doi.org/10.1371/journal.pone.0124609>
- Jones, K.W. (2004). Education for children with mental retardation: Parent activism, public policy, and family ideology in the 1950s. In S. Noll & J.W. Trent, Jr. (Eds.), *Mental retardation in America: A historical reader* (pp. 322-350). New York: NY: New York University Press.

- Kim, K., & Turnbull, A. (2004). Transition to adulthood for students with severe intellectual disabilities: Shifting toward person-family interdependent planning. *Research and Practice for Persons with Severe Disabilities*, 29(4), 53–57.
- Law, M., King, S., Stewart, D., & King, G. (2002). The perceived effects of parent-led support groups for parents of children with disabilities. *Physical and Occupational Therapy in Pediatrics*, 21(2), 29–48. https://doi.org/10.1300/J006v21n02_03.
- Leiter, V., & Wyngaarden Krauss, M. (2004). Claims, barriers, and satisfaction: Parents' requests for additional special education services. *Journal of Disability Policy Studies*, 15(3), 135–146. <https://doi.org/10.1177/10442073040150030201>
- Liberman, & Trope, Y. (2008). Psychology of transcending the here and now. *Science*, 322(5905), 1201–1205. <https://doi.org/10.1126/science.1161958>
- Miodrag, N., Burke, M.M., Tanner-Smith, E.E., & Hodapp, R.M. (2015). Adverse health in parents of children with disabilities and chronic health conditions: A meta-analysis using the Parenting Stress Index's Health sub-domain. *Journal of Intellectual Disability Research*, 59, 257-271.
- Mueller, T. G., Milian, M., & Lopez, M. I. (2009). Latina mothers' views of a parent-to-parent support group in the special education system. *Research and Practice for Persons with Severe Disabilities*, 34(3–4), 113–122. <https://doi.org/10.2511/rpsd.34.3-4.113>
- Nichols, K., & Jenkinson, J. (2006). *Leading a support group [electronic resource] : A practical guide* / Keith Nichols and John Jenkinson. Open University Press.
- O'Connor, C., Kadianaki, I., Maunder, K., & McNicholas, F. (2018). How does psychiatric diagnosis affect young people's self-concept and social identity? A systematic review and synthesis of the qualitative literature. *Social Science & Medicine*, 212, 94-119.

- Patton, M. Q. (2002). Two decades of developments in qualitative inquiry: A personal, experiential perspective. *Qualitative Social Work, 1*(3), 261–283.
<https://doi.org/10.1177/1473325002001003636>
- Rossetti, Z., & Burke, M. M. (2019). Reaching out to culturally and linguistically diverse families: Strategies and challenges reported by parent training and information center staff. *Exceptionality, 27*(3), 215-231. <https://doi.org/10.1080/09362835.2018.1433042>
- Sanderson, K. A., Burke, M. M., Urbano, R. C., Arnold, C., & Hodapp, R. M. (2017). Who helps? Characteristics and correlates of informal supporters to adults with intellectual disabilities. *American Journal on Intellectual and Developmental Disabilities, 122*, 492 - 510. <https://doi.org/10.1352/1944-7558-122.6.492>
- Scott, L. A., Thoma, C. A., Gokita, T., Bruno, L., Ruiz, A. B., Brendli, K., Taylor, J. P., & Vitullo, V. (2021). I'm trying to make myself happy: Black students with intellectual and developmental disabilities and families on promoting self-determination during transition. *Inclusion (Washington, D.C.), 9*(3), 170–188. <https://doi.org/10.1352/2326-6988-9.3.170>
- Silverstein, A. B. (1975). Comparing all the means to the grand mean. III. An application to pattern analysis. *Psychological Reports, 37*, 1093-1094.
- Sloper, P. (1999). Models of service support for parents of disabled children. What do we know? What do we need to know? *Child: Care, health and development, 25*(2), 85–99.
- Solomon, P. (2001). The benefits of mutual support groups for parents of children with disabilities. *American Journal of Community Psychology, 29*(1), 113–132.
<https://doi.org/10.1023/A:1005253514140>

- Tajfel, H. (1979). Individuals and groups in social psychology. *British Journal of Social & Clinical Psychology, 18*(2), 183–190. <https://doi.org/10.1111/j.2044-8260.1979.tb00324.x>
- Taylor, J. L., Hodapp, R. M., Burke, M. M., Waitz-Kudla, S. N., & Rabideau, C. (2017). Training parents of youth with autism spectrum disorder to advocate for adult disability services: Results from a pilot randomized controlled trial. *Journal of Autism and Developmental Disorders, 47*, 846-857. <https://doi.org/10.1007/510803-016-2994-z>
- Van Swol, L. M., & Kane, A. A. (2019). Language and group processes: An integrative, interdisciplinary review. *Small Group Research, 50*, 3–38. <https://doi.org/10.1177/1046496418785019>
- Wehmeyer, M. L., & Schalock, R. L. (2013). The parent movement: Late modern times (1950 CE to 1980 CE). In M. L. Wehmeyer, *The story of intellectual disability: An evolution of meaning, understanding, and public perception* (pp. 187-231). Baltimore, MD: Paul H. Brookes.

Table 1*Demographics of Participants*

	% (n)
Gender	
Male	6.5% (26)
Female	93.5% (373)
Race/ethnicity	
White, non-Hispanic	82.1% (320)
African-American	12.3% (48)
Hispanic	2.8% (11)
Asian-American	2.1% (8)
Other	.8% (3)
Educational Background	
Graduate degree or higher	36.7% (147)
College degree	29.9% (120)
Some college or Associates Degree	27.9% (112)
High school graduate	5.5% (22)
Role*	
Individual with a Disability	4.2% (17)
Parent or Family Member	64.7% (262)
School Provider	12.3% (50)
Non-school Provider	20.2% (82)
Student	8.6% (35)
Other	7.9% (32)
Hierarchy Coding of Roles	
Individual/Family	66.4% (269)
School Provider	9.1% (37)
Non-school Provider	16.3% (66)
Students and Other	8.1% (33)
Number of Roles	
1	85.9% (348)
2	11.4% (46)
3	2.5% (10)
4	.2% (1)

*Participants could select “all that apply”.

Table 2

Insider Scale: Comparison to the Grand Mean and Factor Analysis Results

Item	Mean (SD)	Grand Mean Comparison	Factor Loading	
			I Organizational Involvement	II Social Connectedness
-Serve on boards, committees, or perform other leadership roles for one or more disability organizations	2.19 (1.45)	L	.848	
-Know what is going on in terms of the area's disability initiatives or activities	3.35 (1.18)		.776	
-Belong to local disability organizations	2.63 (1.40)	L	.762	
-Devote time to disability-related groups, causes, or activities	3.11 (1.15)		.663	
-Insider in the disability community in the local area	3.08 (1.24)		.640	
-Disability organizations as the main cause or activity they engaged in	3.08 (1.30)		.555	(.539)
-Have friends or socialize with parents of individuals with disabilities or individuals with disabilities themselves	4.00 (1.08)	H		.775
-Belong to listservs, Facebook, chat rooms, or other disability-related social media	3.61 (1.39)	H		.752
-Have a mentor that they frequently ask advice from about disability issues	3.44 (1.35)			.680
-Receive newsletters, e-mail alerts, or other written information from one or more disability organizations	3.57 (1.28)	H		.620
Eigenvalue			5.235	1.014

Note. For all highs (H) and lows (L), item means differed at $p < .001$ from Grand Mean ($\bar{x} = 3.21$).

Table 3*Results by Factor and Role*

Role	Yes <i>M(SD)</i>	No <i>M(SD)</i>	<i>t</i>	<i>p</i>
Organizational Involvement				
Individual Roles				
Individual with Disability	3.19(.98)	2.90(1.02)	1.15	.250
Parent	2.94(1.01)	2.85(1.03)	.80	.422
School Provider	2.97(1.10)	2.90(1.01)	.44	.660
Non-school Provider	3.24(.98)	2.83(1.01)	3.30	.001**
Student	2.35(1.03)	2.96(1.00)	-3.42	.001**
Multiple Roles (>1)	3.19(1.10)	2.86(1.00)	2.25	.025*
Social Connectedness				
Individual Roles				
Individual with Disability	3.55(.95)	3.66(.97)	-.456	.648
Parent	3.83(.92)	3.34(.99)	5.04	.000***
School Provider	3.49(.94)	3.68(.97)	-1.27	.206
Non-school Provider	3.89(.81)	3.59(1.00)	2.85	.005**
Student	3.09(1.16)	3.71(.93)	-3.09	.004**
Multiple roles (>1)	3.93(.86)	3.61(.98)	2.30	.022*

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