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Training Parents of Youth with Autism Spectrum Disorder to Advocate for Adult Disability Services: Results from a Pilot Randomized Controlled Trial

Julie Lounds Taylor^{1,4}, Robert M. Hodapp^{2,4}, Meghan M. Burke³, Sydney N. Waitz-Kudla⁴, and Carol Rabideau⁴

¹Department of Pediatrics, Vanderbilt University Medical Center, Nashville TN USA

²Department of Special Education, Vanderbilt University, Nashville TN USA

³Department of Special Education, University of Illinois at Urbana-Champaign, Champaign, IL

⁴Vanderbilt Kennedy Center, Vanderbilt University Medical Center, Nashville TN USA

Abstract

This study presents findings from a pilot randomized controlled trial, testing a 12-week intervention to train parents of youth with autism spectrum disorder (ASD) to advocate for adult disability services—the Volunteer Advocacy Project-Transition (VAP-T). Participants included 41 parents of youth with ASD within two years of high school exit, randomly assigned to a treatment ($N = 20$) or wait-list control ($N = 21$) group. Outcomes, collected before and after the intervention, included parental knowledge about adult services, advocacy skills-comfort, and empowerment. The VAP-T had acceptable feasibility, treatment fidelity, and acceptability. After participating in the VAP-T, intervention parents (compared to controls) knew more about the adult service system, were more skilled/comfortable advocating, and felt more empowered.

Keywords

autism spectrum disorder; parents; intervention; transition to adulthood; services; advocacy; empowerment; randomized controlled trial

Correspondence concerning this article can be addressed to: Julie Lounds Taylor, Vanderbilt Kennedy Center, PMB 40 – 230 Appleton Pl., Nashville, TN 37203. Phone: 615-343-5659. Julie.l.taylor@vanderbilt.edu.

Julie Lounds Taylor, Department of Pediatrics, Vanderbilt University Medical Center, Nashville TN USA; Robert M. Hodapp, Department of Special Education, Vanderbilt University, Nashville TN USA; Meghan M. Burke, Department of Special Education, University of Illinois at Urbana-Champaign, Champaign, IL; Sydney N. Waitz-Kudla, Vanderbilt Kennedy Center, Vanderbilt University Medical Center, Nashville TN USA; Carol Rabideau, Vanderbilt Kennedy Center, Vanderbilt University Medical Center, Nashville TN USA.

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Compliance with Ethical Standards

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For students with intellectual and developmental disabilities, the transition from school to adulthood is difficult. As students leave high school, they may lose their friends, who go on to college or to work lives that are often less available to young adults with disabilities. They lose as well the familiarity and routines of school days and years. Maybe most importantly, students lose the array of mandated academic and supportive services that schools have provided to them for almost 20 years. Considering these many losses and the difficulties in attaining adult services, parents often describe their son or daughter's movement from school to adult life as "falling off a cliff"; others consider transition as the "second shock" of parenting a child with disabilities (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995).

Although many youth may struggle during the transition to adulthood, individuals with autism spectrum disorder (ASD) are at even greater risk. Compared to same-aged individuals with other disabilities, youth with ASD more often receive no formal supports after leaving high school (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011), and rates of disengagement from paid employment or post-secondary education are especially high (Howlin, Goode, Hutton, & Rutter, 2004; Shattuck et al., 2012; Taylor & Seltzer, 2011). Further, the services needed for individuals with ASD who do versus do not have a co-occurring intellectual disability (ID) may differ. For example, individuals with ASD (without ID) may successfully pursue competitive employment with time-limited or intermittent supports, whereas individuals with ASD and ID may need ongoing, intensive supports in a supported employment setting. Taken together, the transition years may constitute an especially difficult time for young adults with ASD and their families.

In responding to the transition-related needs of these youth, researchers and service systems have embarked on a series of interventions. Focusing on social, employment, or adaptive skills; cognitive-behavioral, pharmaceutical, and other therapies; or transition planning or other services, such interventions generally target the individual with ASD, with most emphasizing a single skill or functional domain. Although a number of interventions have been attempted, most studies to date have been of poor quality; there is little evidence that these interventions conclusively improve adult outcomes (Taylor et al., 2012).

A different approach emphasizes parents as the ideal targets of intervention. Indeed, over their child's first 18–22 years of life, it is parents who have dealt with early interventionists, teachers, and administrators; who have learned about and advocated for services for their child; and who, under federal education law, have served as the "accountability mechanism" for the appropriate provision of special educational services (IDEA, P.L. 108–446). At later ages as well, parent-family contacts and social networks seem instrumental in helping adults with disabilities acquire both employment (Petner-Arrey, Howell-Moneta, & Lysaght, 2015) and informal supports (Sanderson, Burke, Urbano, Arnold, & Hodapp, in press). Summarizing the role of parents during the transition and early-adult years, Timmons et al. (2004) concluded that parents serve as the linchpin for services, holding together as a single unit the complex service systems that assist young adults with disabilities.

This focus on parents as the linchpins for services makes possible expansions of earlier, school-focused interventions into the transition and early adult years. In one such program, the Volunteer Advocacy Program (or VAP), parents and other individuals were trained to

develop the knowledge and skills needed to advocate effectively for school-aged children with disabilities within special education. Parents and other individuals attended a 12-week advocacy training program, with some participants attending on-site, and others receiving the training via webcasts to other sites within the same state (Burke, 2013). VAP attendees learned about the Individuals with Disabilities Education Act, Section 504 of the American Rehabilitation Act, and other federal laws and court cases; special education rights and procedures; the Individualized Educational Plan (IEP) process; and non-adversarial advocacy. To date, the VAP has been shown to boost attendees' knowledge about rights under special education law and their advocacy skills (Burke, Goldman, Hart, & Hodapp, 2016).

In the current study, we adapted the VAP workshop sessions to emphasize the needs of young adults with ASD and to focus on advocating for adult disability services (vs. school-aged disability services). Similar to the original VAP, the Volunteer Advocacy Program-Transition (or VAP-T) also featured a 12-week workshop series, with each week featuring a specific topic and led by a trained workshop facilitator with guest expert(s). In contrast to the original VAP's focus, we made special efforts to introduce parents to person-centered planning (i.e., set of tools to organize and guide decision-making for people with disabilities) and to discuss such adult-disability topics as the Medicaid Waiver, Supplemental Security Income (SSI), post-secondary education and employment supports/options, and housing/residential issues. Discussions centered on the nature of each service, eligibility criteria, applying for and becoming eligible for services, and inter-connections among diverse service-delivery programs.

Primary outcomes targeted by the VAP-T program included parental knowledge, skills-comfort, and empowerment. Both knowledge and skills-comfort were also targeted in the original VAP, and have been shown to be sensitive to the intervention (Burke et al., 2016). For the VAP-T, we focused on knowledge because parents need to know about the adult service system before any change is possible in their son/daughter's receiving services. We hypothesized that parents who are more skilled and comfortable in advocating on behalf of their son/daughter with ASD will be more successful in obtaining adult services. Our final outcome involved parental empowerment. Although not examined in the original VAP study, our sense was that VAP-T parent attendees might show improvements in their empowerment as advocates of adult disability services. Conceptualized as a psychological process that goes beyond coping per se, parental empowerment involves parents actively attempting to change or eliminate stressful events by applying knowledge and skill (Gutierrez, 1994). Long used to help parents of children with psychiatric conditions (e.g., Bickman, Heflinger, Northrup, Sonnichsen, & Schilling, 1998; Rodriguez et al., 2011), parental empowerment has been associated with more minutes of and greater satisfaction with children's mental health services (Kutash, Duchnowski, Green, & Ferron, 2011; Resendez, Quist, & Matshazi, 2000). Empowerment has recently received attention in terms of its role mediating distress and mental health among parents of children with ASD (Weiss, Cappadocia, MacMullin, Vecili, & Lunsky, 2012; Weiss, MacMullin, & Lunsky, 2015).

In this study, we used a pre-post, waiting-list control design (Campbell & Stanley, 1966) with random assignment to examine the efficacy of the VAP-T for parents of youth with

ASD. We had two primary aims: 1) Establish the feasibility, acceptability, and treatment fidelity of the VAP-T; and 2) Determine whether, relative to a control group, parents who participated in the VAP-T had greater knowledge of adult disability services, rules, and procedures; greater comfort and skills in advocating for their son or daughter; and a greater sense of parental empowerment. Finally, in exploratory analyses we examined several potential factors that might influence benefits gained from the VAP-T. These included whether the youth with ASD did or did not also have ID; whether the parent attended a session in the group as opposed to at home; and whether the family participated at the main or at a distance site.

Method

Participants

Overall—A total of 41 families of adolescents and young adults with ASD participated in this study. Of these, 20 families were randomly assigned to the intervention group and 21 to the wait-list control group. One parent from each family was designated as the “primary respondent” and he/she filled out all forms (pre-test and post-test) and attended the sessions. The other parent was permitted to also attend the sessions if he/she desired. Demographic characteristics are presented in Table 1.

Eligibility—For families to be eligible to participate, there were four inclusion criteria. First, the youth with ASD had to be in the “transition years,” defined as within two years before or after high school exit. Second, to be eligible the youth must have received a previous medical or educational diagnosis of an ASD, which was confirmed during a clinical evaluation. Third, families must have lived in one of the metropolitan areas in which the program was being delivered (in-person in BLINDED or by webcast in BLINDED or BLINDED), and the primary respondent (see above) from each family was willing/able to travel to the specific project site to participate in the intervention sessions on Monday evenings for 12 consecutive weeks. In addition, because much of the information presented in the VAP-T was state-specific, families were required to live within the state for which the program was developed. Fourth, participants needed to be willing to be randomized to either the intervention group (i.e., taking the program in the fall of 2015) or control group (i.e., taking the program in the spring of 2017).

ASD diagnoses were confirmed using the Autism Diagnostic Observation Schedule-2 (Lord et al., 2012), administered by research-reliable clinicians to the son/daughter with ASD. Once ASD diagnosis was confirmed, families were enrolled in the study and randomized to either the treatment or wait-list control group.

Randomization—A total of 115 families contacted us about participating in the study and were screened. Of these, 92 were deemed potentially eligible, dependent on diagnostic confirmation. From among the 92 families, 20 declined participation after hearing more about the study, 25 could not commit to weekly evening sessions (either because they were too busy or had conflicts during that time), and 2 did not respond to attempts to schedule the diagnostic evaluation. This resulted in 45 respondents who completed the diagnostic evaluation, pre-test, and were subsequently enrolled and randomized to either the treatment

group ($n = 22$) or wait-list control group ($n = 23$). Groups were assigned using a random number generator, stratified by project site and whether the youth had ID in addition to ASD. Because an ID diagnosis is a significant determinant of disability service access among youth with ASD (Taylor & Henninger, 2015), we stratified by this variable to ensure that any group differences in services could not be attributed to unequal distributions of youth who had ID. Similarly, we wanted to ensure that any group differences could not be attributed to different proportions in each group of those who were taking the program in-person (at the host site) vs. through distance technology. Finally, in the three months between pre-test and post-test, four of the original 45 families were lost to attrition (2 each from the treatment and control groups); we thus have complete pre-test and post-test data from 20 respondents in the intervention group and 21 in the control group.

Procedures

This study employed a randomized controlled trial (RCT) with a waitlist control design. Data collection is ongoing; parent-related outcomes (which are the primary outcomes and the focus of this report) were collected from both groups (treatment and control) prior to randomization during the summer of 2015 and after the completion of the 12-week program in the winter of 2015/2016. Secondary outcomes will be collected 6 months and 12 months after the intervention. In the spring of 2017, after the 12-month follow-up data collection is completed, control group participants will have the opportunity to participate in the VAP-T program.

All participants were recruited from three metropolitan areas in a mid-Southern state. Recruitment took place through a number of venues, including other autism studies and research registries; medical clinics and local medical providers; disability agencies and centers; and school personnel. Families who met eligibility criteria were scheduled to come to the main project site, where trained clinicians performed structured observation/testing of the youth with ASD and parents provided behavioral information about the youth. Parents also filled out demographic information about themselves, their son or daughter with ASD, and the family overall.

Those families assigned to the treatment group participated in the VAP-T program in the fall of 2015. Sessions were held for 12 consecutive weeks on a weekday evening. The intervention was delivered in-person at the host site (a large academic medical center), and webcast to two distance sites within the same state. Although participation in-person (either at the host site or at one of the two distance sites) was encouraged, those who were unable to attend were invited to view the webcast from home (or at another location of their choosing) in real time. Real-time participation allowed families to ask questions of the speakers and facilitators and to participate in discussions. Those who were unable to attend a session in real time were invited to view the recorded session, available the day after that session took place. The control group received a list of local disability resources, as well as publically-available toolkits pertaining to the transition to adulthood and employment for people with disabilities. Other than periodic emails about local transition-related seminars or workshops (sent to both groups), research staff did not provide other resources to the control group during the intervention sessions, nor throughout the 12-month follow-up period.

Intervention: Volunteer Advocacy Program – Transition (VAP-T)

The VAP-T is a 30-hour advocacy training to educate parents of youth with ASD about the adult service delivery system and to enable parents to advocate for services. An adaptation of the VAP (Burke, 2013), the VAP-T was developed using the input of an Advisory Committee that included national experts in ASD, adult disability service providers, disability advocates, parents of youth with ASD, and youth with ASD. Prior to the RCT, we piloted the VAP-T with parents of older youth with ASD, making revisions according to participants' feedback.

The VAP-T is comprised of didactic instruction, family-sharing activities, case studies, and group discussions. Similar to the VAP, the VAP-T was directed by an experienced group facilitator, in this case a licensed clinical social worker who has been trained in Person-Centered Planning and has over two decades of experience working both individually and in groups with individuals with disabilities and their families. In most sessions, the workshop facilitator was aided by content experts who presented the specifics of each topic. Experts included representatives from the Parent Training and Information Center, The Arc, the University Centers for Excellence in Developmental Disabilities, and various government agencies, as well as attorneys and parents of individuals with ASD.

The VAP-T curriculum reflected multiple domains: person centered thinking (i.e., how to incorporate the desires and dreams of the person with ASD into post-secondary plans), secondary education, post-secondary education, financial support, employment, Medicaid, future planning, medical services, and advocacy. Within each domain, there were 1–3 topics. For example, with respect to financial support, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), and a statewide family support program were discussed whereas, regarding the Medicaid waiver, only the current and proposed Home and Community Based Services waiver was discussed. Additionally, for each domain, participants were asked to complete a section of a Letter of Intent (i.e., a planning tool for individuals with disabilities). By aligning the Letter of Intent with each domain, each participant completed a written document about the services their son or daughter needs (per each domain) and strategies to obtain such services. Each participant was also provided a binder of materials, which for each topic included a PowerPoint presentation, required readings, tip sheet(s), and activities.

Both the host site (where speakers presented in-person) and each distance site had a facilitator (or team of facilitators) who set up the technology and assisted in interactions between sites. Through the use of web-based software (Adobe Connect), each distance site was able to communicate with the host site through both spoken and written means. In this way, each site could develop group cohesion, as well as take part in interactions with the speakers at the host site and with participants at the other two sites.

Measures

Treatment Fidelity and Feasibility/Acceptability—Prior to implementing the VAP-T, we developed three to six learning objectives to examine treatment fidelity for each session. Feasibility was examined through attendance records for each session, recorded as: (1)

attending in person at the main site or the distance sites: (2) watching the session via webcast from home in real-time; (3) watching a recording of the session at a later time; (4) no attendance. We determined acceptability by examining participants' response to a brief internet survey after each session, which included a question asking respondents to rate how satisfied they were with that session (from "1 = not satisfied at all" to "4 = highly satisfied").

Outcomes

Knowledge about the adult service system—We examined the extent of parents' knowledge about the adult service system through a scale developed for this project (based on a measure developed to evaluate the VAP; Burke et al., 2016). The measure consisted of 25 multiple-choice questions asking factual information about adult disability services and the adult disability service system. Example questions included: "During the trial work period, how long can an individual with a disability work without receiving any cut to their SSDI benefits?"; "How can you apply for a housing voucher?"; and "Under the current provision, to which office do you apply for Medicaid waiver services?" Each response was coded as either "correct" (1) or "incorrect" (0), with potential scores ranging from 0 through 25 and higher scores equaling greater knowledge of the adult disability system. This measure was piloted among a group of parents of older sons and daughters with ASD to ensure that floor and ceiling effects were avoided. In this sample, pre-test scores ranged from 5 to 22, post-test scores from 7 to 23.

Advocacy skills and comfort—We assessed the degree to which parents felt comfortable and skilled in advocating for their son/daughter with ASD (Burke et al., 2016). The measure was comprised of 10 items, on which participants responded on a 5-point Likert scale (1 = not at all; 2 = below average; 3 = average; 4 = good; 5 = excellent). Examples included "How knowledgeable do you think you are about your rights in the adult service system?"; "How well do you think you stay calm and non-adversarial with agencies, providers, or professionals?"; and "How able are you to assert yourself in trying to get services and/or supports for your child?" Items were averaged to get an overall score of parents' advocacy skills and comfort, with higher scores indicating more skills-comfort. Internal reliability was acceptable at pre-test and high at post-test (Cronbach alphas = .75 and .92, respectively).

Parental empowerment—Parental empowerment was measured using the 34-item Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992). Developed for families of children with emotional disabilities, the FES measures the extent to which parents feel empowered across three dimensions: family; the service system; and the larger community and political environmental. Items are rated on a 5-point Likert Scale from 1 = not at all true to 5 = very true. Item scores are summed to form an overall score, with higher scores indicating greater empowerment. Reliability and validity of this measure have been established in other studies (Koren et al., 1992); in the present sample as well, good internal consistencies were found (Cronbach's alphas of .92 and .95 at pre-test and post-test, respectively).

Demographic and Behavioral Measures—At baseline, we collected demographic information on parents and families, information on formal service access, and behavioral information about the youth with ASD. Parent/family information included parent sex, age, race/ethnicity, education (1 = less than 8th grade to 9 = professional degree), marital status (1 = married, 0 = not married), and family income (1 = \$20,000 or less to 9 = \$200,001 or higher). We also collected additional information about the youth with ASD, including his/her age, sex, and when he/she was planning on leaving high school. Parents reported on their son or daughter’s autism symptoms using the Social Responsiveness Scale-2 (Constantino & Gruber, 2012); co-occurring psychiatric diagnoses using the Rochester Health Interview (Davidson et al., 2008); and adaptive behavior using the adaptive behavior composite of the Vineland Scales of Adaptive Behavior-II (Sparrow, Cicchetti, & Balla, 2005). An abbreviated IQ score was gathered from youth using the Stanford-Binet-5 Scales of Intelligence (Roid, 2003). These last two measures – IQ and adaptive behavior – were combined to determine whether the youth had ID, using well-established guidelines (American Association on Intellectual and Developmental Disabilities, 2010). We also collected information about the number of services that the youth was receiving using questions from the National Longitudinal Transition Study-2 (www.nlts2.org).

Data Analysis

Treatment Fidelity and Feasibility/Acceptability—Treatment fidelity was examined by having study staff rate whether each learning objective of each session was fully met, partially met, or not met. Two independent raters were used for 25% of the sessions, and percent agreement was calculated. To examine feasibility, we examined how many sessions intervention group participants attended in-person or from home (either in real-time or recordings after the session). Acceptability was determined by the frequency of participants who reported feeling “satisfied” or “highly satisfied” with each session.

Analysis of Group Differences—Analysis of variance and chi-squares were used to test for between-group differences in demographic variables or baseline scores of the parent outcomes (i.e., knowledge, skills-comfort, empowerment). Although we considered analyzing treatment effects using an Intention to Treat (ITT) approach (i.e., including all participants in the analyses, regardless of whether they dropped out of the study), we instead conducted an “as-treated” (AT) analysis (only including those participants who received the intervention). We chose the AT approach because this was the first test of a novel intervention. The goal of this project was to determine the efficacy of the VAP-T (not the effectiveness); thus, an ITT approach would be too conservative, inflating the likelihood of a type-II error to an unacceptable amount (Amijo-Olivo, Warren, & Magee, 2009).

To determine if participating in the VAP-T resulted in differences in the outcomes relative to controls, we used Analysis of Co-Variance (ANCOVA) models. Dependent variables were the post-test scores of parental knowledge, advocacy skills-comfort, and empowerment. For each model, the baseline score of the particular dependent variable was statistically controlled, and group assignment (treatment vs. control) was entered as the independent variable. Although we had planned to enter as co-variates any demographic variables that demonstrated significant between-group differences at pre-test, none emerged (see Results).

Cohen's *d* effect sizes were calculated for the between-group post-test effects controlling for pre-test scores.

To determine whether the RCT results might be biased by attrition, we examined differences between those ($n = 4$) families who dropped out and the remaining participants. Relative to families who continued in the study, those who dropped out were more likely to be racial/ethnic minorities and to have incomes less than \$40,000, Fisher's Exact Test *p*-values = .01 and .04, respectively. All four families lost to attrition were from the distance sites. Overall, 22% of the distance site families were lost to follow-up, compared to none of the host site families, Fisher's Exact *p*-value = .02. Finally, although not statistically significant, families who had a son/daughter with ID (relative to families of those without ID) were more likely to drop out of the study (18.8% vs. 3.4%, respectively), Fisher's Exact *p*-value = .12. Overall, however, we had very low rates of attrition (4 of 45 families, or 8.9%); no differential attrition between treatment and control groups (response rates = .909 for treatment group and .913 for the control group); and low-to-moderate correlations between the factors that distinguished responders/non-responders and outcomes (Spearman rho correlations ranging from $-.01$ to $.25$). Taken together and using guidelines from the What Works Clearinghouse (2011), we concluded that attrition was highly unlikely to bias study findings.

Exploratory Analyses—For intervention participants ($n = 20$), we also examined whether treatment gains related to the modality of treatment—attending with a group versus accessing content from home (for these analyses, we combined those watching from home in real-time and those who watched the recording after the session). To determine the proportion of content accessed in the group setting across participants, we divided the number of sessions attended in-person by the number of sessions accessed in any way. We then used partial correlations, controlling for the number of sessions in which the VAP-T content was accessed (by any means) and the baseline scores of the respective variables, to determine if accessing a higher proportion of content in the group setting related to higher post-test scores on knowledge, advocacy skills-comfort, or empowerment.

Finally, we ran ANCOVA models to explore whether these three outcomes were influenced by site (host vs. distance sites) or if the youth did or did not have co-occurring ID. The first set of ANCOVA models included the independent variable of host site vs. distance site, with the baseline score of the relevant outcome as a covariate. The second set of ANCOVA models included the independent variable of whether the son/daughter with ASD did or did not have ID.

Results

Treatment Fidelity and Feasibility/Acceptability

The intervention was determined to have been delivered with reasonable fidelity. For 8 of the 12 sessions, every learning objective was fully met. For 3 sessions, one learning objective was partially met, and the others were fully met. For one session, two learning objectives were partially met, and one was fully met. The two raters agreed on 8 of the 9 learning objectives (88.9%) that were double-rated.

In terms of feasibility, we successfully webcast all 12 sessions to both distance sites and had good attendance at the host and distance sites. Of those treatment group participants who remained in the study ($n = 20$), 75% attended 9 or more of the 12 sessions in-person (10% attended all 12 sessions; 25% attended 11 sessions; 30% attended 10 sessions, and 10% attended 9 sessions). When adding alternate ways to access the VAP-T curriculum (either at home in real-time or via a recording later), 45% of participants ($n = 9$) accessed the curriculum for all 12 sessions, and every participant but one (95%, $n = 19$) accessed the curriculum for at least 75% of sessions. Acceptability of the sessions was generally good. The percentage of participants who indicated that they were “highly satisfied” or “satisfied” was two-thirds or more for every session; 9 of the 12 sessions had 80% or greater who were “highly satisfied” or “satisfied.” Anecdotally as well, participants seemed to value attending the VAP-T sessions, with many participants arriving early or staying late (often to catch up with other participants).

Analyses of Group Differences

Baseline Analyses—Table 1 presents descriptive information and statistical tests for group differences in the demographic variables. Relative to youth in the intervention group, those in the control group had slightly higher mean adaptive behavior scores and seemed somewhat more likely to have a comorbid psychiatric diagnosis; however, neither difference reached statistical significance. Similarly, upon entry into the study, there were no significant group differences in parents’ knowledge about the adult service system, their skills and comfort in advocating for their son/daughter with ASD, or in empowerment (see Table 2).

Treatment Effects—Table 3 shows group means, standard deviations, and tests for group differences in post-test scores of the three outcomes. After controlling for baseline scores and relative to the control group, parents in the intervention group knew more about the adult service system, felt more comfortable and skilled in advocating for their son/daughter, and felt more empowered. Considering a Cohen’s d of .80 or greater as a “large effect” (Cohen, 1992), effect sizes for group differences were large for both knowledge and skills-comfort, and approached a large effect for empowerment.

Examined another way, one could compare the proportion of individuals within each group who showed positive change. Every parent in the intervention group but one (95%) showed an increase in knowledge about adult services, as opposed to 48% of the control group. Only one person in the control group (5%) rose more than 5 points in their 25-item knowledge scores across the two testings, compared to 40% of intervention group parents. Similarly, 30% of parents in the intervention group showed advocacy skill-comfort gains of 1 or more points (on a 5-point scale), compared to no parents (0%) in the control group. In terms of empowerment, 65% of intervention group parents showed an improvement of .5 or more standard deviations (i.e., 10-point or greater change), compared to 29% of the control group.

Exploratory Analyses

Of all intervention-group participants, 30% accessed all content in person (e.g., if they accessed content for 10 sessions, it was all in-person), 50% accessed more than half of content in person but watched at least one session from home, and 20% accessed less than

one-half of the content in-person. After controlling for the total number of sessions (accessed by any means) and the baseline scores of the respective variables, those intervention group participants who attended more sessions in the group setting (vs. at-home, online) had higher scores on advocacy skills-comfort and empowerment, $\eta^2 = .58$ for both, p s = .01. Interestingly, although parents who attended more sessions in-person felt more empowered and comfortable advocating, no relationship existed between the number of sessions accessed in-person and the amount of knowledge parents gained about the adult service system, $r = .04$, *ns*.

After controlling for baseline scores, there was some evidence that intervention group participants at the host site (versus the distance sites) had more knowledge about the adult service system at the end of the VAP-T ($M = 17.21$, $SE = .97$ for host site, $M = 14.04$, $SE = 1.51$ for distance sites), $F(1) = 3.03$, $p = .10$. Participants from the host site also had post-test scores that were slightly higher than those from the distance sites on advocacy skills-comfort ($M = 4.21$, $SE = .12$ for host site, $M = 3.94$, $SE = .19$ for distance sites) and empowerment ($M = 138.44$, $SE = 4.74$ for host site, $M = 129.97$, $SE = 7.41$ for distance sites); however, no differences reached marginal or statistical significance. Although estimated means suggested that parents of those with ASD and ID might have benefitted slightly more than those with ASD without ID, none of the group differences by intellectual disability were marginally or statistically significant.

Discussion

Although a small number of RCT's have begun to examine training individual skills for transition-aged individuals with ASD (e.g., social skills, interviewing skills, job training), this study is the first to combine an RCT with parent-training, a multi-session workshop series, and an explicit focus on the many services needed by these young adults. The VAP-T also emphasized parental advocacy and was provided at our home site as well as via web technology to two distance sites. This study had two main findings, each of which has important implications for future interventions and clinical practice.

Our first finding involved the VAP-T's feasibility, fidelity, and acceptability. Working with a variety of experts and agencies, we were able to revamp the original VAP curriculum to focus on parents of transition-aged individuals and to recruit content experts who intimately knew about SSI, SSDI, the Medicaid waiver, employment, post-secondary education, and other topics. Our experienced workshop facilitator (along with content experts) was able to deliver this intervention as planned, with all topics and sub-topics covered and virtually all learning objectives fully met (a few were only partially met). Finally, our intervention-group participants reported themselves satisfied or highly satisfied with most sessions.

Beyond these straightforward findings, however, a few complications also arose. Even before randomization occurred, 25 of 92 potential families felt that they could not commit to 12 weekly sessions that each lasted 2–1/2 hours. And while the large majority of participants attended most sessions in-person, we needed to add alternatives to live participation at the host and distance sites. Thus, in some cases, participants viewed a session from their own

homes, either at the same time as their co-participants or at a later time from the recording of the session.

Although such modifications seemed necessary for attendees to access as many sessions as possible, eliminating the in-person requirement may also have come at a cost. Increasingly as we proceeded with this project, we came to appreciate that many families were isolated from one another, with most knowing few other families who had sons or daughters with ASD at a similar life stage. As a result, many families valued the group format. In the workshops themselves, our workshop facilitator encouraged such cross-family sharing through activities and discussions; informally as well, several parents habitually arrived at sessions early or stayed later to catch up with other parent participants. Overall, though, either in a group or by oneself at home, we successfully provided disability-system information and parents felt satisfied.

Our second set of findings related to effects of the VAP-T training on parent knowledge, advocacy skill-comfort, and empowerment. Compared to parents in the control group, parents who participated in the VAP-T program knew more about adult services, felt more comfortable advocating for services on behalf of their son/daughter with ASD, and felt more empowered. We found large (or nearly large) effect sizes for all outcomes; in addition, extreme amounts of positive change were more often noted among individual participants in the intervention versus control groups. Overall, then, the VAP-T fostered improvements among these parent attendees.

An interesting interplay was observed in our exploratory analyses, between how the intervention was delivered and parental knowledge, skills-comfort, and empowerment. In terms of knowledge, no relation existed between the proportion of sessions accessed in-person and the amount of knowledge parents gained about the adult service system. Such null findings between live and webcast information are consistent with longstanding findings on the use of distance vs. in-person education on academic performance (Shachar & Neumann, 2010). More recently, distance-education has extended to special education, with examples including the delivery via distance technology of a graduate course in applied behavior analysis (Hudson, Knight, & Collins, 2012) and of professional development trainings to rural special educators (Erickson, Noonan, & McCall, 2012). In each case, distance attendees learned similar amounts of information as did attendees attending in person.

But when considering parents' skills-comfort and empowerment, it may matter enormously whether one personally attends a group or simply watches on-line by oneself. In this case, the more sessions that a participant attended with the group, the higher their advocacy skills-comfort and the higher their sense of empowerment. Granted, this finding was based solely on the proportion of sessions attending live versus watching on one's own (a relatively simplistic measure). Still, group participation seems important for parents to foster their skills-comfort and empowerment.

In considering this intriguing finding, several issues emerge. First, although our focus centered on parental advocacy, knowledge seems a necessary-but-not-sufficient condition for

a thoughtful, informed advocate. Simply stated, one cannot advocate successfully if one does not know enough about the adult disability system, its many types of services, agencies, rules, and criteria. In this sense, our decision seemed justified to allow participants, when necessary, to access sessions by themselves on their own computers.

But at the same time, knowledge alone may not be enough, and the VAP-T's knowledge and social-emotional components may both be important. Such a conclusion also seems borne out from several types of parent interventions. In the non-disability field, Sanders' (2008) widely-used "Triple P-Positive Parenting Program," while aimed at preventing children's severe emotional problems, explicitly fosters parents' knowledge, skills, and confidence. So too is there analogous evidence concerning parents of children with disabilities. Although these parents have been the focus of relatively few intervention studies (Dykens, 2015), those parental interventions that incorporated multiple components—that went beyond solely teaching parents behavioral techniques or solely providing emotional support—have been shown to be most effective (Singer, Ethridge, & Aldana, 2007). In this case too, parents appeared to value both knowledge about adult services and the social support of the group, of the workshop facilitator, and of other parents.

Note that our findings regarding modality of treatment and parental gains should be interpreted somewhat cautiously, given the small sample and exploratory nature of the analyses. Further research should expand upon these findings to carefully consider how interventions are delivered in this age group. The appropriate modality of delivery might be even more important to discern among parents of individuals with ASD, who are likely to be experiencing high levels of stress (Hayes & Watson, 2013) and might have fewer financial resources due to the costs of caring for a child with ASD (Cidav, Marcus, & Mandell, 2012). It will be important to examine, with larger samples, the potential advantages of taking the VAP-T (or related programs) in a group-format versus the convenience of offering the program in an on-demand, at-home setting.

Although these VAP-T findings are promising, several limitations of this study must also be mentioned. A first, obvious limitation concerns the way in which all outcomes involved parent-report and were short-term. For some constructs—e.g., how much parents learned about the adult-disability system—having parents fill out a multiple-choice questionnaire seemed a good form of assessment. For outcomes such as advocacy skill or comfort, however, future research might involve more "in vivo" measures, as our current self-report measure may have simply indicated what parents would hope to be the case (i.e., "I think that I am now a great advocate, but I will not know for sure until I do it"). All of these outcome measures are, at present, also short-term. Part of our later, follow-up testings will determine whether parents maintain over time their increased knowledge of adult services, better advocacy skills/comfort, and increased feelings of empowerment. Future testings will also examine whether these parental improvements lead to better service access and transition outcomes for youth with ASD.

In terms of other measurement limitations, we did not formally measure any services sought out (either by the intervention or control group) during the 12-week period when the treatment group was participating the VAP-T training. Although we have no reason to

suspect differential changes in service access between groups (unrelated to the intervention), future studies will need to carefully document any changes in services during this time that might impact parental knowledge and attitudes. Further, some of the primary parent outcome measures (knowledge, advocacy skills-comfort) were adapted for this study. The advocacy skills-comfort measure yielded findings that were consistent with the well-established Family Empowerment Scale, so indications suggest that it is a valid indicator of parental attitudes toward advocacy. Yet future research with larger samples is needed to conduct more careful psychometric testing of these new measures.

So too were we limited in terms of our sample's diversity and size. Although we actively recruited participants who were of racial/ethnic minorities and who were less well-off financially, several of these participants dropped out of the study, unable to continue their commitment to a weekly program. Our study thus reaffirmed work suggesting that interventions targeting racial/ethnic minority groups or families with lower socioeconomic resources likely need to be developed and delivered differently (Castro, Barrera, & Holleran, 2010), taking into account the unique needs and experiences of these families. Future research should examine which specific factors make it more difficult for underrepresented or less-resourced families to participate in programs like the VAP-T, and explore ways to modify the program so that these more vulnerable families are also able to access information about adult disability services. Further, the VAP-T was developed to train parents in one specific state; particular pieces of this curriculum may not be applicable nation-wide. A next step will be for us to develop a national VAP-T curriculum which can be bolstered with state-specific rules and regulations.

Finally, we acknowledge that this study examined relatively few participants. Although well-powered to detect between-group effects, this study, with only 20 parents in the intervention group, leaves unanswered important questions of moderation and treatment response. For example, is the VAP-T more effective for parents of youth with ASD who also have ID, as compared with those with average or above average intellectual functioning? Did participants at the distance sites benefit from the program to the same extent as those at the host site? Our follow-up analyses suggested that participants at the host site and those whose son/daughter had ID in addition to ASD might benefit more from the program, but such findings were far from conclusive. Larger studies are needed to answer such questions, which have significant implications for how the VAP-T is delivered and who it targets.

Still, despite these limitations, this study contributes to our knowledge about how to better support youth with ASD and their families during the transition to adulthood. Featuring an RCT, across three sites, of a multi-topic workshop that trained parents about (and how to advocate concerning) adult disability services, this study found important short-term improvements in parental knowledge, skill-comfort in advocating, and parental empowerment. Our hope is that, in the "real world" as well, families can more efficiently and effectively access the array of services and supports that might be available to them. With further testing, we expect that the VAP-T can be incorporated into a suite of individually-oriented interventions that might then be used, in tandem or as needed, to improve transition outcomes.

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Table 1

Demographic information and statistical tests of group differences for participants

	Overall – M (SD) or % (n)	Intervention – M (SD) or % (n)	Control – M (SD) or % (n)	t-value or χ^2
Parent				
Site				1.01
Host Site (in person)	65.9% (27)	70.0% (14)	61.9% (13)	
Distance 1	24.4% (10)	25.0% (5)	23.8% (5)	
Distance 2	9.8% (4)	5.0% (1)	14.3% (3)	
Sex				.98
Male	2.4% (1)	0	4.8% (1)	
Female	97.6% (40)	100% (20)	95.2% (20)	
Age	49.99 (5.89)	49.38 (7.08)	50.57 (4.58)	-.64
Income	4.80 (2.41)	4.85 (2.39)	4.76 (2.49)	.12
Education				6.27
High school or less	4.9% (2)	10.0% (2)	0	
Some college	24.4% (10)	10.0% (2)	38.1% (8)	
Bachelor's degree	39.0% (16)	40.0% (8)	38.1% (8)	
Post Bachelor's	31.7% (13)	40.0% (8)	23.8% (5)	
Married				.20
Yes	68.3% (28)	65.0% (13)	71.4% (15)	
No	31.7% (13)	35.0% (7)	28.6% (6)	
Race				2.31
White	87.8% (36)	90.0% (18)	85.7% (18)	
African-American	7.3% (3)	5.0% (1)	9.5% (2)	
Other	4.8% (2)	5.0% (1)	4.8% (1)	
Youth				
Sex				.12
Male	82.9% (34)	85.0% (17)	81.0% (17)	
Female	17.1% (7)	15.0% (3)	19.0% (4)	
Age	18.24 (1.87)	18.14 (1.74)	18.34 (2.02)	-.34
High School Status				.90
Already exited	14.6% (6)	20.0% (4)	9.5% (2)	
Exiting spring 2016	31.7% (13)	30.0% (6)	33.3% (7)	
Exiting spring 2017	53.7% (22)	50.0% (10)	57.1% (12)	
Intellectual disability				.20
Yes	31.7% (13)	35.0% (7)	28.6% (6)	
No	68.3% (28)	65.0% (13)	71.4% (15)	
Abbreviated IQ	80.10 (24.75)	78.74 (26.27)	81.40 (23.83)	-.33
Adaptive behavior	58.00 (13.20)	55.40 (15.51)	60.48 (10.32)	-1.24
Autism symptoms	80.66 (8.97)	81.85 (8.37)	79.52 (9.57)	.83
Comorbid psychiatric diagnosis			2.11	
Yes	41.5% (17)	30.0% (6)	52.4% (11)	

	Overall – M (SD) or % (n)	Intervention – M (SD) or % (n)	Control – M (SD) or % (n)	t-value or χ^2
No	58.5% (24)	70.0% (14)	47.6% (10)	
Number of services	3.02 (2.20)	2.85 (2.46)	3.19 (1.97)	-.49

*
 $p < .05$

**
 $p < .01$

 $p < .001$

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Table 2

Group means and statistical tests of group differences on baseline measures of parental outcomes

Pre-test Outcomes	Treatment group M (SD)	Control group M (SD)	t-value
Knowledge of adult service system	11.25 (3.68)	12.10 (4.23)	-.68
Advocacy skills/comfort	3.54 (.46)	3.45 (.61)	.49
Empowerment	122.30 (19.81)	121.58 (17.59)	.12

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

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Table 3

Results from ANCOVAs looking at differences by group in post-test measures, controlling for pre-test measures.

Post-test Outcomes	Treatment group estimated M (SE)	Control group estimated M (SE)	F-value	Effect size – Cohen's d
Knowledge of adult service system	16.58 (.76)	12.17 (.74)	17.41***	1.07
Advocacy skills/comfort	4.10 (.15)	3.31 (.14)	15.02***	1.10
Empowerment	135.66 (3.77)	119.66 (3.67)	9.24**	0.77

* $p < .05$

**

$p < .01$

$p < .001$

Note. Effect size is measured by Cohen's D for the post-test group difference, controlling for pre-test score