

Title: Insideriness Within the Disability Community

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Introduction: Throughout their lives, individuals look to connect with others through groups. Being an “insider” and belonging to certain groups can provide members with a sense of unity and, in certain cases, privy to special advantages; for example, individuals of particular groups might join organizations, participate in certain shared activities, and receive valuable networking and emotional support. The disability community is likely to have its own “insider” community; individuals who are deeply involved in disability organizations and perceive themselves to be insiders are more likely to receive newsletters, have friends with similar circumstances, and spend time working for disability initiatives. Little is known regarding how various attributes of “insideriness” go together as a construct, or whether sub-constructs exist. In addition, research has yet to examine how individuals with different demographic characteristics may be higher or lower on this construct(s), along with the associated underlying mechanisms. Our goals were threefold: (a) to determine the nature of “insideriness” via a new scale; (b) to analyze levels across different types of individuals (i.e., roles); and (c) to examine the “voices” of participants with via open-ended responses.

Method: This study uses a questionnaire developed for applicants to the Volunteer Advocacy Project, a 40-hour training program designed to train individuals to become special education advocates to provide instrumental and affective support for families of children with disabilities. The application was comprised of four sections: applicant information, open-ended responses, the Insider Scale, and VAP-related questions. Our dependent variables were items related to the idea of “insideriness”. Our independent variables related to gender, race/ethnicity, present occupation, and education level, along with several open-ended responses related to advocacy. We conducted three sets of analyses: (a) a repeated-measures ANOVA and factor analysis to evaluate the nature of “insideriness”, (b) paired t-tests to compare the extent of participants’ “insideriness” by factor and a one-way ANOVA to compare “insideriness” by role, and (c) coding for open-ended responses to explore themes to potentially tie findings together.

Results: Per the repeated-measures ANOVA, belonging to disability organizations; receiving newsletters, e-mail alerts, or written information; belonging to listservs, Facebook, chat rooms, or social media; having friends or socializing with parents or individuals; and having a mentor about disability issues all had higher means relative to the Grand Mean. Factor analyses indicated that “insideriness” was subdivided into two discrete categories: organizational involvement and social connectedness. An additional finding concerned the extent of participants’ disability “insideriness” by factor; participants showed greater mean insider scores for the social connectedness factor than the organizational involvement factor. Finally, open-ended responses indicated that “insideriness” is not dichotomous (insider versus not)- it is a continuum. In terms of an advocacy training, organizational involvement may trump social involvement.

Discussion: Our findings have implications for both research and engaging various stakeholders in the disability community. Given that “insideriness” was discretely subdivided into organizational involvement and social connectedness, researchers might consider examining how each factor individually corresponds with known correlates (e.g., specialized disability knowledge, health, and psychological well-being). Given that social connectedness indicated greater “insideriness” participation, members wanting to join the disability community might first consider joining related platforms (e.g., Facebook groups) to connect to others “in the know.” Further, given that most members of this factor were parents, schools and non-profits might consider facilitating events where such individuals can network with one another. Finally, researchers might also use this study to inform recruitment and study sampling. Specifically, the applicability of research findings is likely biased towards disability “insiders” because study samples are primarily comprised of this group. Thus, findings might not fully generalize to the broader intellectual and developmental disability (IDD) field. Ultimately, it is important to understand to what extent “insider” status matters so that research can generalize findings to influence society more broadly.

References: Hodapp, R. M., Rosemergy, J., Garcia, B. L., Meskis, S. A., Hart, M., & McMillan, E. (2018). Information and Referral Services in IDD. In *International Review of Research in Developmental Disabilities* (pp. 211–250). Elsevier.
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