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Pulling Back the Curtain: Issues in Conducting an Intervention Study with Transition-Aged Youth with ASD and their Families

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Abstract

The transition from high school to adulthood is difficult for youth with autism spectrum disorder (ASD) and their families. Recognizing these challenges, there is a small but emerging body of literature testing interventions to improve the transition process. But there are many challenges in performing intervention research that have yet to be fully addressed. We discuss issues that should be considered when conducting interventions with individuals with ASD to improve the transition to adulthood, drawing from our study of a parent training to facilitate access to adult services during the transition years. Issues covered include: (1) timing (when is an intervention most effective?); (2) mode of delivery (what is the best way to present information?); (3) outcomes (how can intervention outcomes be accurately measured?); (4) target population (who is the intervention designed to help?); and (5) level of intervention (who should the intervention target?). Our answers, though preliminary, show the need to be flexible, to adopt a trial-and-error stance, and to listen to the needs—both explicit and implicit—of youth with ASD and their parents as they navigate the difficult transition from adolescence to adulthood.

When transitioning to adulthood, most adolescents and young adults assume increasing amounts of responsibility as they plan for pursuing post-secondary education, living independently, and securing meaningful employment (Bianco, Garrison-Wade, Tobin, & Lehmann, 2009). Although young adults with autism spectrum disorder (ASD) may have these same desires, their transition into adulthood often requires the involvement of various service delivery systems. During transition, these young adults shift from a familiar entitlement system (i.e., the school) to an unfamiliar, complex, and eligibility-based adult service delivery system (Hanley-Maxwell, Whitney-Thomas, & Pogoloff, 1995). For youth with ASD, who have relied on the routine and familiarity of school for almost two decades, this transition to the uncertainty of adult services is often difficult. Further, difficulties procuring needed services lead to challenges in numerous domains of daily life. After leaving high school and entering the adult service system, youth with ASD tend to

experience: slowing of behavioral improvement, increasing social isolation, and difficulties obtaining and maintaining post-secondary work and education (Shattuck et al., 2012; Taylor & Seltzer, 2010; Taylor, Adams, & Bishop, 2017; Taylor & DaWalt, 2017).

This transition period is also a challenging time for parents of these young adults. During their offspring's transition from high school to adulthood, parents are often viewed as the "linchpins" of services (Timmons, Whitney-Thomas, McIntyre, Butterworth, & Allen, 2004), simultaneously navigating the adult service delivery system (Timmons et al., 2004), continuing to provide caregiving (Smith et al., 2010), and advocating for appropriate services (Fong, Wilgosh, & Sobsey, 1993). Many parents even go so far as to describe their son or daughter's transition from high school to adulthood as "falling off a cliff" or the "second shock" of parenting a child with a disability (Hanley-Maxwell et al., 1995). Parents, then, are central players in the successful transition from school to adulthood for most youth with ASD (Burke, Patton, & Taylor, 2016).

In spite of transition's importance and the central role played by parents, few intervention studies have focused on the overall transition process for youth with ASD, fewer still have focused on their families (Taylor, Dove, et al., 2012). Instead, most studies examine single-focused interventions, for example evaluating the effectiveness of an intervention designed to improve social skills (e.g., Program for the Education and Enrichment of Relational Skills or PEERS; Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015) or job interviewing skills (e.g., Morgan, Leatzow, Clark, & Siller, 2014; Smith et al., 2014). Also, studies typically do not address the role of parents or of the service delivery system. Without appreciating that interventions must work in the "real world" and that parents are integral partners in the transition process, it is difficult to determine whether such interventions actually make a difference for transition-aged youth with ASD.

In this article, we describe the challenges and potential solutions in conducting intervention research with transition-aged youth with ASD and their families. Using as an example our own intervention study that targets parents of transition-aged youth with ASD - called the Volunteer Advocacy Program-Transition or VAP-T - we explore issues to consider when conducting intervention research to improve the transition to adulthood.

Characteristics and Research Issues Related to the VAP-T Program

VAP-T Program Description

The VAP-T is an approach to equipping families by training them about how to effectively advocate for adult services on behalf of their son/daughter with ASD. The VAP-T is a 12-week, 30 hour advocacy training. The curriculum reflects multiple domains: person-centered thinking, secondary education, postsecondary education, financial support, employment, Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, future planning, medical services, and advocacy. A professional instructor facilitated each session, with content experts directing individual sessions. Further details about the VAP-T program and curriculum can be found in Taylor et al. (2017).

The VAP-T was conducted in-person at the main site and simultaneously video-conferenced to two distance sites. After piloting the curriculum with a group of parents with older youth with ASD, a randomized, waitlist-control group design was used to determine the effect of the VAP-T on parent empowerment, knowledge of adult services, and perceived advocacy skills. Control group participants took the VAP-T approximately one year after the intervention group completed the program (see Taylor et al., 2017). Thus, the VAP-T was delivered three times: the pilot; the intervention group; and the waitlist-control group. The VAP-T was revised after each iteration. Findings suggested that, after taking the VAP-T, intervention group parents (relative to wait-list controls) knew more about the adult service system, felt more skilled and comfortable advocating on behalf of their son or daughter, and had higher empowerment scores (Taylor et al., 2017).

Five Issues to Consider

In developing and testing the VAP-T, several issues arose. Before describing each issue, we provide a brief vignette from the VAP-T to illustrate each challenge (vignettes are italicized). We then describe how these issues manifested in our study and how these issues are relevant to various types of intervention studies focused on the transition to adulthood.

(1) Timing: When is an intervention most effective?—Jessica, the parent of a high school senior with ASD, was randomized to the waitlist-control condition, meaning that she would not receive the VAP-T for a year (i.e., after her son had already left high school). Jessica complained that her son would be in college in the upcoming year and, thus, the information provided by the VAP-T would come too late and would no longer be useful.

When considering any intervention program for transition-aged youth with ASD, one must determine when that program should be delivered. The researcher needs to determine whether the intervention should be offered before a person needs specific knowledge and skills or, alternatively, when a person is in the midst of needing such knowledge and skills. If provided earlier (before being needed), participants may not fully understand the need for the program; also, participants may forget the details of the knowledge or skills learned. Alternatively, if the program is offered at a later time, participants may have already formed habits and/or misconceived notions, which the intervention then needs to address. Also, participants may have missed some potential opportunity to benefit from the skills or information being offered. As suggested in the vignette, if a program is offered later, the information may no longer be relevant.

Of course, this issue is not specific to interventions for transition-aged youth with ASD. However, the issue of timing, and in particular offspring age, becomes particularly important when considering interventions targeted at improving adult disability services. Transition-aged youth with ASD are stuck between two service worlds: school-aged services and adult services. School-aged services are designed to help streamline the transition to adult services by conducting transition planning. This process should begin when the adolescent with ASD is 16 years old. The transition plan should include needed services, supports, and agency involvement to ensure positive employment, educational, and independent living outcomes. Within transition plans, students are also required to have “appropriate measurable

postsecondary goals based upon age-appropriate transition assessments related to training, education, employment, and, where appropriate, independent living skills” (IDEA, 2004, 300.320(b)).

When designing the VAP-T, we had to decide when to offer the program. Should parents receive the VAP-T while their offspring were still in high school and receiving school services, or when school-based services had ended and their child was in the adult service system? The answer is unclear. On one hand, transition plans should begin to connect families to post-school adult services. However, transition plans rarely address the specific adult services that might be available to the son and daughter, nor the intricacies of searching out, applying for, and coordinating services (Tillman & Ford, 2001). Adult service agencies are often not invited to transition meetings (Agran, Cain, & Cavin, 2002) or, if invited, agencies are not assigned any responsibilities in the transition plan (Everson, Zhang, & Guillory, 2001). Thus, although there should be continuity between school and adult services during the transition process, such coordination often does not happen. Given these common limitations to transition planning in the schools, a program like the VAP-T – which covers the array of adult services that might be available after high school exit as well as how to access those services – might be an invaluable resource prior to high school exit, as families might be better able to plan for the transition out of school-based services and into the adult service system. At least in theory, youth may be able to begin services earlier, which could lead to better outcomes.

On the other hand, during our pilot work there was anecdotal evidence to suggest that earlier might not always be better. Given the complexities of sufficiently covering the adult disability service system, we provided families with a very large amount of information in the VAP-T, expecting that each family would attend most to the information that was relevant for their son or daughter. Yet, it was difficult for families of high school-aged offspring to anticipate which services or supports might be most helpful after high school exit. Several families entered the study expecting that most of the information would not be relevant to them, as their son or daughter was planning on attending college and would likely not need adult disability services. For some, maintaining a college program or a job proved to be more challenging than expected. For families of youth who faced these difficulties, taking a program like the VAP-T after high school exit seemed to be more helpful; they had some experience in the “adult world,” had experienced some setbacks, and, thus, had a better idea of which services and supports might be most helpful to their son or daughter.

Further, the timing of service-related interventions may vary depending on the services targeted. For example, a parent cannot apply for SSI until the month before their child turns 18. Explaining the SSI application process to a parent of a 16-year-old may not be worthwhile, as the parent has to wait two years to apply that knowledge. In contrast, Vocational Rehabilitation services can be provided during the school years. It may therefore make sense to educate parents about Vocational Rehabilitation services when adolescents are beginning transition planning (i.e., age 16). In this way, a representative from Vocational Rehabilitation can attend the transition meeting and begin providing services.

The issue of timing also extends beyond intervention services. For example, employment skills interventions may be started among younger adolescents with ASD. Thus, the students would still be protected under IDEA and be able to have their transition plans address their employment skills. On the other hand, it might be more helpful to begin an employment skills intervention after youth are out of high school and have some work experience (successful or not) under their belts; in this model, the intervention could address those aspects that been shown to be most difficult for that person. Broadly put, the timing of the intervention should almost certainly depend on the specific skills that are being taught.

(2) Mode of delivery: What is the best way to present information?—The VAP-T was held in-person at a host site in Tennessee, with two other sites in different parts of the state participating via videoconferencing. At one distance site, four parents consistently attended, although the site facilitator sometimes interrupted the training sessions, making it difficult for participants to hear the speaker at the host site. Further, at the host site, many participants informally reported that they did not know other parents of transition-aged youth with ASD. After a few initial VAP-T sessions, participants began coming to sessions early so they could interact with one another. At the end of the final VAP-T session, participants shared their contact information with one another so they could stay in touch.

Traditionally, interventions have been delivered in-person. As the internet has become increasingly available (File & Ryan 2013), however, distance technology has also become more accessible (via Skype, Adobe Connect, etc.) and more often used for service delivery (Casale, Stainbrook, Staubitz, Weitlauf, & Juarez, 2017). The VAP-T was offered in a group setting, both in-person at the host site and via distance technology to two other sites. But as described in the vignette, having distance sites created extra challenges, including: the ability to control or monitor group dynamics (e.g., making certain that the site facilitator did not speak over the in-person speaker); facilitating opportunities for real-time participation at all sites; and ensuring that those at the distance sites felt as invested in the program as those at the host site.

Additional issues relate to whether the intervention should be offered only in a group format or if individuals could receive the intervention in their own homes, without peers. During the VAP-T, as with all interventions, life often intervened. Participants would sometimes have things come up (e.g., sickness, car problems), requiring them to stay at home instead of attending the VAP-T in-person. Because of the videoconferencing embedded in the VAP-T, participants were still able to attend the VAP-T from their own homes. For weeks when participants were not available during the group time, we also offered the option of watching a recording of the session at a later time.

Although participants sometimes accessed the VAP-T information from home (either in real-time during the group session or at a later time), the in-person group dynamic seemed to strengthen the intervention. Previous studies have documented the positive effects of peer support on parents' well-being (e.g., Solomon, Pistrang, & Barker, 2001; Shilling et al., 2013). Similarly, our own preliminary findings from before to after the (12-week) experimental session supported this finding. Compared to parents who attended greater numbers of sessions in-person, parents who accessed a greater proportion of their sessions at

home by themselves (either live or later) did equally well on knowledge of the adult service system, but not as well on feeling comfortable advocating for their son/daughter or on parental empowerment (Taylor et al., 2017). The group component, then, may catalyze the intervention's effectiveness, allowing parents to move beyond an understanding of adult services to develop the self-confidence and empowerment to implement that knowledge.

These benefits must, however, be balanced with the logistical restrictions faced by many parents. Given that many parents of young adults with ASD have limited time (Smith et al., 2010), attending an intervention from one's home may increase the feasibility of attendance by eliminating the time for traveling to a site; home attendance may also reduce traveling expenses (Anderson, Balandin, Stancliffe, & Layfield, 2014; Cason, Behl, & Ringwalt, 2012). Further, by allowing individuals to teleconference from their own homes, receiving the intervention might also become easier for individuals from rural areas, who have financial hardships, or who themselves have disabilities that preclude travel (Carter, Muir, & McLean, 2011).

Regardless of the type of transition intervention, mode of delivery is an important consideration. Given the increasing availability of technology, interventionists should consider the best ways to use technology such that it improves the quality of an intervention *and* reaches a broader sample. In the context of intervention research for youth with ASD and their families, it is important to balance the convenience of participating in an intervention via distance technology with designing a program that one expects to net the greatest benefits. Although it might be tempting to err on the side of convenience, maximizing the potential benefit to those participating in the intervention should always be weighted just as heavily, if not more so. Teaching interviewing skills, for example, might be conducted through virtual reality platforms (e.g., at home, on the participants' own time) with similar efficacy as more logistically-demanding, in-person sessions. Social skills intervention, on the other hand, might be most effectively delivered in-person, in a group format. The balance of convenience versus efficacy is a testable question, and should be considered in research designs testing transition interventions for youth with ASD.

(3) Outcome: How can the outcomes of the intervention be accurately measured?—The mother of a young adult with ASD, Latonya, was participating in the VAP-T. After completing the battery of post-survey measures, Latonya contacted the project coordinator questioning the need for these measures. Latonya mentioned struggling to complete the measures, noting that some services have waitlists and extended time periods to prove eligibility, making it take longer to access services. As a waitlist-control group participant, Latonya was also frustrated that she had to complete the same survey measures twice, before receiving the VAP-T intervention one year later.

The dearth of high-quality outcome measures for intervention trials is a problem throughout intellectual and developmental disability (IDD) research, and is even more complicated in interventions focused on the transition to adulthood. To date, there is little consensus on what constitutes a “good” transition: objective indicators like community employment or independent living might penalize those youth who have more significant support needs, making it less likely (relative to those with fewer support needs) that they would experience

a “good” transition (Taylor, in press). Some have discussed including more subjective indicators of transition outcomes (e.g., happiness, subjective quality of life), but it is unclear whether these should replace more objective, functional indices. Further, we have few, psychometrically-sound measures to capture any of these constructs among youth with ASD, making it more difficult to observe intervention effects.

An additional issue pertains to the timing of the proximal and distal outcomes. With the VAP-T, the targeted proximal outcome was to improve parent empowerment, knowledge about adult disability services, and advocacy skills (Taylor et al., 2017). The distal outcomes are to improve receipt of services for the transition-aged youth with ASD, as well as their employment, educational, social, and residential outcomes. Methodologically, it is easier to determine an intervention’s impact on immediately measurable, proximal outcomes. It becomes more difficult to measure distal outcomes due to the time needed to see if a change has occurred.

With regard to interventions aimed at improving service access, it takes time to see an increase in the acquisition of services (Burke et al., 2017). When more time elapses between the intervention and the intended outcome, a greater potential arises for outside variables to influence outcomes. It can thus be difficult to determine when to collect measures of proximal and distal outcomes, as well as how and when to measure potential intervening events or influences. Put simply, when conducting applied intervention research with individuals with ASD and their families, one must consider the social validity of the intervention.

When considering interventions, it is also important to consider context. Again, we encountered this issue in the VAP-T: a parent can feel empowered, be knowledgeable about adult services, and have tremendous advocacy skills but, if services are not available, then advocacy skills may not matter. For example, an important component of state disability services concerns Medicaid waivers. Every state has Home and Community-Based Services (HCBS) Medicaid waiver funds (Braddock et al., 2014). Upon receiving the waiver, individuals with IDD have fewer unmet service needs (Caldwell & Heller, 2007; Heller, Miller, & Hsieh, 1999). Yet 43 states have waiting lists for adults with IDD to receive the HCBS waiver (Research and Training Center on Community Living, 2013). When a state has such a large waiting list, as noted in the vignette above, parent advocacy may have less of an influence on formal service access, as everyone waits for services.

Issues related to measurement – including which outcomes to choose, how to measure them, and when to measure them – are important to carefully consider in all intervention studies to improve the transition to adulthood. If an intervention aims to improve service access, then the researchers should incorporate into the design and measurement scheme the limitations of the local adult disability service system (e.g., amount of time to get a service, lack of funding or long waiting lists). For other types of transition interventions, the appropriate primary and secondary targets should be decided. For example, academic interventions should not only focus on getting into a post-secondary educational program, but also on facilitating the skills needed to successfully complete that program. Because generalization

can be difficult for individuals with ASD (Foxx, 2008), measurement should be incorporated to determine whether the intervention results in meaningful, real-life change.

At the same time, it is also important to identify and measure external influences that may mediate the effectiveness of the intervention. In addition to monitoring upcoming changes in laws, regulations, and subsequent services, one must consider other external influences when intervening with adolescents and young adults with ASD. For example, potential hormonal or biological changes may impact the effect of an intervention (Smedley & Syme, 2000). Other changes may relate to the family structure or to natural transitions among adolescents (e.g., graduating from high school, dating). Although researchers cannot control for these outside influences, by measuring them we can ensure that our research accurately captures the effect of an intervention.

(4) Target population: Who is the intervention going to help?—In developing the VAP-T curriculum, two parents—Mary and Vanessa—were asked to share their insights. Mary had a son with ASD who was applying to four-year colleges while Vanessa’s high school-aged son had greater cognitive limitations. Vanessa hoped her son would work in a supported employment setting and live in a group home with support. In reviewing the curriculum, both parents commented that, due to their son’s respective abilities, certain policies or content areas were not applicable. They suggested that the VAP-T include different tracks—one track for parents of children with ASD without intellectual disabilities (ID), another for parents of children with co-occurring ASD and ID. Further, both Mary and Vanessa questioned why the intervention was only offered to parents of offspring with ASD, when families of transition-aged children with other types of disabilities were also desperate for information about adult services.

Given the range of communicative and cognitive abilities of children with ASD, needed services almost certainly vary for youth across the spectrum of functioning. In the context of parent comments like those of Mary and Vanessa, we had many discussions about whether the VAP-T needs to have different content depending on the abilities of the youth with ASD. With respect to secondary education, for example, we initially thought to offer two tracks. For parents of youth who plan to receive a regular education diploma, the track would include the requirements for a regular education diploma, along with available supports and services to receive that diploma. For parents of offspring who planned to receive an alternate diploma (e.g., occupational or special education diploma), the track would include information about the requirements for those diplomas, as well as their implications.

During the initial pilot of the VAP-T, however, it became clear that offering two tracks may not be appropriate. Many participants wanted information about both tracks, as they were unsure of which secondary diploma/certificate option was most appropriate and wanted all of the information about secondary education so they could make informed decisions. Thus, while the heterogeneity of ASD poses challenges when developing interventions for families, one needs to utilize both participant feedback and trial-and-error experience to fine-tune interventions.

Regardless of the focus of intervention research, researchers may struggle with how to address and effectively intervene with individuals with ASD who have varying abilities. Given that the effectiveness of an intervention may differ in relation to the cognitive abilities of the youth with ASD (Machalicek, et al., 2008), interventions may be limited to only those youth who have average or above average intellectual functioning. For some types of interventions, this might be appropriate. However, this approach has resulted in a significant dearth of interventions and programs aimed at improving transition outcomes for youth with ASD who have more significant support needs. With this in mind, we encourage researchers to be as inclusive as possible when designing interventions to improve transition outcomes for youth with ASD. It might be that an intervention focused on a set of skills, such as daily living skills, could be modified slightly to be relevant to those with greater support needs. Making these modifications might also open up the intervention to be tested in other populations of individuals with ID. Regardless of where the researchers land in terms of their targeted population, the question of who should be offered the intervention is one that requires serious thought, and decisions should be based on the skills being taught, knowledge to be gained, and objectives of the intervention.

(5) Level of intervention: Should one intervene at the level of the youth or the family?—The Advisory Panel for the VAP-T included several self-advocates with ASD. When developing the VAP-T, the self-advocates would often ask how transition-aged youth with ASD would be included in the intervention.

As adolescents and young adults, individuals with ASD should increasingly be taking the reins of their own advocacy and demonstrating self-determination. Indeed, during adolescence, many educational practices focus on increasing the independence of youth with ASD. When developing an intervention program for these individuals, then, it is important to consider how to involve the offspring with ASD themselves.

Person-centered planning is a common practice of involving transition-aged youth with disabilities in preparing for adulthood. Defined as practices that facilitate change with individuals with disabilities and their families and friends (O'Brien & Lovett, 1992), person-centered planning helps to ensure that the individual with a disability has supports tailored to his or her individual needs and preferences. The historic importance of person-centered planning cannot be overstated. After centuries of individuals with disabilities being marginalized to lesser or even non-existent roles, person-centered planning empowers these individuals to have primary roles in decision-making about their lives. Common person-centered practices include having youth facilitate their own transition meetings (e.g., self-directed individualized education program meetings, Martin et al., 2006) and practicing person-centered planning in relation to future planning (e.g., Heller & Caldwell, 2006).

However, the complexity inherent in adult disability services is not always conducive to person-centered planning. Service delivery systems are notoriously hard to navigate, as individuals need to identify appropriate services, understand different eligibility requirements, and apply for, receive, and maintain services. For example, over 96 federal policies directly impact individuals with ASD and other disabilities (Silverstein, 1999). Each policy and related service delivery system is unique and difficult to navigate. To complicate

matters further, policies are typically written at a reading level that make them inaccessible to those with disabilities, with some policies such as special education procedural safeguards (an explanation of special education rights and description of dispute resolution options) written at a 16th grade reading level (Mandic, Rudd, Hehir, & Acevedo-Garcia, 2012).

Given the complexity of adult disability services and the need for parents to serve as brokers to procure needed services, transition-aged youth with (versus without) disabilities may be more likely to rely on their parents for support (Bianco et al., 2009). Thus, the concept of person-centered planning may need to be expanded to include parents and other family members as supports, guides, advocates, and mentors for their young adult with ASD.

Regardless of the specific type of transition intervention, “person-family interdependent planning” might serve as a useful framework when considering the role of the individual versus the role of the family. Unlike person-centered planning—which focuses on the individual with a disability—person-family interdependent planning also considers the role of the family (Kim & Turnbull, 2004). This approach ensures that the individual and the family are informed and jointly choose services and goals for the individual, exercise their rights and have economic resources, and are satisfied with services and their life situations (Accreditation Council on Services for People with Disabilities, 1995).

Contemplating these issues as we planned the VAP-T, we attempted to reach a middle-ground, one in which we focused on parents as the direct recipients of the VAP-T intervention, but also included the needs and perspectives of the adolescents and young adults with ASD themselves. From the beginning, we targeted parents as the focus of the intervention. But given that services would ultimately go to the youth, we wanted to ensure that the curriculum reflected person-family interdependent planning. To this end, in the pilot of the VAP-T, we offered four sessions that youth with ASD could attend. Because of the varying needs of these youth, however, these initial experiences did not work well and we concluded that the VAP-T sessions should involve parents only. Still, in later iterations of the VAP-T, we revised the curriculum such that person-centered planning was the topic of the first session of the VAP-T, and was referred to throughout sessions. In this way, the offspring with ASD became the foundation for the rest of the VAP-T, which focused on how parents could access such person-centered services.

Although we debated as to whether we should intervene with the parents or with the youth themselves, most transition-focused interventions have not struggled with this issue. Instead, most intervention studies have been conducted with youth who are more cognitively able, and focus on building skills or capacities with the youth or young adult directly (e.g., Laugeson, Gantman, Kapp, Orenski, & Ellingsen, 2015; Smith et al., 2016). But even in those cases, the idea of interdependence is one that researchers should consider when designing transition interventions. For many youth with ASD, families remain intricately involved in their lives, as sources of both formal and informal support. Interventions that leverage this important commitment from families might more effectively improve transition outcomes than those which intervene only with young adults themselves. Such considerations grow in importance when programs include youth with greater cognitive disabilities, who are even more likely to rely on family support in adulthood.

Developing Interventions: Lessons Learned

Reflecting on the challenges in conducting the VAP-T and other interventions related to youth with ASD and their families, below, we discuss how the lessons learned inform the continued development of the VAP-T program as well as highlight some overarching themes for future intervention research.

Informing the Continued Development of the VAP-T

In regards to some of the issues raised above, our pilot work with the VAP-T provided some clear evidence to guide the future development of the project. When examining the mode of delivery, we found that parents who attended the VAP-T in-person in a group setting (versus at-home, via distance technology) made greater gains in advocacy skills and empowerment (Taylor et al., 2017). Although further work is needed to conduct more rigorous tests of modes of delivery (including providing families with written information without training or offering the program in a virtual setting), we nevertheless conclude that the group format is an important aspect of the VAP-T, allowing parents to develop connections with other parents and with the experts who are presenting information about adult services. Thus, in future iterations of the VAP-T, we plan to focus on the group format.

Other issues cannot be adequately addressed without larger-scale intervention trials. With respect to timing, anecdotes suggested that, for some research participants, receiving the VAP-T information before high school exit might not be as beneficial. In contrast, other parents wanted to receive the information about adult services as early as possible, and our formal findings were inconclusive. As our studies were also underpowered to identify whether the presence of ID impacted the effectiveness of the VAP-T (Taylor et al., 2017), we plan to examine both age and presence/absence of ID as moderators in larger-scale trials of the VAP-T. In this way, we can determine when to best administer the intervention and who is mostly likely to benefit.

Regarding measurement as well, we have learned lessons that will help shape future VAP-T iterations. First, recognizing that states vary in their service delivery systems, especially with respect to HCBS waiver services, we plan to test the VAP-T in different states. Notably, we will ensure that these states represent different adult service landscapes; for example, states should reflect differing levels of spending on adult services. By choosing diverse states, we can determine whether the VAP-T can be nationally relevant and can account for the effects of different service delivery systems in our analyses. In relation to the level of intervention, we plan to continue our focus on the person-family interdependent model. We believe that our curriculum acknowledges the importance of person-centered planning but, given the complexity of adult services, requires the involvement of parents as service navigators for their offspring with ASD.

Importance of Flexibility, Trial and Error, and Different Forms of Feedback

When the VAP-T was initially conceptualized, we focused on being flexible to meet the needs of youth with ASD and their families. Given the limited research about families of adolescents and young adults with ASD (Burke et al., 2016; Taylor, McPheeters, et al.,

2012), few studies existed to help us determine how to create the most effective interventions for this population. Without much guidance, it seemed necessary to be flexible in creating the VAP-T. To this end, the VAP-T underwent three different iterations. After each iteration, we identified problems or less effective techniques and then we were able to substantially modify these before the next trial. Put simply, the multiple iterations of the VAP-T demonstrate the need for numerous trials of an intervention for youth with ASD and their families.

Another aspect of flexibility involved considering all forms of feedback. For the VAP-T, we solicited explicit feedback from individuals who were in the Advisory Board and the pilot group, as well as participants in the experimental group and in the wait-list control group. We made many changes based on such feedback. However, not all feedback was explicit and not all explicit feedback was correct. For example, some participants wanted to watch the VAP-T from their own homes. Our initial decision—supported by participants—was that the mode of delivery (live vs. in-home) would not matter, that all outcomes would be identical whether one attended in person with the group or alone at home. In our first pre-post study, however, there were moderate-sized correlations between attending more sessions in person with the group (versus more sessions from home) and greater gains in advocacy skills and empowerment (Taylor et al., 2017). Thus, group cohesion may be particularly important for some families and for certain intervention outcomes. One must thus pay attention to explicit feedback from intervention participants, but also to more implicit signals to determine whether protocols and information are feasible and effective.

Need to Go Beyond Principles of Disability and Intervention Research

Although little research exists about supports for families of transition-aged youth with disabilities (including ASD), there are established principles related to disability and to intervention research. When designing and implementing an intervention for families of youth with ASD, however, we have found it necessary to use such principles only as general guidelines. Ultimately with the VAP-T, we decided to focus on person-family interdependent planning and to emphasize person-centered planning in the first session (to be used throughout). This decision required ongoing dialogue and actual attempts, with specific disability principles serving as general—but not as specific—guidelines to the ultimate decision.

It was also necessary to think beyond basic principles of intervention research. The VAP-T was designed and implemented as a randomized waitlist-control group design—a relatively strong design in intervention research (Shadish, Cook, & Campbell, 2002). In the context of the VAP-T, however, the changing nature of the service delivery systems needed to be considered in relation to the intervention and the related research design. Specifically, eligibility for the HCBS Medicaid waiver changed during the course of the randomized control trial. Due to the change in eligibility over the one-year waiting period, individuals in the waitlist control group (versus intervention group) may be more able to access Medicaid waiver services. Thus, when conducting an intervention in the “real world”, it becomes necessary to consider potential intervening events.

We conclude with what may be the major, albeit obvious, lesson from the VAP-T: one cannot know what will happen until one performs actual studies with participants for whom the intervention is designed. One can solicit feedback from hypothetical or real participants; one can use general principles from the intervention research or disability fields; one can try to predict the best intervention practices from analogous studies. Ultimately, however, only with actual intervention-research studies will we know how to overcome the many challenges identified in this paper and, eventually, how to develop more effective, evidence-based interventions for youth with ASD and their families.

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