Community Based   Occupational Therapy Graduate Research

7-2019

Advocacy-Related Occupations Among People with Disabilities: Assessing Program Outcomes of an Advocacy Workshop

Audrey Tarbutton
Grand Valley State University

Stefanie Austin
Grand Valley State University

Rachel Bendewald
Grand Valley State University

Hayley Monforte
Grand Valley State University

Advocacy-Related Occupations Among People with Disabilities: Assessing Program Outcomes

of an Advocacy Workshop

Audrey Tarbutton, Stefanie Austin, Rachel Bendewald, Hayley Monforte

Faculty Mentor: Jennifer Summers OTD

Grand Valley State University

Abstract

Objective: An emerging area of occupational therapy (OT) practice includes program development for persons with disabilities (PWD). These programs are designed to train PWD how to identify issues and advocate for inclusion and accessibility (Umeda et al., 2017). Among the available literature on community-based advocacy programs, results show positive social outcomes including increased self-advocacy knowledge and related behaviors (i.e. Kramer, 2015; Mishna et al., 2011). Regarding the present study, an advocacy training program titled "Community Organizing Advocacy Skills Training" (COAST) was developed using the Midwest Academy Training Manual for the Advocate. The purpose of this study was to pilot a tool developed to measure participants' perceptions of confidence related to self-advocacy skill to inform program development for the COAST workshop.

Method: Researchers designed pre-workshop and post-workshop attitudinal questionnaires that were given to a seven-person convenience sample. Inclusion criteria required participants to be at least 18 years of age at the time of data collection and attend at least three or more of the five workshops.

Results: Data was assessed using a cross-tabulation analysis to compare descriptive statistics of pre and post workshop questionnaires. Results showed no change among participants' perceived level of confidence regarding advocacy-related behaviors and occupations.

Conclusion: Results were inconclusive due to a small sample size and insufficient statistical testing of the designed tools. However, this pilot study offered relevant information for tool development, insight into program evaluation for future advocacy workshops, and an understanding of the scope of advocacy practice within the field of OT.

Implications for Occupational Therapy Practice

The implications for this research support the use of community-based advocacy programs to foster the development of advocacy skills and abilities among persons with disabilities. The following is a list of the benefits of this research for the field of occupational therapy:

- Advocacy training programs are indeed useful for building related skills among participants.

- Community-based advocacy training programs may help persons with disabilities build confidence related to occupations associated with advocacy (organizing demonstrations, attending city hall meetings, meeting with policy-makers).

- Advocacy-based training workshops help participants build connections among each other, fostering social participation and community involvement.

- Advocacy-based training workshops expose participants to a variety of tools and skills needed to address the topic of advocacy within their communities.

Advocacy-Related Occupations Among People with Disabilities: Assessing Program Outcomes

of an Advocacy Workshop

Persons with disabilities (PWD) make up the largest minority group in the United States (Breslin & Yee, 2009). As of 2010, the number of able-bodied individuals outweighs the number of those who have disabilities by five to one (United States Census Bureau, 2010). Disability is a complex term defined by the World Health Organization (WHO) as including physical impairments, activity limitations, and participation restrictions experienced by an individual resulting from an interaction between the person's body and the society in which he or she lives (2016, n.d.). A person's experience with his or her disability is dependent upon both societal and personal factors and influences the ability to engage in occupations (Stover, 2016). Occupations are the activities people need to, want to, or are expected to do daily, and all people have basic human rights to fulfill such occupations (WFOT, 2006). PWD often live with significant social and environmental limitations. These barriers may impact their ability to fully access and participate in both community and individual occupations (Krahn, Walker, & Correa-De- Araujo, 2015).

Disparities as Occupational Performance Issues

PWD often face a unique set of barriers throughout their lives. Not only is there a greater health disparity among this population, they also have limited access to appropriate health care, health promotion services, and disease prevention programs (Breslin & Yee, 2009). PWD experience political, economic, and cultural injustices such as marginalization, oppression, and alienation (Hammel et al., 2013). Marginalization occurs when people with disabilities are treated as insignificant or peripheral in society. Oppression is the vast and deep injustices that groups suffer because of both overt and subtle discrimination by people and cultural institutions

(Young, 1990). Alienation, in this context, refers to the exclusion of a person or group with disabilities from participation or access to functions of society (Oxford's living dictionaries, n.d.). Cultural injustices among people with disabilities can lead to decreased participation within society and can decrease health and well-being (Hammel et al., 2013). It is important that occupational therapy (OT) practitioners collaborate with organizations serving individuals with disabilities by addressing restrictions to participation in daily activities. OT practitioners work to promote engagement in the community by encouraging citizenship and social participation among people facing disability-related disparities (Hammel et al., 2013). Therefore, social change must be considered to effectively address these disparities.

The Social Model of Disability

Implementation of social change begins by exercising self-advocacy power, informing other community members, and disseminating research that is applicable beyond the local community. Social change is implemented through utilization of the social model of disability, which has brought about advancements in policy regarding civil rights related specifically to PWD (Hammel et al., 2013). The social model of disability provides a lens for viewing disability, through which a person's disability is believed to be caused by the way society is organized rather than the individual's limitation (Disability Nottinghamshire, 2018; Anastasiou & Kauffman, 2013; Kinn, 2016). This model was created by PWD to challenge the traditional medical model. They believed it provided a better explanation of their experiences and empowered them to fight for change in the societies in which they live (Burchardt, 2004). While those who practice the medical model are focused on treating the disability as a medical "condition," the social model addresses societal changes and making communities more

accessible (Disability Nottinghamshire, 2018). One method of initiating societal change is through self-advocacy education and training.

The Need for Self-Advocacy Education and Training

Advocacy-based education is designed to empower the individual being served while promoting community access and inclusion. Advocacy is a critical facet of the OT scope of practice, defined as efforts directed toward promoting occupational justice (AOTA, 2014). Through advocacy-based education and training, OT practitioners can educate both able-bodied persons and PWD about social change. However, self-advocacy is a unique concept in that it refers to an individual's ability to effectively communicate, negotiate, or assert his or her interests, needs, and rights (Goodman et al., 2011). For example, an individual with a disability may be a self-advocate by pursuing accommodations within public spaces, school systems, or workplaces (AOTA, 2014). OT practitioners are well-equipped to serve as allies for PWD by serving as consultants for community-based advocacy workshops (Hammel et al., 2013). OT consultation, as part of this process, is an interactive process that includes helping individuals, organizations, or populations solve existing or potential problems (Jaffe & Epstein, 2011).

Advocacy workshops function to organize events and projects that provide self-advocacy training and support. Self-advocacy occupations may include lobbying, organizing, speaking at educational conferences, and producing research that reflects the impactful issues in the community (Midwest Academy, n.d.). These occupations allow the voice of citizen groups to be heard in the political environment. For example, PWD can lobby for change by presenting complicated barriers such as public transportation and community accessibility to their local legislators.

Literature review. Among the available literature on advocacy programs regarding PWD, results often show positive social outcomes including increased self-advocacy knowledge, advocacy-related behaviors, and self-determination. For example, students with learning disabilities significantly increased their self-reported self-advocacy knowledge and ability from the Walk a Mile in My Shoes workshop which taught them skills related to advocacy (Mishna, Muskat, Farina, Wiener, 2011). In addition, students with developmental disabilities who participated in Project TEAM (Teens making Environment and Activity Modifications) identified environmental barriers and supports, generated modification strategies, and requested reasonable accommodations (Kramer, 2015). PWD also engaged in social participation in their communities more frequently after participating in advocacy workshops (Umeda, 2017).

Although researchers in fields such as public health, psychology, and social work have studied the influence of disability-led advocacy organizations and workshops in detail, there are gaps in the literature emphasizing the importance of OT within this topic area (Tsuda & Smith, 2004; Goodley, 1998; Goodley, Armstrong, Sutherland, & Laurie, 2003). Part of the professional responsibility of an OT practitioner is to assess and document client improvement in advocacy-related occupations (AOTA, 2014; AOTA, 2009). However, there is limited data supporting the development and implementation of OT-specific assessment tools that measure self-perceptions related to advocacy after taking part in such workshops and advocacy-based programming.

Assessment tools are valuable because they allow the therapist to appropriately measure the occupational performance outcomes of people involved in self-advocacy programs. These tools can be used as a baseline to form intervention strategies and target outcomes for the client or group of interest. Additional research from an OT perspective is needed to examine the efficacy of advocacy-related program outcomes. Furthermore, this research may encourage

development, implementation, and sustainability of OT driven self-advocacy workshops in the future.

COAST and The Midwest Academy

The Community Organizing Advocacy Skills Training (COAST) is a self-advocacy training workshop for PWD held in Grand Rapids, Michigan. At COAST, PWD follow Midwest Academy procedures designed to target social change (Bobo, Kendall, & Max, 2001). The Midwest Academy is a national training institute committed to support social, economic, and racial justice (Midwest Academy, n.d.). This training provides an organizational philosophy that includes methods and skills that enable people to actively participate in the democratic process using direct action (Midwest Academy, n.d.). Direct action is based on three principles that distinguish it from other types of organizing: the desire to win concrete improvements in the community, the establishment and realization of one's own power, and an alteration in the relations of power (Bobo, Kendall, & Max, 2001). The members of the organization strive to win real, immediate, concrete improvements in community living (Bobo, Kendall, & Max, 2001). Through direct action, members learn to exercise their own power and abilities rather than using a third party to handle a problem (Bobo, Kendall, & Max, 2001). This is achieved by deconstructing the problem into an issue, or a solution to the problem, and then creating short-term, attainable goals to win the issue (Bobo, Kendall, & Max, 2001).

Method

Grand Valley State University's Master of Science in Occupational Therapy (GVSU MSOT) students have partnered with PWD to assist with the COAST advocacy workshops since 2016. Aside from debriefs lead by the students, the results of these workshops were not accounted for using a quantifiable measure of participants' self-confidence with advocacy

occupations. This study aimed to pilot tools in the form of attitudinal questionnaires to inform program development for the future. Attitudinal questionnaires are shown in the literature to be effective for predicting how people will behave in the future, providing a measure of state-of-mind and how they may interact with their external environments (Oppenheim, 1992). Such questionnaires were designed to determine the extent to which people feel confident with advocacy-related behaviors before and after the workshop.

Measures

Pre and post workshop evaluation questionnaires were developed after a thorough review of the Midwest Academy literature. Questions were composed at an eighth-grade reading level using the Microsoft Word 2007 reading grade-level assessment tool. To address face validity, the researchers recruited DAKC community affiliates to ensure the questions appeared relevant, clear, and unambiguous. Content validity was based on judgement, as no objective methods exist for statistical analysis. Prior to administration, the questionnaires were examined by researchers to determine whether questions reflected the concepts being studied and that the scope of the questions were adequate. Closed-ended questions included in the pre and post-workshop questionnaires were measured on a 5-point Likert scale (strongly disagree to strongly agree). Internal consistency, a measure of reliability, was used to check whether the participants' responses were to be consistent prior to administration. Several items on the questionnaire were designed to propose the same general construct.

Data Collection

Data were collected in partnership with a community-based organization and Center for Independent Living, Disability Advocates, in Kent County, Michigan. Participants were recruited the first day of the COAST workshop. The participants were recruited on a voluntary

basis and were informed that, if they chose to participate in the study, they could withdraw at any time. Participants were asked to read and sign the informed consent form if they agreed to participate (see Appendix C). Individuals who chose to volunteer for the study and met the inclusion criteria were included in the sample. All questionnaires were self-administered, although researchers and caretakers were available to read the questionnaires to the participants if they had difficulty reading the questionnaires on their own. The pre-workshop questionnaire was administered at the beginning of the first session that the participant attended (see Appendix A). The post-workshop questionnaire was administered the last 30 minutes of the fifth workshop day (see Appendix B).

Sample. The sample included individuals who reside in Grand Rapids and the surrounding area with disabilities. A total of seven PWD participated in the study. Inclusion criteria required participants to be at least 18 years of age at the time of data collection who attended at least three or more of the five workshops. GVSU MSOT students were excluded from the study.

Pre-workshop questionnaire. For the pre-workshop questionnaire, part A included demographic information (e.g., sex, age, race, disability status) (see Appendix A). Part B contained closed-ended questions which assessed confidence levels associated with self-advocacy, such as their confidence in developing goals for oneself and developing tactics to address advocacy-related issues. Closed-ended questions also assessed expectations for the workshop, such as their belief that the workshop will provide them with the necessary skills to develop leadership and empowerment. Part C was used to gather more detailed information about the attendees. These questions were used to identify familiar advocacy activities, what

types of activities the participants have done, and what they plan to do in the future (i.e. petition

drive, meeting with a decision maker, mass demonstration).

Post-workshop questionnaire. The post-workshop questionnaire was administered the

last 30 minutes of the fifth workshop day (see Appendix B). Part A included a closed-ended

question regarding the number of workshops attended ranging from one to five. Part B contained

closed-ended items regarding the extent to which participants found the training useful in

developing advocacy-related skills (i.e. leadership, strong communication style), and their

intentions to participate in advocacy-related actions in the future (i.e. confronting a decision-

maker to make a policy change). Additional questions prompted participants to rank their

feelings of empowerment and confidence related to self-advocacy and further assessed their

feeling of power and ability to advocate for themselves or their respective organizations. Part C

of the post-questionnaire was used to identify if any new advocacy activities had become

familiar, if participants had been involved in any types of these activities since the start of the

workshop, and what activities (if any) do they plan to be a part of in the future (i.e. petition drive,

meeting with a decision maker, mass demonstration). Further areas in this section were used to

inform the researchers of what the participants felt was most important and least important about

the training and how the training could be improved. Data collected from these questionnaires

were used to assess their perceived efficacy and confidence levels related to advocacy-related

behaviors.

Data Analysis

An online Survey Monkey was created to replicate the questionnaires. Frequency of

attendance and demographic percentages were calculated using this service. Participant

responses were manually entered into Survey Monkey by researchers, then exported into SPSS

24.0 (SPSS Inc, Chicago, IL). Responses from the Likert scale (Part B of both questionnaires) were collapsed to ''disagree,'' "neutral," or ''agree'' to reduce chance of researcher error, as each questionnaire had 18 Likert-style questions each. Cross-tabulation tables were used to determine descriptive statistics for changes in confidence with advocacy-related concepts between pre- and post- responses, as no other statistical test could be used to determine significance given the small sample size (Hellevik, 1984). To assess respondent literacy, internal consistency was measured by providing four rephrased question duplicates and assessing for any variation using two by two cross-tabulation tables that met assumptions to run the McNemar test for paired, nominal data (Eliasziw & Donner, 1991).

Results

The prediction for the current study included an increased sense of confidence and efficacy related to advocacy-related behaviors (occupations) among participants after participating in the COAST five-day advocacy workshop. An additional prediction for the study included that these questionnaires were to be useful, accurate tools for examining changes in attitudes towards advocacy among participants, as well as a tool to guide program development and improve the workshop for the future.

Part C of the pre-workshop questionnaire inquired if participants had exposure to activities associated with advocacy in the past (refer to Appendix A). Figure 1 shows the activities that participants were familiar with prior to the workshop, while Figure 2 shows activities that participants have done (see Appendix E). All participants had exposure to advocacy-related activities prior to the workshop. Part A of the post-workshop questionnaire required participants to choose how many days of the workshop they attended ranging from one to five (refer to Appendix B). Six participants out of seven attended all five workshop days, the

remaining participant attended four days. Part C of the post-workshop questionnaire required participants to choose which activities they would be interested in after completing the workshop; such responses can be seen on Figure 3 (see Appendix E).

Descriptive Statistics

Participants' responses on the questionnaires were evaluated using an analysis of the cross-tabulation tables. Such tables allowed for an appropriate quantitative method of examining the relationship among responses on Part B of the pre and post workshop questionnaires. The cross-tabulation output displayed changes that were seen among the results for Part B on both questionnaires among all seven participants. Eighteen cross tabulation tables were constructed for each of the questions on Part B, comparing post-responses to pre-responses. The results of such comparisons can be seen on Table D1 (see Appendix D). There were five questions that displayed changes among participant responses (see table D1). Cross-tabulation output was included only for the questions that yielded change among responses (see tables D2-D6). For example, regarding question 5, "I feel a sense of belonging in my community," one participant changed their response from "neutral" on the pre-workshop questionnaire to "agree" on the post-workshop questionnaire. One participant also changed from neutral to agree on questions such as "I have the skills I need to decide positions on important issues" and "I feel confident that I can interact with people I am trying to target for advocacy." These results show that some participants responded to certain questions with an increased sense of efficacy, although responses to many other questions stayed the same (see table D1). When comparing pre to post data, the McNemar test showed that respondents answered four out of four internal consistency questions similarly without variance.

Sample demographics. Part A on the pre-workshop questionnaire included responses on disability status, race/ethnicity, gender, age, affiliation with a community organization, and past attendance of the workshop (refer to Appendix A). Regarding disability status, 60% of participants had a physical disability, 12% visual, 29% intellectual, 29% mental, and 0% hearing/auditory. 58% of participants were female, 42% male. 57% of participants identified as white/Caucasian and 43% identified as black/African American. 57% of participants belonged to a community organization including work programs, DAKC, and community and family partnerships. 14% of participants attended the workshop in the past while 86% did not.

Discussion

The objective for this pilot research was to evaluate a tool in the form of pre and post attitudinal questionnaires for assessing confidence levels related to advocacy after participation in the COAST five-day advocacy skills training workshop. Such results were intended to be used to inform program evaluation for the future and to improve the workshop based upon participant responses on the tools. The results from our sample indicate that no significant change was found from pre to post workshop responses. When comparing cross-tabulation results of both questionnaires, one respondent changed their answer(s) on several questions from neutral to agree, including questions such as "I feel a sense of belonging in my community" and "I feel confident in interacting with people I am trying to target for advocacy" (see table D1). At the same rate, another participant responded to several questions changing answers from "agree" to "neutral" for questions such as "I have the skills I need to decide on positions for important issues" (see table D1). Most other respondents did not change their answers from pre to post. Therefore, the results that can be drawn from the cross-tabulation analysis were inconclusive. Participant demographics also did not influence the nature of responses.

These results are comparable to many other studies involving advocacy training programs. Related literature on the topic shows that people involved in advocacy activities can develop a critical worldview regarding their struggles within society, and they become more confident in their ability to act on issues that are important to them (Krauss, 1983). However, the effectiveness of advocacy training programs has not been evaluated consistently (Gardner, 1980). Similar to the present study, the reported effects of related research on advocacy training programs are null (Cook, Howell, & Weir, 1985). There are some studies that show increases in group members' engagements with decision makers during advocacy training, and the number of reported outcomes suggest an overall improvement in the effectiveness of these programs (Balcazar, Seekins, Fawcett, & Hopkins, 1990).

Further research is recommended to fine-tune the statistical power of the questionnaires to ensure adequate internal validity as well as external validity and generalizability to the greater public. Statistical analyses such as Cronbach's alpha, as a measure of internal consistency, are well-known and beneficial tests used to evaluate the use of a new tool (i.e. Ventry & Weinstein, 1982). Although the tools used for the present pilot study yielded inconclusive results, valuable information regarding the effectiveness of these tools can be used to refine their development for future research. The responses on the pre and post workshop questionnaires generally remained the same, indicating that participants did not lose knowledge and confidence related to advocacy-based skills after workshop participation. As the tools and stated methodology are refined to better target confidence and competence levels among participants, the COAST workshop can be improved for future cohorts.

Limitations

There are several important limitations of this study to consider for future research. Balcazar and colleagues (1990) note that there is value in longitudinal research with consumer organizations and advocacy programs, such that significant results may more likely be seen over a longer period of time. Regarding longitudinal research, it is possible that advocacy workshops held for a longer time period may generate stronger results, as some studies report that people with disabilities were monitored for up to two years when participating in training (i.e. Balcazar et al., 1990). Due to the small sample size, it is possible that longitudinal analysis of this same participant group over time may yield more identifiable results regarding confidence and knowledge of advocacy-related skills. In the present study, an analysis of G-power during data analysis showed that the questionnaires used in this study would need a sample of at least 114 respondents to show adequate reliability. Upon recruitment of a larger sample of participants, nonparametric statistical analyses such as a Wilcoxon Signed Rank test may be useful for determining the differences between pairs of data that are not normally distributed (Woolson, 2007).

The participant sample used for the present study were also identified to have prior advocacy knowledge prior to the workshop as demonstrated in Figures 1 and 2. Although no individuals in the sample had participated in the COAST workshop prior to this study, one speculation for a null result implies that participants simply did not broaden their knowledge of advocacy-related skills as a result of the workshop. It may be likely that they were already competent in the skills that were covered across all five workshop days. Future researchers studying this topic may choose to pre-screen for confidence levels related to advocacy when

assessing a participant sample and may choose to only include individuals in a sample who do not have prior advocacy experience.

Furthermore, the use of self-report questionnaires may have influenced inconclusive results. Self-report questionnaires require researchers to rely on the honesty and introspective abilities of the participants (Hoskin, 2012). Participants may vary among their understanding or interpretation of different questions (Hoskin, 2012). For example, participants may often interpret and use scales differently; what one person might rate as '8' on a 10-point scale, someone with the same opinion might only rate as a '6' because he or she may interpret the meanings of the scale points differently (Hoskin, 2012). Furthermore, it is possible that participants may utilize different methods of answering questions on rating scales. Some participants may tend to be 'extreme responders,' using the edges of the scales whereas others may be more likely to select answers near the midpoints (Hoskin, 2012). This phenomenon can interfere with the content validity of the chosen questionnaire (Hoskin, 2012).

Conclusion

The present study is informative to the field of occupational therapy for several reasons. Advocacy programming for individuals with disabilities remains an emerging area of practice in need of statistical evidence and empirical support. The available literature related to advocacy-based workshops for developing skills among participants remains inconsistent, with limited data supporting the use of assessment tools that are specific to the field of occupational therapy (Tsuda & Smith, 2004). Furthermore, the social model of disability has yet to make a widespread appearance across the breadth of occupational therapy literature focusing on the effect of advocacy and its impact on the greater society. More research is needed to determine how

occupational therapy professionals can hone the delivery of advocacy education and program development for individuals of all skill levels and abilities.

References

American Occupational Therapy Association [AOTA]. (2014). Occupational therapy practice

framework: Domain and process (3rd ed.). *American Journal of Occupational Therapy*,

68, S1-S48.

American Occupational Therapy Association [AOTA]. (2009). Occupational therapy's

commitment to non-discrimination and inclusion. *American Journal of Occupational

Therapy, 63*, 819–820. doi:10.5014/ajot.63.6.819.

Anastasiou, D., & Kauffman, J. M. (2013). The social model of disability: Dichotomy between

impairment and disability. *The Journal of Medicine and Philosophy: A Forum for

Bioethics and Philosophy of Medicine*, *38*(4), 441-459. doi:10.1093/jmp/jht026.

Balcazar, F. E., Seekins, T., Fawcett, S. B., & Hopkins, B. L. (1990). Empowering people with

physical disabilities through advocacy skills training. *American Journal of Community

Psychology, 18*(2), 281-296.

Bobo, K. A., Kendall, J., & Max, S. (2001). *Organizing for social change: Midwest Academy

manual for activists*. Seven Locks Press.

Breslin, M. L., & Yee, S. (2009). The National Council on Disability. *The Current State of

Health Care for People with Disabilities*. Washington D. C.: National Council on

Disability.

Burchardt, T. (2004). Capabilities and disability: The capabilities framework and the social

model of disability. *Disability & Society*, *19*(7), 735-751.

Cook, A. K., Howell, R. E., & Weir, I. L. (1985). Rural leadership programs and changing

participation of men and women in public affairs. *Journal of the Community

Development Society, 16*, 41-56.

Disability Nottinghamshire. The social model vs. the medical model of disability (2018).

    Retrieved from www.disabilitynottinghamshire.org.uk/about/social-model-vs-medical-

    model-of-disability/

Eliasziw, M., & Donner, A. (1991). Application of the McNemar test to non-independent

    matched pair data. *Statistics in Medicine*, *10*(12), 1981-1991.

Goodley, D. (1998). Supporting people with learning difficulties in self advocacy groups and

    models of disability. *Health & social care in the community, 6*(6), 438-446.

    doi:10.1046/j.1365-2524.1998.00136.x

Goodley, D., Armstrong, D., Sutherland, K., & Laurie, L. (2003). Self-advocacy, "learning

    difficulties," and the social model of disability. *Mental Retardation, 41*(3), 149-160.

Goodman, G., Radford, R., Smith, L., Marie, L., Shisila, K., Valley, J., & Davison, D. (2011).

    Transition to college for students with disabilities: Lessons from a pilot program. *Home

    and Community Health Special Interest Section Quarterly, 18*(4), 1-4.

Hammel, J., Charlton, J., Jones, R. A., Kramer, J. M., & Wilson, T. (2013). Disability rights and

    advocacy: Partnering with disability communities to support full participation in society.

    In *Willard and Spackman's Occupational Therapy: Twelfth Edition* (pp.1031-1050).

    Wolters Kluwer Health Adis (ESP).

Hellevik, O. (1984). *Introduction to causal analysis: exploring survey data by crosstabulation*.

    Allen & Unwin.

Hoskin, R. (2012, March 03). The Dangers of Self Report [Web log post]. Retrieved April 04,

    2018, from http://www.sciencebrainwaves.com/the-dangers-of-self-report/

Jaffe, E. G., & Epstein, C. F. (2011). Consultation: Collaborative interventions for change. In K.

    Jacobs & G. L. McCormack (Eds.), *The occupational therapy manager* (5th ed., pp.

521–545. Bethesda, MD: AOTA Press.

Kinn, A. (2016). Reflections on the social model of distress or madness: How to make the social model of disability accessible to people with mental health challenges. *Mental Health and Social Inclusion, 20*(4), 231-237. doi:10.1108/MHSI-06-2016-0018

Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R. (2015). Persons with disabilities as an unrecognized health disparity population. *American Journal of Public Health, 105*(S2), S198-S206.

Kramer, J. M. (2015). Identifying and evaluating the therapeutic strategies used during a manualized self-advocacy intervention for transition-age youth. *Occupation, Participation and Health, 35*(1), 23-33. doi:10.1177/1539449214564146

Krauss, C. (1983). The elusive process of citizen activism. *Social Policy, 13*, 50-55.

Marginalization (n.d.) In *Oxfords living dictionary*. Retrieved from: https://en.oxforddictionaries. com/definition/marginalization

Midwest Academy. (n.d.). *Mission and history.* Retrieved from http://www.midwestacademy.com/about/mission-history/

Mishna, F., Muskat, B., Farina, F., Wiener, J. (2011). The effects of a school-based program on the reported self-advocacy knowledge of students with learning disabilities, *Alberta Journal of Educational Research, 57*(2), 185-203.

Oppenheim, A. N. (1992). *Questionnaire design, interviewing and attitude measurement*. London: Pinter

SPSS Inc. Released 2007. SPSS for Windows, Version 16.0. Chicago, SPSS Inc.

Stover, A. D. (2016). Client-centered advocacy: Every occupational therapy practitioner's responsibility to understand medical necessity. *American Journal of Occupational*

Therapy, 70(5), 7005090010p1-7005090010p6.

Tsuda, E. & Smith, J. G. (2004). Defining and organizing self-advocate centered groups:

Implications of survey research on self-advocacy groups in Japan. *Disability & Society,*

19(6), 627-646. doi:10.1080/0968759042000252542

Umeda, C. J., Fogelberg, D. J., Jirikowic, T., Pitonyak, J. S., Mroz, T. M., & Ideishi, R. I.

(2017). Expanding the implementation of the Americans with Disabilities Act for

populations with intellectual and developmental disabilities: The role of organization-

level occupational therapy consultation. *American Journal of Occupational Therapy,*

71(4), 7104090010p1-7104090010p6.

United States Census Bureau, 2010. Nearly 1 in 5 people have a disability in the U.S. Retrieved

from https://www.census.gov/newsroom.releases/archives/miscellaneous/cb12-134.html

Ventry, I. M., & Weinstein, B. E. (1982). The hearing handicap inventory for the elderly: a new

tool. *Ear and Hearing, 3*(3), 128-134.

Woolson, R. F. (2007). Wilcoxon signed-rank test. *Wiley Encyclopedia of Clinical Trials*, 1-3.

World Health Organization. (2016). *Disabilities.* Retrieved November 30, 2017 from

http://www.who.int/topics/disabilities/en

World Federation of Occupational Therapists. (2006). Position statement on human rights.

Available online at:

http://www.wfot.org/office_files/Human%20Rights%20Position%20Statement

%20Final.pdf

World Health Organization (n.d.). World report on disability. Retrieved January 27, 2018, from

http://www.who.int/disabilities/ world_report/2011/en/

Young, I. M. (1990). Five faces of oppression. In *Justice and the politics of difference* (39-65).

Princeton, New Jersey: Princeton University Press.

Appendix A

Questionnaire – Pre-Workshop

Demographic Information:

Age: _____

Do you have a disability? (circle one)

Yes

No

If YES, what type of disability? (circle all that apply)

Physical

Visual

Hearing/Auditory

Intellectual

Other: _____

Prefer not to respond

What gender do you identify as? (circle one)

Male

Female

Transgender

Other: _____

Prefer not to respond

Ethnicity: (circle one)

Caucasian/White

African American

Hispanic/Latino

Asian American

Other _____

Prefer not to respond

What is your zip code? _____

Do you belong to a Community Organization? Circle YES or NO

If you answered YES, please specify which organization you belong to: _____

Are you here on their behalf? YES or NO

<div style="border:1px solid black">

Participant Number:
_____

This is for research purposes only. Please do not write here.

</div>

How did you hear about this workshop?

_____

Have you attended this workshop with Grand Valley State University students in the past?
    Circle   YES or NO

If you answered YES, how many times? _____

Circle the statement you agree with for each question
1= Totally Disagree; 2=Somewhat Disagree; 3=Neutral; 4=Somewhat Agree; 5=Totally Agree

As of now…

	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
I feel included in my community	1	2	3	4	5	Unsure
I feel empowered to make a difference in my community	1	2	3	4	5	Unsure
	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure

As of now…						
I have the skills to advocate for the issues I find important	1	2	3	4	5	Unsure
I have the skills I need to decide positions on important issues	1	2	3	4	5	Unsure
I feel a sense of belonging to my community	1	2	3	4	5	Unsure
I can be a leader in advocacy-related efforts	1	2	3	4	5	Unsure
I have the skills I need to help others with advocacy-related efforts	1	2	3	4	5	Unsure
My involvement in advocacy-related efforts strengthens my organization as a whole	1	2	3	4	5	Unsure

As of now, I feel confident that I can…

	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
Raise concerns that I have	1	2	3	4	5	Unsure
Develop goals for myself for advocacy	1	2	3	4	5	Unsure
Interact with people I am trying to target for advocacy	1	2	3	4	5	Unsure
Develop tactics to address advocacy-related issues	1	2	3	4	5	Unsure
Work within a group	1	2	3	4	5	Unsure
Come up with ways to confront advocacy-related problems	1	2	3	4	5	Unsure
Explain the process of direct action to a friend or family member	1	2	3	4	5	Unsure

Define a solution to a problem	1	2	3	4	5	Unsure
	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
As of now, I feel confident that I can…						
Convince target people to make decisions in my and/or my organization's favor	1	2	3	4	5	Unsure
Come up with some ideas to help solve a problem	1	2	3	4	5	Unsure

Out of these popular advocacy tactics, circle all the ones that you are familiar with (circle all that apply):
a)   Petition drive
b)   Letter writing
c)   Meeting with a decision maker
d)   Turnout event
e)   Public hearing
f)   Mass demonstration
g)   Attend local government meetings such as a city/township, county council meetings, school board meetings, etc
h)   Speak with local news (TV/paper) about an issue of importance
j)   Other: _____

Out of these popular advocacy tactics, circle all the ones that you have participated in (circle all that apply):

a)   Petition drive

b)   Letter writing

c)   Meeting with a decision maker

d)   Turnout event

e)   Public hearing

f)   Mass demonstration

g)   Attend local government meetings such as a city/township, county council meetings, school board meetings, etc

h)   Speak with local news (TV/paper) about an issue of importance

j)   Other: _____

Appendix B

Questionnaire – Post-Workshop

My group's issue was _____

Did you attend the meet and greet event held on June 9th?
Yes   No

Of the 5 days the workshop was held, *circle all* of the days you attended.
| Day 1 | Day 2 | Day 3 | Day 4 | Day 5 |
| (Mon., July 9) | (Tues., July 10) | (Wed., July 11) | (Thurs., July 12) | (Sat., July 14) |

Circle the statement you agree with for each question:
1= Totally Disagree; 2= Somewhat Disagree; 3= Neutral; 4=Somewhat Agree; 1= Totally Agree

After attending the workshop…

1= Totally Disagree; 2=Somewhat Disagree; 3=Neutral; 4=Somewhat Agree; 5=Totally Agree

	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
I feel included in my community	1	2	3	4	5	Unsure
I feel empowered to make a difference in my community	1	2	3	4	5	Unsure

	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
I have the skills to advocate for the issues I find important	1	2	3	4	5	Unsure
	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
After attending the workshop…						
I have the skills I need to decide positions on important issues	1	2	3	4	5	Unsure
I feel a sense of belonging to my community	1	2	3	4	5	Unsure
I can be a leader in advocacy-related efforts	1	2	3	4	5	Unsure
I have the skills I need to help others with advocacy-related efforts	1	2	3	4	5	Unsure

My involvement in advocacy-related efforts strengthens my organization as a whole	1	2	3	4	5	Unsure

After attending the workshop, I feel confident that I can…

	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
Raise concerns that I have	1	2	3	4	5	Unsure
Develop goals for myself for advocacy	1	2	3	4	5	Unsure
Interact with people I am trying to target for advocacy	1	2	3	4	5	Unsure
Develop tactics to address advocacy-related issues	1	2	3	4	5	Unsure
Work within a group	1	2	3	4	5	Unsure

Come up with ways to confront advocacy-related problems	1	2	3	4	5	Unsure
Explain the process of direct action to a friend or family member	1	2	3	4	5	Unsure
	Totally Disagree	Somewhat Disagree	Neutral	Somewhat Agree	Totally Agree	Unsure
After attending the workshop, I feel confident that I can…						
Define a solution to a problem	1	2	3	4	5	Unsure
Convince target people to make decisions in my and/or my organization's favor	1	2	3	4	5	Unsure
Come up with some ideas to help solve a problem	1	2	3	4	5	Unsure

Out of these popular advocacy tactics, circle all the ones that you plan to be a part of in the future (circle all that apply):
a)   Petition drive
b)   Letter writing
c)   Meeting with a decision maker
d)   Turnout event
e)   Public hearing
f)   Mass demonstration
g)   Attend local political meetings such as a city/township, county, or school
h)   Speak with local news (TV/paper) about an issue of importance
j)   Other: _____

How do you think COAST training could be improved?

_____
_____
_____
_____

What was most important about the training?

_____
_____
_____
_____

What was least important about the training?

_____

_____

_____

_____

Appendix C

Informed Consent Document

1. **TITLE:** Participation in Advocacy Related Occupations Among People with Disabilities: Assessing Program Outcomes of an Advocacy Workshop

2. **RESEARCHERS:**
Stefanie Austin, Rachel Bendewald, Audrey Tarbutton, Hayley Monforte, Dr. Jennifer Summers

3. **PURPOSE** The reason for this study is to look at the results of this advocacy workshop. We want to know if you feel more confident completing advocacy activities after going through this workshop. We would like to know if this workshop is actually beneficial to you and other participants.

4. **REASON FOR INVITATION** We are inviting you to help us understand the results of the workshop. This research is for people who do not have guardians and are independent.

5. **HOW PARTICIPANTS WILL BE SELECTED** Anyone with a disability can be included in the study. Student researchers will not be included in this study.

6**. PROCEDURES** You will fill out a survey before you start the workshop. Then, you will fill out another survey at the end of the last workshop day. Both surveys will take 15-20 minutes to do. There is no cost for taking the survey. Being a part of this study will not put you at risk.

7. **RISKS** We do not think there is any risk to you from participating in this research.

8. **POTENTIAL BENEFITS TO YOU** If we find that the workshop is beneficial, you will know that your time spent at the workshop is worth it for building advocacy skills.

9. **POTENTIAL BENEFITS TO SOCIETY** Our research is used to determine your confidence with different skills taught in the workshop. We will use this data to decide what changes could be made to improve the workshop in the future. This study is important because advocacy skills are necessary when living within the community

10. **VOLUNTARY PARTICIPATION** Your participation in this research study is completely voluntary. You do not have to participate if you do not want to. You may quit at any time without any penalty to you. Your services at DAKC will not be affected if you choose not to

participate. Your involvement with the COAST workshop will not be affected if you choose not to participate.

11. **PRIVACY AND CONFIDENTIALITY** Your name will not be given to anyone other than the research team. All the information collected from you or about you will be kept confidential to the fullest extent allowed by law. In very rare circumstances specially authorized university or government officials may be given access to our research records for purposes of protecting your rights and welfare.

12. **RESEARCH STUDY RESULTS** If you wish to learn about the results of this research study you may request that information by contacting Jennifer Summers at frieseje@gvsu.edu

13. **PAYMENT** There will be no payment for participation in the research.

14. **AGREEMENT TO PARTICIPATE** By signing this consent form below you are stating the following:
·   The details of this research study have been explained to me including what I am being asked to do and the anticipated risks and benefits;
·   I have had an opportunity to have my questions answered;
·   I am voluntarily agreeing to participate in the research as described on this form;
·   I may ask more questions or quit participating at any time without penalty.

_____ (Initial here) I have been given a copy of this document for my records.

Print Name: _____

Sign Name in ink: _____

Date Signed:_____

15. If you have any questions about this study you may contact the lead researcher as follows:

NAME:_____

PHONE: _____ _____

E-MAIL: _____

If you have any questions about your rights as a research participant, please contact (name omitted)

If you have any questions, please contact the Office of Research Compliance and Integrity at (name omitted)

Appendix D

Table D1

Summary of Cross-Tabulation Results and Descriptive Statistics

Question	Result
1. I feel included in my community.	No change – one participant remained neutral, six participants responded "agree"
2. I feel empowered to make a difference in my community	No change – all participants responded "agree"
3. I have the skills to advocate for the issues I find important	No change – all participants responded "agree"
4. I have the skills I need to decide positions on important issues	One participant changed from "neutral" to "agree," one participant changed from "agree" to "neutral" (see table D2)
5. I feel a sense of belonging to my community	One participant changed from neutral to agree (see table D3)
6. I can be a leader in advocacy-related efforts	One participant changed from agree to neutral (see table D4)
7. I have the skills I need to help others with advocacy-related efforts	No change – all participants responded "agree"
8. My involvement in advocacy-related efforts strengthens my organization as a whole	No change – all participants responded "agree"
9. Raise concerns that I have	No change – all participants responded "agree"
10. Develop goals for myself for advocacy	No change – all participants responded "agree"

11. Interact with people I am trying to target for advocacy	One participant changed from neutral to agree and one participant changed from agree to neutral (see table D5)
12. Develop tactics to address advocacy-related issues	No change – one participant stayed neutral, six participants responded "agree"
13. Work within a group	No change – all participants responded "agree"
14. Come up with ways to confront advocacy-related problems	No change – all participants responded "agree"
15. Explain the process of direct action to a friend or family member	No change – One participant stayed neutral, 6 participants responded "agree"
16. Define a solution to a problem	No change – all participants responded "agree"
17. Convince target people to make decisions in my and/or my organization's favor	One participant changed from "agree" to "neutral" (see table D6)
18. Come up with some ideas to help solve a problem	No change – all participants responded "agree"

Note: Table D1 shows the summary of cross-tabulation results. Participants' responses to questions on part B of the pre and post-workshop questionnaires were compared, displaying answers that were changed or not changed.

Table D2

Cross-Tabulation One

| | | | I have the skills I need to decide positions on important issues | | |
			Neutral	Agree	Total
I have the skills I need to decide positions on important issues	Neutral	Count	0	1	1
		% within I have the skills I need to decide positions on important issues	0.0%	100.0%	100.0%
	Agree	Count	1	5	6
		% within I have the skills I need to decide positions on important issues	16.7%	83.3%	100.0%
Total		Count	1	6	7
		% within I have the skills I need to decide positions on important issues	14.3%	85.7%	100.0%

Note: "I have the skills I need to decide positions on important issues"

Table D3

Cross-Tabulation Two

| | | | | I feel a sense of belonging to my community | |
| | | | | Post-Test | |
				Agree	Total
I feel a sense of belonging to my community	Pre-Test	Neutral	Count	1	1
			%	100%	100%
		Agree	Count	5	5
			%	100%	100%

Note: "I feel a sense of belonging in my community"

Table D4

Cross-Tabulation Three

				I can be a leader in advocacy-related efforts		
				Post-Test		
				Neutral	Agree	Total
I can be a leader in advocacy-related efforts	Pre-Test	Agree	Count	1	6	7
			%	14.3%	85.7%	100%

Note: "I can be a leader in advocacy-related efforts"

Table D5

Cross-Tabulation Four

				Interact wih people I am trying to target for advocacy		
				Post-Test		
				Neutral	Agree	Total
Interact with people I am trying to target for advocacy	Pre-Test	Neutral	Count	0	1	1
			%	0%	100%	100%
		Agree	Count	1	5	6
			%	16.7%	83.3%	100%

Note: "Interact with people I am trying to target for advocacy"

Table D6

Cross-Tabulation Five

			Convince target people to make decisions in my and/or my organization's favor		
			Neutral	Agree	Total
Convince target people to make decisions in my and/or my organization's favor	Agree	Count	1	6	7
		% within Convince target people to make decisions in my and/or my organization's favor	14.3%	85.7%	100.0%
Total		Count	1	6	7
		% within Convince target people to make decisions in my and/or my organization's favor	14.3%	85.7%	100.0%

Note: "Convince target people to make decisions in my and/or my organization's favor"

Appendix E

Figure 1. Percentages of Participants that were Familiar with Advocacy Occupations prior to Workshop
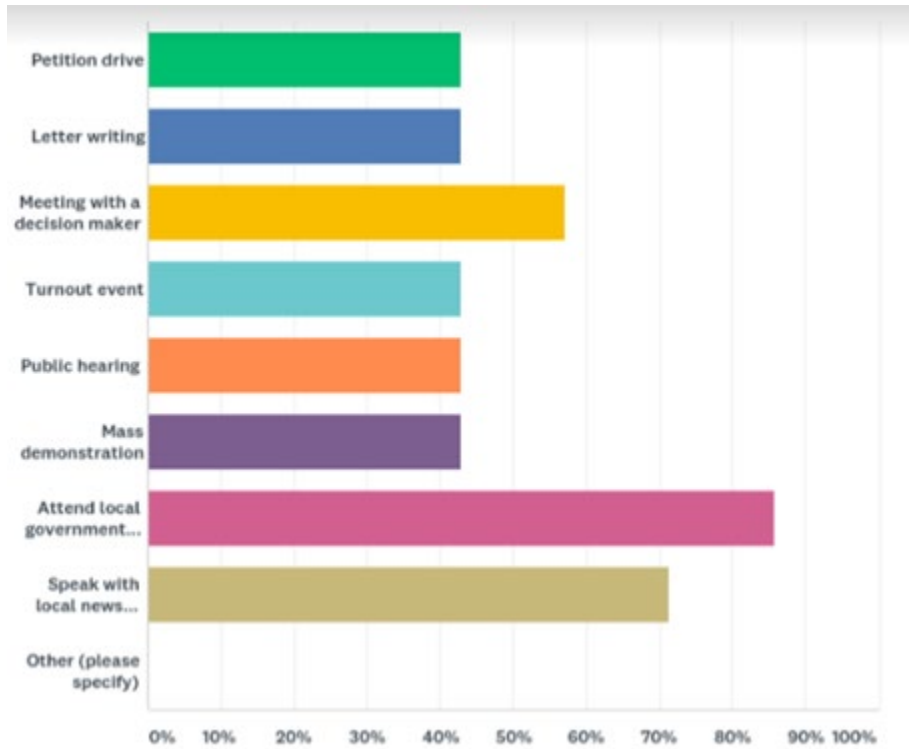
Figure 2. Percentages of Participants who have Participated in Advocacy-Related Occupations
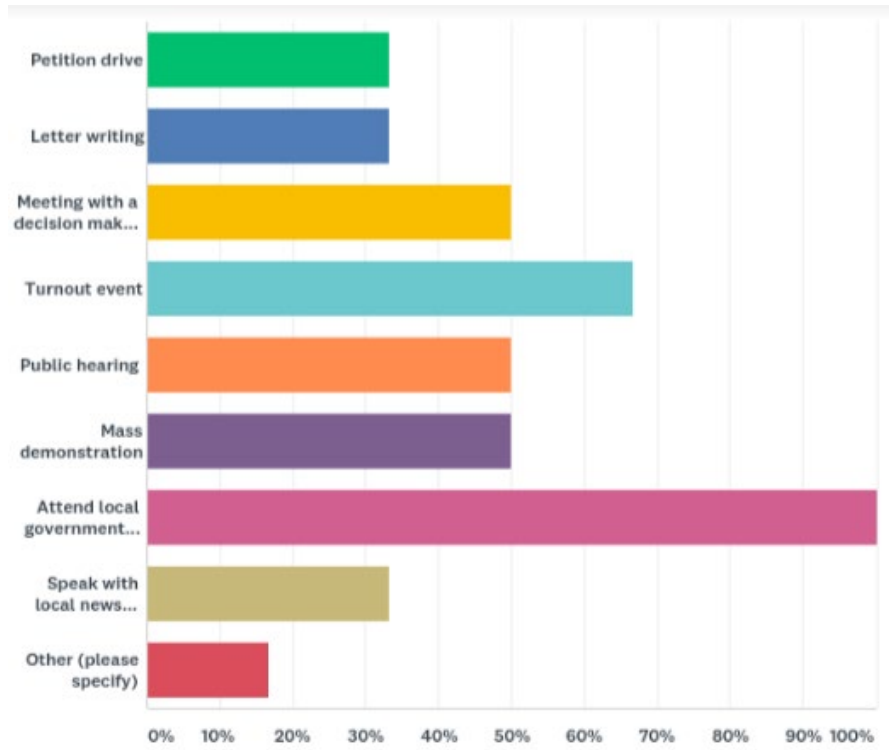
Figure 3. Advocacy-Related Occupations that Participants Want to do in the Future