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Discovering Behavioral Intervention: A Parent's Interactive Guide to ABAⁱ

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ABSTRACT

Autism spectrum disorders (ASD) affect one in 110 children in the U.S. Parents of children with ASD need clear and accurate information to communicate with professionals as they seek appropriate services, including applied behavior analysis (ABA) based intervention. Behavioral professionals can assist parents in this endeavor by recommending resources, including online courses. This paper describes the development and evaluation of an online course on ABA for parents of children with ASD. Parents completing a summative field test (N=21) made significant gains in knowledge and reported high levels of satisfaction. Implications include the potential for enhanced parent-professional collaboration in treatment decision-making.

KEYWORDS: autism spectrum, eLearning, online courses

INTRODUCTION

The prevalence of Autism Spectrum Disorders (ASD) has skyrocketed in recent years, with current estimates showing that ASD affects one in every 110 children (Centers for Disease Control and Prevention, 2011). ASD represents a class of three related neurodevelopmental disorders, Autistic Disorder, Asperger Syndrome and Pervasive Developmental Disorder: Not Otherwise Specified. Typically diagnosed before the age of three, ASD immediately and profoundly affects the young child's ability to communicate, develop language, form social relationships and respond appropriately to environmental stimuli (U.S. Department of Health and Human Services, 2008).

The diagnosis of ASD often takes parents by surprise. In addition to the need for social support, parents immediately require clear and accurate information so they can communicate effectively with professionals from medical, psychological and education communities, and in turn receive appropriate services (Powers, 2000; Harris & Weiss, 1998). For example, behavioral support planning requires professionals and family members to participate together in activities that involve information sharing, creative problem solving and shared decision making (Marshall and Mirenda, 2002). Only when parents are well informed and knowledgeable about intervention options can they begin to gauge the quality and therapeutic potential of services made available to them, and then proceed with confidence to advocate for the best of these approaches (Levy, Ae-Hwa & Love, 2006; Dawson, 2001). In one study, parents of children with Down syndrome, ASD and Fragile X syndrome who participated in three separate focus groups

were in strong agreement that education on syndromes and services, and parent advocacy, all affected the quality of care their children received (Minnes & Steiner, 2009). Knowledge acquisition may also serve as an interim step in encouraging parents to participate directly in the delivery of interventions with their children, which has the potential to enhance intervention effectiveness (Kobak, Stone, Wallace, Warren, Swanson & Robson, 2011), provided they then receive skills-based training (Crockett, Fleming, Doepke & Stevens, 2007).

Early intervention approaches based on applied behavior analysis (ABA) focus heavily on the development of early communication and social skills, and have the strongest and most consistent scientific support for teaching children with ASD and reducing maladaptive behaviors (Eikeseth, 2009; Howlin, Magiati Charman, 2009; Peters-Scheffer, Didden, Korzilius & Sturmey, 2011; Rogers, Vismara, 2008). However, for parents who have little experience arranging ABA and other disability-related services, understanding this new terrain can be immensely challenging (Hamad, Serna, Morrison & Fleming, 2010). Parents seek information on ABA through various media channels, including the Internet. Unfortunately the information they encounter there can be unsupported by scientific evidence, inaccurate, incomplete, or biased toward product promotion (Kabot et al., 2003). There is a need for online coursework for parents which is objective, accurate and unbiased, and that utilizes media and a family-friendly context to effectively convey information.

What role can behavior analysts and related professionals play to help inform and guide parents in these endeavors? Aside from their role in developing and implementing individualized ABA programs, behavior analysts are in a strong position to provide support to families by pointing them to legitimate educational resources while working collaboratively with them to implement and evaluate interventions (Kabot et al, 2003). Online materials geared for parents that present ABA information in an engaging (e.g., media-based, interactive) and largely jargon-free manner, provide another tool that psychologists can recommend with confidence to parents.

In response to this need we developed and field-tested an introductory course entitled *Discovering Behavioral Intervention: A Parent's Interactive Guide to ABA* (hereafter, *DBI*). We describe each of the steps we took in developing and evaluating this course, including: 1) formative evaluation, using parent and professional focus groups; 2) course design and development; and 3) summative evaluation, in which we field tested the course with parents as participants. We end by discussing strengths and limitations of the project and suggesting some next steps for research and practice.

FORMATIVE EVALUATION

Approval to conduct all aspects of this study was provided by the University of Massachusetts Medical School's Institutional Review Board. We began with a formative evaluation, in which we held three 1½-hour focus groups, two with parents of children with ASD, and one with board certified behavior analysts who provide ABA services. Participants were recruited from regional ASD support groups and organizations (parents), and through a local behavior analysis organization. Extensive notes were taken during the focus groups and later analyzed for thematic content.

PARENT GROUPS

Sixteen (16) parents participated in two groups (8 per group). All had children who had been diagnosed with an ASD in the first 3-4 years of their lives. Parents were asked how they first learned about ABA, how easy or difficult it was for them to understand the different types of services made available to them, what they felt was important to know about ABA, how parents judged therapist-child and therapist-family fit, and any advice they would give to other parents. The facilitators (first two authors) presented sample text and pilot video clips of a mother implementing ABA procedures with her son with ASD at home. Participants provided feedback on the coherence and “look and feel” of this content. Parents in both groups were remarkably similar in identifying elements they felt should be included in *DBI*. They emphasized the need to present valid background information on ASD, including possible causes, diagnostic classification, information on the range of emotions and “grieving” that often occurs after receiving the autism diagnosis, and the ways in which ABA could help their child. Parents said it was important to describe the full range of evidence-based ABA approaches, “not *just* Lovaas therapy,” saying that this information had rarely been presented to them. They recommended that we show some simple ABA procedures (e.g., basic positive reinforcement procedures) they could use at home, and discuss how ABA could be incorporated into a family’s life while preserving a sense of family “identity.” Parents reported that ABA was most helpful in teaching their children to communicate, which they initially thought was restricted to the realm of speech and language pathology. They added that communication training had helped to reduce their child’s challenging behavior, another area that they asked be addressed. Upon viewing the video clips, parents were roundly enthusiastic about including video in the course, but suggested that the clips be presented in shorter, more discrete segments, with clear instructions on what to look for. Finally, parents also wanted to make sure that we provided links to support groups and other credible resources.

PROFESSIONAL BEHAVIOR ANALYST GROUP

Nine behavior analysts participated in a single focus group. All had worked extensively in programs for children with ASD and were board certified by the Behavior Analysis Certification Board (BACB), an international organization. All had several years’ experience working with families. They discussed common fears that parents present when considering ABA, for example, that it might involve “men in white coats” who are “sterile, unfeeling technicians,” or that they might not be able to do any of the interventions themselves. They recommended that we help parents understand ABA – what it is, why and how it works, and how they might master some simple procedures to use at home. However, they warned that some parents believe firmly that “more ABA is better,” and overdo intervention by delivering it almost constantly. They indicated, as had parents in their focus groups, that maintaining family balance is important. They also largely agreed that we should help parents understand that autism is apt to be a lifelong disorder for which there is no present “cure.” The professionals indicated that one of their biggest challenges is to help parents to accept their children’s disability, while working with hope and optimism to help children grow and develop as fully as possible. As in the parent groups, the professionals felt that ABA should be demystified, by providing examples, vignettes and video clips of what ABA “looks like.”

In summary, parents and professional behavior analysts were enthusiastic about the potential for *DBI* to provide parents with credible, evidence-based information that would enable them to obtain services earlier and to be better informed as consumers and advocates, all of which would contribute to better outcomes for their children.

COURSE DESIGN AND DEVELOPMENT

We combined focus group information with a review of literature on parent experiences in ABA, a prior analysis we had done on ABA concepts and procedures prioritized as critical by behavior analysis experts (Sulzer-Azaroff, Fleming, Hamad & Bass, 2008), and our team's behavioral and family-support experiences, to design and develop *DBI*. The resulting course addressed the following topics: receiving the autism diagnosis; scientific information on the nature and causes of autism; the meaning of "evidence-based" when evaluating intervention approaches; introduction to the field of ABA; the use of positive reinforcement, prompting and prompt fading in teaching; different ABA approaches (e.g., discrete trial teaching, naturalistic/incidental teaching, picture-assisted methods); positive behavior support (PBS) to support parent-professional partnerships; evaluating research and popular books on ABA.

We designed the course to be *asynchronous*, that is, to be available "any time, anywhere," for use by parents when their hectic schedules permit. We also decided to build *DBI* so that it did not require an instructor. Whereas having an instructor is preferred by most online students, particularly when that instructor is seen as engaging, approachable, patient and passionate about the subject matter (Reupert, Mayberry, Patrick & Chittleborough, 2009), instructors add cost and scheduling constraints that could limit parent participation. Accordingly, we built the course such that it could easily be supplemented by live instruction, but could also be taken without it. This meant that the course content would need to stand on its own. Text and media content would need to be understandable and complete, and it would need to flow in a logical manner as the parent navigated the course. Here is an example of the style and level of language used in the course:

Behavioral intervention relies on the use of a procedure called positive reinforcement. While almost everyone has heard of this procedure, it is often poorly understood...and often used incorrectly. First and foremost, positive reinforcement involves giving immediate rewards to a child following instances of desired behavior. The behavior can be very small at first, an initial step in the right direction!

DBI was developed in Blackboard®, an eLearning product widely used in higher education. We used this product because it had built-in testing applications that supported our summative evaluation needs, was supported by our university's online learning division, *UMASS Online*, and offered sufficient graphic design capabilities to produce an attractive yet functional course. Figure 1 shows a screen capture of one page in *DBI*, and illustrates how navigation is accomplished and text and video content is delivered.

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Learning Module 1:
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Discovering Behavioral Intervention
A Parent's Interactive Guide to ABA

Frequent Reinforcement: Lots of Praise Early in Teaching

Kim gets Ryan going by laying out the cards, putting some of them together, and using some prompts. But it's the frequency of reinforcement that we want to look for in these clips. It may be clear to you that Ryan has put this puzzle together before and probably doesn't need so much reinforcement, but Kim and Ryan thought they would demonstrate how reinforcement is used when activities and tasks are new and challenging.

- What types of positive consequences does Kim use? Remember, consequences do not always have to be praise.
- How many times does Kim provide consequences? Watch a few times and count the times.




Figure 1: Screen capture of a course page with instructional text and embedded video. Parents read questions, watch the video (repeatedly if desired), answer questions and receive programmed feedback.

The ultimate value of *DBI* for parents rests in the development and presentation of content they deem directly useful. To that end we wrote text that was clear and concise; used professional filmmakers to produce edited video of a mother using discrete trial and naturalistic teaching procedures with her 5-year old son in their family home; included a 20-minute interview with a mother of a child with ASD who is also an attorney; wrote engaging reviews of well written books on ABA written for parents (e.g., Koegel & LaZebnick, 2004); summarized journal articles in lay language for parents who wanted to “dig deeper;” developed a frequently asked questions section, named “Questions to Consider;” and offered selected links to science-based websites on causes and diagnosis of ASD (e.g., links to the National Institutes of Health and Centers for Disease Control and Prevention). In terms of ABA content, we incorporated these and other features to support a sequence that covered practical concepts in behavior analysis, discrete trial teaching, naturalistic/incidental teaching, augmentative communication, verbal behavior training, and family-systems-based ABA (via Positive Behavior Support).

SUMMATIVE EVALUATION

A convenience sample of 20 parents and one grandparent (N=21) of children with ASD were recruited through ABA service agencies in the greater Boston, MA and Providence, RI areas, and completed the *DBI* course. Data were collected on participant: 1) demographics; 2) knowledge acquisition, via pre- and post-test assessment; and 3) satisfaction, using Likert-style ratings and an open-ended comment section.

DEMOGRAPHIC AND DESCRIPTIVE INFORMATION

Each participant completed a 12-item online survey that asked about their gender, ethnicity, education, relation to child, age of their child a diagnosis, current age of child, time receiving ABA services, goals for taking the course, prior education/training in ABA, and computer/Internet use. Results are presented in Tables 1-3.

Gender	Ethnicity	Education	Relationship to child	Age of child at diagnosis	Current age of child	Time with ABA services
Female (21)	White (17) Asian (1) Hispanic (1) Native American (1) Other (1)	High School (5) Voc/Technical (1) Associates (2) Bachelors (8) Masters (4) Doctorate (1)	Mother (20) Grand-mother (1)	Mean: 33.8 mos. Range: 17-60 mos.	Mean: 4.7 yrs. Range: 2.5-6 yrs.	Mean: 19.7 mos. Range: 0-60 mos.

Table 1: Participant demographics.

Goals for taking DBI (Select all that apply)	Number reporting	Prior training in ABA (select all that apply)	Number reporting
Gain general knowledge in ABA	7	Observed therapist/teacher	13
Increase ABA knowledge beyond introductory level	12	Attended workshops	4
Learn more about teaching my child	19	Attended lectures or talks	12
Learn more about my child's challenging behavior	16	Read books	17
Learn more about evaluating ABA teaching programs	15	Read materials on web sites	16
Learn more about evaluating ABA behavior management	15	Watched videos	4
Determine if I would want more advanced ABA training	11	Learned from a friend	1
Gain information on how better to advocate for my child	17	Taken formal courses	3

Table 2: Participants' goals for taking the course, and their prior training in applied behavior analysis (ABA).

Frequency of computer and internet use	Number reporting	Type of computer and internet use	Number reporting
Use computer frequently every day	17	Email	21
Use computer about once per day	4	Browse internet for information on ASD	21
Use computer about once per week	0	Take online courses	3
Browse internet frequently every day	8	Participate in online discussion/chat groups	13
Browse internet about once per day	3	Watch online video clips	5
Browse internet about once per week	1		

Table 3: Frequency and type of participants' computer and Internet use.

Participants were mainly mothers (95%) who were white (81%) and female (100%). The group was heterogeneous with respect to participants' levels of education, months of experience receiving ABA services, goals for taking the course and experience learning about ABA. With respect to participant goals, despite the fact that *DBI* was clearly described as introductory in nature, only seven parents had the goal of seeking general knowledge (33%). Most were seeking more advanced knowledge, including skills for more effective advocacy (81%). In order to evaluate whether parents with more experience with ABA services might still benefit from an introductory course, we sought to include parents with a mix of previous ABA exposure levels. We succeeded in recruiting parents who had ≥ 18 months or more experience ($N=9$), along with our primary target group of parents with ≤ 18 months experience ($N=12$). This allowed us to compare differential knowledge acquisition between these groups and begin to determine its potential value to parents at varying levels of experience. Finally, our data on computer and Internet use show relatively heavy computer use at least once per day (100%), and moderate daily Internet use (52%). In terms of *type* of computer and Internet use, all participants reported using technology for emailing and Internet browsing for information on ASD. Relatively few had taken courses online (14%) or watched online video (24%), but 62% had participated in discussion/chat groups. All but two participants had sufficient broadband connectivity and experienced no problems viewing videos. One participant supported what has been our plan to offer access to lower-income families via public computers.

KNOWLEDGE ACQUISITION

All 21 participants completed a 20-item pre- and post-test comprised of multiple choice and multiple select items. Pre- and post-tests were identical, so as not to vary in difficulty, delivered online, and scored electronically. Upon completing the pre-test, participants were presented with their overall score, *but they received no feedback on their performance on individual test items*. Therefore while they had a general sense of how they did, post-test contamination was controlled. Figure 2 presents data for participants whose children had received ABA for ≤ 18 months, and Figure 3 shows results for parents whose children had received ABA for ≥ 18 months or more. We divided participants as such to explore the possibility that parents with more exposure to ABA might perform better on the pre- and post-test than those with less exposure. However, all participants demonstrated similar post-test gains. For the entire group ($N=21$), the mean pre-test score was 56.2%; the mean post-test score was 85.2%. We determined that the data did not closely approximate a normal distribution, so we performed a nonparametric test, the Wilcoxon signed rank test. The Signed Rank for this treatment effect was $S=155.5$, which was highly significant ($p <$

.0001, two-tailed). In sum, parents began their participation in *DBI* with some knowledge, as would be expected by their prior experience (average 19.7 months), but they had room to learn much more, as suggested by the group post-test mean of 85.2%.

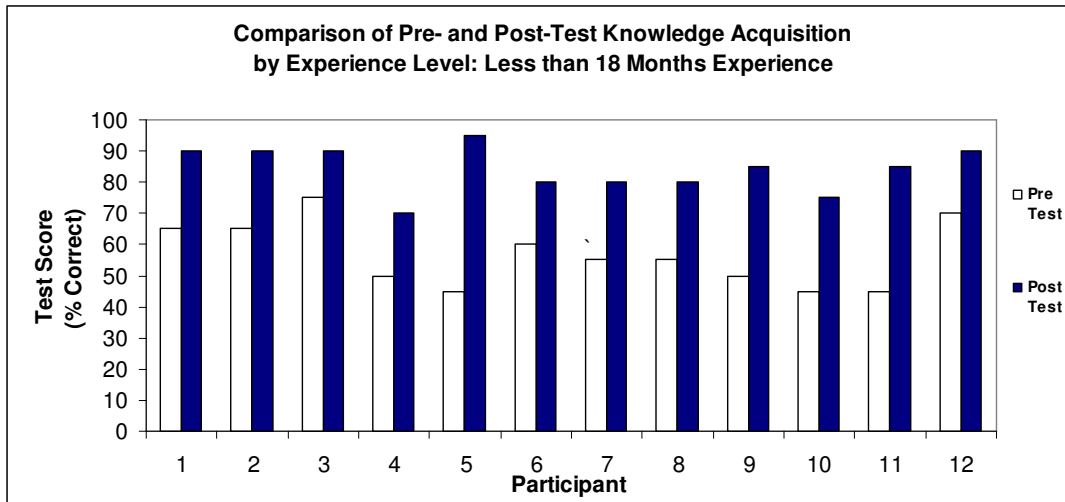


Figure 2: Knowledge acquisition by 12 participants whose children had received ABA for ≤ 18 months.

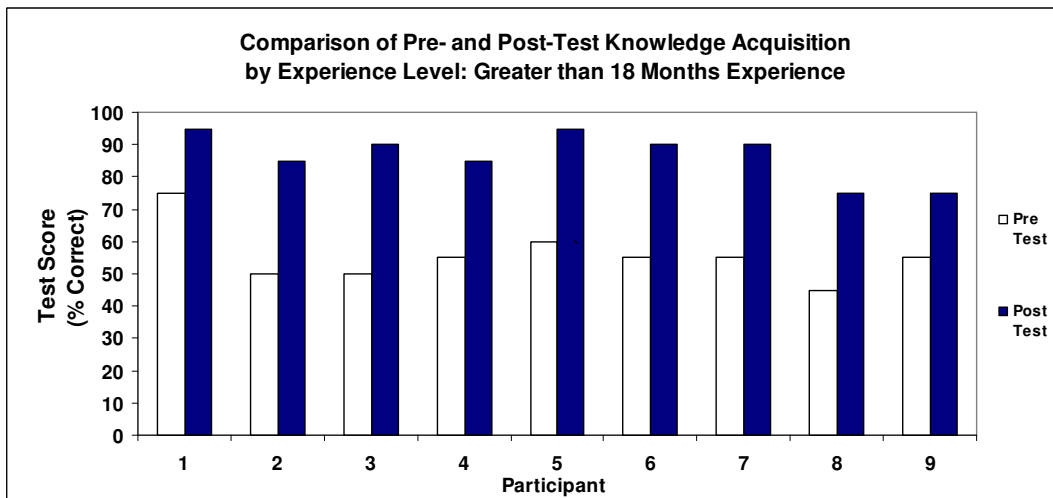


Figure 3: Knowledge acquisition by 9 participants whose children had received ABA for ≥ 18 months

SATISFACTION

Upon finishing the course in its entirety, participants completed a 21-item satisfaction survey and were invited to offer open-ended feedback. Table 4 presents satisfaction data. In general, participants viewed *DBI* in a positive light. They found it relatively easy to navigate (Q. 1-2). In addition, they were moderately to extremely satisfied with the selection, amount, quality and sequencing of the content (Q. 3-5); very to extremely

satisfied with the page design and images (“look and feel”) (Q. 7-8); moderately to extremely satisfied with the clarity of the written content (Q. 9-11); very to extremely satisfied with the two types of video presentation (Q. 12-13); and moderately to extremely satisfied with the links, book reviews and journal summaries (Q. 14-16). Concerning the practicality of taking an online course, given the demands facing a parent of a child with ASD, participants reported being extremely satisfied that they could to complete the course and do so at their own pace (Q. 17). Further, 58% were extremely satisfied that the module was easy to fit in their schedule (Q. 18). Finally, participants were moderately to extremely satisfied that they were better prepared to work with their child’s team, teach their child, and understand if not manage their child’s challenging behavior (Q. 19-21).

Question	Un-satisfied	Somewhat satisfied	Moderately satisfied	Very satisfied	Extremely satisfied
1. Was module easy to navigate?	0	10	16	32	42
2. Was module always available?	0	5	0	32	63
3. Did content meet your needs?	0	5	37	37	21
4. Was information adequate?	0	0	21	47	32
5. How was quality of information?	0	5	5	64	26
6. Was information logical, orderly?	0	5	11	42	42
7. Was page design appealing?	0	5	11	37	47
8. Did images enhance content?	0	0	16	47	37
9. Was language understandable?	0	0	21	37	42
10. Was written content useful in helping you to understand ABA?	0	5	5	58	32
11. Did “questions to consider” help you learn more?	0	5	42	11	42
12. How useful were the teaching video clips of “Kim and Ryan?”	0	10	11	37	42
13. How useful was the video interview with the mother?	0	0	5	84	11
14. Did links to web sites increase your understanding of ASD, ABA?	0	0	10	58	32
15. Were the book reviews useful?	0	0	21	16	63
16. Did journal summaries help you to learn about current research?	0	0	21	16	63
17. Was it helpful to go at your own pace?	0	0	5	11	84
18. Was this easy to fit into your schedule?	0	5	16	21	58
19. Do you feel better prepared to meet with your IFSP/IEP team?	0	15	37	37	11
20. Are you better prepared to teach your child new skills?	5	0	32	37	26
21. Are you better prepared to respond to challenging behavior?	0	1	32	32	21

Table 4: Percent of participants satisfied with course design and content at each of five satisfaction levels.

When asked how long it took them to complete the course, 74% of participants reported that it took 6 hours or less, 11% reported 7-9 hours, 11% reported 10-12 hours and 5% reported more than 12 hours. Finally, participants responded to the open-ended queries, “What advice do you have for the course developers? How could the course be improved? Feel free to comment on any aspect: technology, content, instructional features, etc.” Here is a set of representative verbatim comments:

“I have read much information on behavioral interventions, but I have to say that this is the best course that has helped me to understand the different options for my child. I thank you for allowing me the opportunity to take this course. I hope you know that this course is and will make a difference in my child’s future. Thank you.”

“So many parents of lower income or single - parent challenges have very little time or energy to physically attend a class, so this [course] makes it much easier. That said, there is of course a great percentage of parents who do not have access to this type of online wonder for lack of a computer. Would it be possible to make this course available at public libraries where people of limited financial means could use the computers AND consult the materials you sited? I truly believe that would be a major step in the right direction.”

“I wish that I would have had access to this information 18 months ago when I was plunged into the world of ASD and began the frantic effort of becoming an expert on my child...The video clips themselves were very insightful and as the mother of a nearly five-year-old little boy, especially poignant. Your course should be required reading for families immediately after the diagnosis of ASD is received.”

“I would have liked to see video for the Pivotal Response Training, examples of normalized teaching when out and about (i.e. at the grocery store, a play date, a birthday party, household teamwork) as a generalization technique, the use of activity schedules, Positive Behavior Support use, functional assessment.”

“All outcomes and examples were positive in outcome. There was no advice/support for parents who may have/are trying these techniques and they aren’t working. A bit more emphasis/advice for problem solving might be very helpful.”

DISCUSSION

This small-scale evaluation suggests that an online introductory course in ABA, designed specifically for parents of children with ASD, and as a “stand-alone” course (i.e., not supported by an online instructor), was practical for parents to complete, resulted in significant knowledge acquisition and met with high levels of satisfaction. The data we collected has guided us to undertake development and evaluation of a more comprehensive 10-course *DBI* curriculum, which is currently underway. Our hope is that this complete curriculum, once tested with a larger and more diverse sample, and modified accordingly based on feedback, such as the feedback reported in this study, will help educate and support parents when they receive the diagnosis of autism and search online for credible, understandable information. We also hope that it will assist personnel who work with parents by providing them with a resource they can recommend to them, one that will enhance parents’ participation in treatment decisions and planning, and help them participate more directly in implementing behavioral interventions.

There are a number of limitations in this evaluation. The demographics of this convenience sample point to the need to more actively involve members of diverse racial

and ethnic communities, and fathers, in further testing of *DBI*. African American families tend to access special services and seek professional guidance less frequently than European Americans, instead relying more heavily on family, friends and religious groups (Wilder, Dyches, Obiakor & Algozzine, 2004). A similar pattern has been shown to exist with Latinos (Bailey, Skinner, Rodriguez, Gut & Correa, 1999). Aspects of *DBI* as currently designed may need to be modified based on cultural differences, and it may or may not prove to be as popular an approach in general as it was with the participants in this project.

Research with fathers of children with ASD has demonstrated that when they received training in ABA, they learned and effectively implemented child-teaching skills, which in turn increased their children's initiations and vocalizations (Elder, Valcante, Yarandi, White and Elder, 2005). Elder et al (2005) noted both the lack of research on father-child interactions in ASD and the potential for positive paternal influence on child development. In a subsequent retrospective study using their same data set, Seung, Ashwell, Elder and Valcante (2006) further demonstrated the efficacy of selected father-child and mother-child interactions, finding significant post-training differences in the ratio of utterances of parents and children during play.

Regarding parents' goals, 81% of the participants were interested in more advanced information on ABA and related advocacy skills. As noted, we are currently developing and testing more advanced courses in the *DBI* curriculum. Whereas the current introductory module might have been too easy for some participants, given their average 19.7 months of experience with ABA, parents at all experience levels appear to have had much to learn, and they did so, as evidenced by their pre-test versus post-test scores. Still, the group post-test mean of 85.2% suggests that there was room for more knowledge gain. When we reviewed participants' time spent on each page we found that many did not spend what we would consider sufficient time to learn the more complex material. This can be resolved by requiring successive completion of course sections using short, embedded mastery quizzes. The downside to this design choice is that it would restrict flexible movement in and around the course, which is a feature our focus group participants suggested was highly desirable.

It should be emphasized that *DBI* is a knowledge-oriented course; it is not meant to replace hands-on training by a behavior analyst or other skilled ABA provider. Rather, *DBI* is designed to help parents become more knowledgeable about ABA, which in turn might support their participation in decision making and advocacy about their child's programs, and *perhaps* better prepare them to learn from hands-on training and participate effectively in their children's ABA programs. Current work on the full *DBI* curriculum is incorporating even more interactive media exercises that may help move parents further along the continuum from knowledge to application. These include interactive graphic objects (case studies with decision-making branches and feedback, click and drag exercises to teach challenging concepts, etc.) and interactive video in which parents can test skills such as giving positive reinforcement, or using and fading prompts, by clicking directly on running video and receiving immediate feedback. Advances in affordable media options make such interactivity readily available for online course developers. Research on the extent to which parents are better prepared to transfer these kinds of online experiences to actual face-to-face practice is sorely needed. For example, it would be interesting to know how parents who take a course like *DBI*

perform in actual advocacy-related communications with behavior analysts and other professionals, and in IFSP and IEP meetings. Likewise, will completing video simulation exercises on the use of ABA teaching-skills in the home result in some level of skill development and transfer?

In conclusion, the formative evaluation, design and development activities, and summative field evaluation results for *DBI* suggest that online coursework in behavioral intervention for parents of children with autism may prove to be an effective tool for them, and perhaps for early intervention staff charged with providing ABA. Parent-professional collaboration may be enhanced, which may lead to improved child outcomes. Professional use and further research on *DBI* or related online educational products will determine its effectiveness.

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