

**ADVOCACY AMONG PARENTS OF CHILDREN WITH AUTISM**

by

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A thesis submitted to the Faculty of the University of Delaware in partial fulfillment of  
the requirements for the degree of Master of Arts in Communication

Summer 2013

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## **ACKNOWLEDGEMENTS**

I would like to extend my sincerest appreciation to my advisor, Dr. John Courtright, for the endless contributions he made to this project: cultivating my love for the theory of planned behavior, fine-tuning my APA formatting, and everything in between. Thank you for supporting me in pursuing a project that I cared so deeply about, even if it wasn't the easiest road.

To my committee, Dr. Scott Caplan and Dr. Paul Brewer, thank you for your seamless transitions between patience and haste throughout the course of this project. I truly appreciate your unique perspectives and continued support.

I owe many thanks to the Delaware Autism Program, especially James Osgood and The Brennen School, for going above and beyond to make sure that I could see this project through to the end. Of course, I would be remiss not to formally thank the parents and guardians who participated in this study. I sincerely hope that this research will eventually make a tangible and positive difference for you and your children.

To my cohort, thank you for making me laugh so hard for the past two years that I forgot to cry. I could not have handpicked a more weirdly perfect support group. A special thank you to my roommates, Amanda and Chrissy, for dealing with a dining room full of papers and for offering to take my survey 100 times if no one else did. (Don't worry; it didn't come to that).

Finally, a very special “thank you” to my family, who is always my biggest source of support. John, the family I chose for myself, thank you for your constant positivity. Even when I say I don’t want to hear about the silver lining, I really do. Kelli, my sister and my rock, thank you for being a daily source of support, even from 300 miles away. And to my dad, Jimmy, to whom I promised my first book dedication... how’s this?

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## **ABSTRACT**

The purpose of this study was to examine the determinants of advocacy among parents of children with autism. Existing research related to parental involvement in the autism community has been largely qualitative and/or without a theoretical basis. This study utilized the Theory of Planned Behavior (TPB) to predict and explain parents' intentions to communicate with school staff and to attend autism advocacy event based on their attitudes, social norms, and perceived behavioral control. Respondents included 86 parents of children enrolled in the Delaware Autism Program (DAP), a highly specialized program dedicated exclusively to educating those on the autism spectrum. The survey was available between March 25, 2013 and June 1, 2013; 19 parents returned paper surveys while 67 completed an online version. A multiple regression analysis revealed that past behavior, subjective norms and perceived behavioral control predicted communication and attendance intentions. Attitude was an additional predictor of intention to attend an event. A paired t-test revealed that parents are more likely to communicate about their child than they are to attend an event to benefit the larger autism community. Pearson correlations revealed additional relationships, including a relationship between past advocacy experience and current attitudes toward advocacy. This study adds to autism research, advocacy research, and research expanding applications of the TPB.

## Chapter 1

### INTRODUCTION

#### **Purpose**

Parental advocacy is a critical issue within the autism community. On the individual level, research has consistently identified parental advocacy in the education process as imperative to the success of children with autism. On the more traditional community level, advocacy can increase awareness and funding for autism, which influences the available resources for children with autism and their parents. This study will examine behaviors on both levels.

Despite evidence that demonstrates the importance of parental advocacy, involvement on both levels is unpredictable among parents of children with autism (Fish, 2000; Spann, Kohler, & Soenksen, 2003; Stoner, et al., 2005). A substantial amount of research has assessed the advocacy process, but a systematic examination of the factors that determine whether a parent chooses to advocate does not exist. Furthermore, the studies that do attempt to investigate these factors do so qualitatively or in the absence of a guiding theory or model.

This study will examine what factors determine whether a parent of a child with autism advocates for his or her child within the autism community. The study will use the theory of planned behavior (TPB; Ajzen, 1991), which posits that individuals' behavioral, normative, and control beliefs predict their intention to behave and – ultimately – their

behavior. The purpose of this study is to understand what predicts parental advocacy within the autism community as a means of collecting valuable information for *that* community as well as for the academic community.

By clarifying what deters a parent from advocating for his or her child, we have the potential to eliminate that barrier. For example, in response to an increasing amount of litigation between parents of children with autism and school districts, legal strategy training emerged within the autism community (e.g., The Elizabeth Birt Center for Autism Law & Advocacy). A better understanding of parental concerns may enhance existing resources or guide the development of additional provisions for addressing unmet needs.

Additionally, this study would add significantly to existing academic research. Thus far, there is no theoretically grounded research that examines the advocacy behaviors of parents with children on the autism spectrum. In fact, individual behaviors relating to any type of advocacy are largely absent from the literature. This study also serves to extend the applicability of the TPB itself, which traditionally focuses on health behaviors related to the “self” and not an “other.”

Finally, this study informs communication research in several ways. First, the study is grounded in the TPB, which can serve as formative research for and guide communication campaigns designed to change behavior (Rutter, 2000; Armitage and Conner, 2002; Hardeman et al., 2002). Many studies have utilized the TPB to assess the effectiveness of existing interventions, while others have used it to guide the development of new campaigns (Stead, 2005).

The present study also addresses communication in terms of the target behavior. Although the community-level advocacy behavior reflects parental involvement in the autism community more generally, the individual advocacy behavior specifically addresses communication between parents and educators. Because autism is a pervasive communication disorder, this line of communication is especially important (Stoner, et al., 2005). The significance of communication effectiveness between home and school is echoed throughout the literature (e.g., Kohler, 1999; Lake & Billingsley, 2000; Boutot, 2007), and this study will add to that body of research.

## **Rationale**

Why autism? According to the National Institute of Health, autism is a very active area of research because it involves many unanswered questions, including what causes it and how many people are actually affected. Autism Spectrum Disorder (ASD) is a cluster of lifelong neurodevelopmental disorders evidenced by “persistent deficits in social communication and social interaction across contexts” and “restricted, repetitive patterns of behavior, interests, or activities” (Autism Spectrum Disorder, 2011). The Centers for Disease Control (2012) estimate that 1 in 88 children are on the autism spectrum, a 20 percent rise in diagnoses over a two-year period.

Although the most recent statistics showed a sharp increase in diagnoses, the number has been on the rise for more than a decade. The rise in diagnoses has been met with more fervent lobbying for effective treatment, including increased parental advocacy and involvement (Mulick & Butter, 2002). Children with autism have very extensive and unique needs—needs that the literature suggests are often unmet on multiple levels,

ranging from initial screening to continued access to appropriate health care and education (Mulick & Butter, 2002; Kasari & Rotheram-Fuller, 2005; Hillman, 2006; Kogan, et al., 2008).

Before understanding the more specific individual and community advocacy needs within the autism community, we must understand the conceptualization of advocacy within this study. As discussed, this study will focus on advocacy in two contexts. The first is individual advocacy, which focuses on a parent representing the specific needs of his or her child, particularly in an educational context. The specific behavior addressed in this study is: “Communicating with your child’s teacher(s) and/or service team within the next week.” The second is community advocacy, which reflects a parent’s involvement in the larger autism community. This definition reflects a variety of specific behaviors typical of involvement in a cause (e.g., donating money, participating in an event, signing a petition). The specific behavior will be: “Attending an event sponsored by an advocacy organization (e.g., Autism Delaware) within the next three months.” These behaviors are meant to represent a moderate level of advocacy on the individual and community level.

The inclusion of these particular behaviors is not unfounded. On an individual level, the literature overwhelmingly demonstrates the importance and inconsistency of the involvement of parents in the education process. According to Stoner and Angell (2006, p. 178), “the interaction between parents of children with autism spectrum disorder (ASD) and education professionals is a critical issue.” Despite its importance, this type of advocacy is inconstant among parents. Some literature addresses why this

might be the case (e.g., Fish, 2000; Spann, et al., 2003; Stoner, et al., 2005), but none has used a theoretical framework. Much of the extant research is qualitative, which is extremely useful in terms of highlighting important themes. However, a systematic analysis of factors that have emerged through this research will add a great deal to the literature.

In terms of community advocacy, Autism Speaks (2012) reported that these kinds of efforts have aided in making autism screening more accessible, among other successes. According to their website, Autism Speaks is “the nation's largest autism science and advocacy organization” (“Autism Speaks,” 2012). The autism community is concerned with a wide variety of issues that require the support of individuals. For example, the site has links for individuals to donate money, participate in events, and become politically involved. Advocacy issues include health insurance, education opportunities, treatment, and a wide variety of research that could benefit individuals with autism and their families. Despite the important implications of this type of involvement, there is virtually no research that specifically examines community advocacy in support of autism.

Furthermore, extant literature suggests that children with autism and their families face exceptional issues that make parental advocacy, at once, more necessary and more difficult (Landau, 1996; Dunlap & Fox, 1999; National Research Council, 2001; Allik, Larsson, & Smedge, 2006; Schieve, et al., 2007; Schaaf, et al., 2011). For example, Kogan and his colleagues reported that, “Children with special health care needs with autism spectrum disorder are significantly more likely to have problems regarding access to care and unmet needs, and their families have greater financial, employment, and time

burdens compared with other children with special health care needs” (2008, p. 1149). Although existing research alludes to these stressors as potential barriers to parental involvement (Bennett, 2012), none has explicitly examined this relationship.

As such, the importance of what specific factors might determine whether a parent chooses to take on the additional responsibility of advocating for his or her child cannot be overstated. Although research has acknowledged that explicit determinants may impact if and in what ways a caregiver is involved in the autism community (Mandell & Salzer, 2007), this body of literature is largely unexplored. The TPB is designed to predict and explain human behavior in terms of specific, determinant factors, which makes it the most appropriate theoretical framework for the current study.

Generally, TPB offers several notable advantages to this type of research that other theoretical frameworks do not. Most importantly, TPB is a belief-based model, which allows researchers to understand the underlying perceptions of those who do and do not intend to perform a certain advocacy behavior. The TPB posits that an individual’s intention to behave predicts behavior. This intention is a function of attitude toward the behavior, subjective norms surrounding performance of the behavior, and the individual’s perceived behavioral control (i.e., the individual’s perceived ability to perform the behavior).

The TPB is an extension of the theory of reasoned action (TRA; Fishbein & Ajzen, 1975), which only included the first two components. Recent meta-analyses have revealed that the components of TPB account for almost half of the variance in intentions to behave, and for only slightly less variance in behavior (e.g., Armitage & Conner,

2001). Research pertaining to health communication has been successful in utilizing TRA and TPB models to promote and influence healthy behaviors, such as eating well, exercising, using sunscreen, getting regular mammograms, etc. According to both theories, each component is a product of relative beliefs. According to Ajzen (1991, p. 189), “People can hold a great many beliefs about any given behavior, but they can attend to only a relatively small number at any given moment.” These *salient beliefs* are considered to be the prevailing determinants of a person’s intentions and actions.

Attitude reflects the totality of a person’s salient beliefs that performing a behavior is associated with certain outcomes (i.e., behavioral beliefs) and an evaluation of each of those outcomes. A great deal of literature suggests that many parents hold a surprisingly negative evaluation of the educational advocacy process, particularly its outcomes (e.g., Fish, 2000; Spann, et al., 2003; Stoner, et al., 2005). As such, a parent’s attitudes toward advocacy behaviors may play an important part in predicting his or her willingness to advocate.

Subjective norms reflect beliefs about whether important others think the individual should or should not perform advocacy behaviors (i.e., normative beliefs), as well as the motivation to comply with those important others. Such norms may be important in several contexts. For example, some parents believe that educators do not want their input or involvement (Fish, 2000). On the other hand, parents may feel a sense of social pressure to advocate if they believe family or friends perceive it as a desirable behavior.

Perceived behavioral control (PBC) refers to a person's beliefs about the ability to perform the behavior (i.e., control beliefs). Perceived behavioral control reflects an individual's beliefs that certain factors will be present and the perceived power of those factors to inhibit or facilitate the behavior. According to Ajzen (2002, p. 7), items measuring PBC "are often said to capture the respondent's sense of self-efficacy with respect to performing the behavior." This will likely be an interesting component in examining parental advocacy in the autism community, where resources such as time and money are often an issue (Kogan, et al., 2008). In fact, several studies explicitly examine autism and parental self-efficacy in some sense (Sofronoff & Farbotko, 2002; Hastings & Brown, 2002; Kuhn & Carter, 2006). According to the theory, PBC can predict both intentions to behave and actual behavior (Ajzen, 1991).

## **Literature Review**

### **Need for Parental Advocacy**

**Individual advocacy.** Because there is no proven cure for autism, "the goal of treatment is to improve the overall functional status of the child by promoting the development of communication, social, adaptive, behavioral, and academic skills as well as lessening maladaptive and repetitive behaviors" (Woodgate, Ateah, & Secco, 2008, p. 1075). Thus, educational services have become the focus for those in the autism community, both in literature and legislation. The importance of parental involvement and the relationship between parents and educators has been the focus of an increasing amount of literature, which will be reviewed in depth later.

The need for parental advocacy in the education of children with autism also sparked legislation. One of the primary focuses of the Individuals with Disabilities Education Act (IDEA) legislation is promoting and facilitating the role of parents in the education process. In fact, the most recent amendments (1997) to IDEA mandate parents' right to involvement in developing their child's individualized education program (IEP). According to the U.S. Department of Education, IDEA "is a law ensuring services to children with disabilities throughout the nation. IDEA governs how states and public agencies provide early intervention, special education and related services to more than 6.5 million eligible infants, toddlers, children and youth with disabilities" (idea.ed.gov).

In general, parental involvement has a positive impact on educational success (Eccles & Harold, 1993; Newmann & Wehlage, 1995; Spann, et al., 2003), particularly in the cases of children with special needs (Koegel, Koegel, & Schreibman, 1991; Spann, et al., 2003). However, despite consistent evidence of its importance, parental involvement remains inconsistent. One example of this is in examinations of parental involvement in IEP meetings.

According to Fish (2000), "Parental roles have not increased in IEP meetings" despite the IDEA mandates (p. 56). Other studies reported that parents who do attend IEP meetings "often have no involvement in developing objectives, interventions, or methods of evaluation" (Spann, et al., 2003, p. 228). For example, Lynch and Stein (1982) reported that, of 400 parents surveyed, 71 percent reported involvement in the meeting, but only 14 percent offered specific opinions. This is concerning because a lack of parental participation in the IEP process has potentially resulted in "legally inappropriate

and educationally unsound” programs for the children of those parents (Fish, 2000, p. 56).

**Community advocacy.** The literature also demonstrates the need for advocacy on a community level. According to McGuire (2011), “Autism advocacy groups have taken on a more prominent and powerful role in North American society and thus have been influential in shaping public understandings of autism through awareness campaigns, fundraising appeals, and so on” (p. 62). Most often, the idea of advocacy is considered on a large scale, such as in Jenkins’ (1987) definition: “[Advocacy is] any attempt to influence the decisions of an institutional elite on behalf of a collective interest” (p. 297). Similarly, Wallack, Dorfman, Jernigan, and Themba (1993) suggested that advocacy should focus on public health goals.

However, these macro-level definitions of advocacy fail to address the individual behaviors that contribute to the success of such campaigns (e.g., donating, participating in an event, signing a petition). If we are able to combine and define these individual behaviors as “advocacy,” we have the potential to enhance our explanations and predictions of what factors determine individuals’ intention to advocate for a cause. Understanding advocacy in this individualistic sense is critical, because the realization of social and political health goals is most often preceded by a movement of activism and advocacy at the individual level.

Koren, Dechillo, and Friesen (1992) cite several levels at which advocacy occurs, including the service system and the community. Service system “primarily involves the parent's actively working . . . to get services that are needed by his or her child” (p. 308),

which is similar to the individual advocacy discussed earlier. Community or political involvement focuses on “the parent's advocacy for improved services for children in general, rather than specifically for her/his own child” (p. 308). This most closely reflects the community advocacy discussed here.

As in the case of individual advocacy, the literature suggests parental involvement in community advocacy varies. For example, Stoner and Angell (2011) interviewed four couples who had a child with autism and found that “the role of advocate varied among participants,” but that “these advocacy efforts did not focus solely on their own children” (p. 185). For example, one parent in the study served on the boards of several autism organizations. One mother volunteered in her son’s classroom and two other mothers were involved in an outreach program for parents of newly diagnosed children.

Zaretsky’s (2004) results reflected a different perspective of parental advocacy in a study investigating the interaction between the elementary school principals and parent advocates. The results of the interviews reported that “most principals expressed their concern with some parent advocates’ solitary focus on the individual needs of the students they were representing without regard for other students’ needs in the school” (p. 277). Zaretsky noted that this finding was consistent with previous research (Kalyanpur & Harry, 1999; Vincent, 2000).

In general, the research suggested that, “Once parents were able to achieve desired outcomes for their own children, they were subsequently likely to develop a further interest in supporting other parents with similar struggles in schools” (Zaretsky, 2004, p. 277). However, research in this area is largely underdeveloped. In fact, Stoner

and Angell (2011) noted that additional research focused on the role of parents is necessary, particularly in terms of “levels of advocacy among parents of children with all disabilities” (p. 185). The current study adds to such research.

### **Barriers to Parental Advocacy**

Thus far, the literature presented has established the importance of parental advocacy and the inconsistency of this type of involvement. The following section focuses on the barriers that exist for parents that might discourage participation, as demonstrated in previous research. First is a lack of access to appropriate resources and services. Second is a negative parental perception of the advocacy process, including feelings of confusion and helplessness. The final barrier consists of the wide range of personal and family issues associated with having a child with autism, including higher levels of stress, health issues, and a significant strain on time and money.

**Access to services.** Woodgate, Ateah, and Secco (2008) recruited 21 parents from 16 families from a support group and interviewed them about their experiences as a parent of a child with autism. The authors identified an “inaccessible system,” “unsupportive professionals,” and “inappropriate resources” as primary concerns of those within in the sample (p. 1079). These concerns are echoed throughout the literature. McWilliam et al. (1995) asked 539 parents about their satisfaction with early intervention services and found that parents had issues accessing services. Additionally, families indicated that they were not given choices and did not receive services that they requested.

Fish (2000) interviewed seven families with a child or children with autism who attended public schools. The goal of the study was to compare “experiences between satisfied and non-satisfied parents towards IEP meetings” (p. 59). All of the participants indicated that their “overall initial IEP experiences had been negative” (p. 61). Five out of seven participants reported disagreeing with educators regarding appropriate services for their children. Parents also indicated that educators perceived them “as being unreasonable due to requesting services that school districts believed to be unnecessary or too expensive” (p. 61). Stoner, Bock, and Thompson (2005) reported similar results. They conducted a collective case study of four sets of married parents who had a child with autism. Parents reported difficulty obtaining necessary services, including proper placement, classroom assistance, and speech and language services.

Kohler (1999) surveyed 25 families recruited from four separate agencies: two private schools for children with autism and two “wrap-around service” providers (p. 151). The survey was based on a review of the literature, but was not grounded in any specific theory. According to Kohler (1999), 40 percent of families reported difficulty in accessing services and 40 percent reported needing “greater allotments of existing services” (p. 155). Sixty percent reported communication problems with agencies. Similarly, Dunlap, Robbins, and Darrow (1994) reported that the majority of the 78 families that they surveyed in their study found that resources for their children with autism were limited and/or not useful.

**Negative perceptions of advocacy.** In addition to accessing appropriate services, parents of children with autism expressed other concerns with the educational advocacy

experience. One notable concern is the parents' inability to understand the educational advocacy process. This is demonstrated in literature that focuses on parental experiences (e.g., Goldstein, 1993; Lytle & Bordin, 2001; DiGregorio, Hixson, Stoff, & White, 1992; Kalyanpur & Harry, 2004), as well as in the autism community's call for advocacy training. According to Fish (2000, p. 57), "Many parents feel ill-equipped to address the educational needs of their children," which leaves them at a disadvantage. The parents in Fish's study "expressed a need for making special education law and IEP meetings easier to understand" (p. 64). Parents in the study by Stoner, et al., (2005) reported having "traumatic" experiences entering the special education system (p. 44). All of the parents interviewed recalled being confused in initial IEP meetings.

Participants in Fish's (2000) study suggested that school districts could "improve IEP meetings by educating parents about the IEP process," including formal training and workshops (p. 64). Bradford (2010) concluded that parents "may benefit from professional support in identifying and insisting on services from the school" (p. 153). In response to their findings, Stoner, et al., (2005) recommended "providing training to parents that will facilitate an understanding of ASD and special education services" (p. 48). Additionally, many autism organizations, websites, and support groups encourage and/or offer training for parent advocates.

In addition to struggles understanding the overall process, many parents of children with autism have also indicated other negative evaluations of advocacy experiences. One common theme is "tension" or otherwise poor communication between parents and educators (Lake & Billingsley, 2000; Stoner, et al., 2005). This often results

in parents feeling that their role is undervalued. According to Fish (2000, p. 58), “Due to parental perception of unequal status, many parents may become discouraged from becoming actively involved in their child's education,” while others try to level the field through litigation.

Lake and Billingsley (2000) examined factors that contribute to conflict between parents and schools in special education. This study uniquely involved a diverse sample of parents ( $N = 22$ ), school officials ( $N = 16$ ), and conflict mediators ( $N = 6$ ). Their findings included negative perceptions of communication among parents and school officials as a factor that escalated conflict (p. 246). Ninety percent of participants in the study cited “discrepant views of a child or a child’s needs” as a factor in escalating conflict. This primarily referred to parents’ frustration with the way school officials spoke about their child (p. 244).

As these studies demonstrate, parents of children with autism or related disabilities reported inadequate services and difficulty in obtaining those services (Dunlap, Robbins, & Darrow, 1994; Kohler, 1999; McWilliam, Young, & Harville, 1995). Research also reflected dissatisfaction with the process and/or outcome of educational advocacy efforts (McWilliam, et al., 1995; Covert, 1995; Kohler, 1999; Turnbull and Ruef, 1997). This suggests that parents may hold overall negative attitudes about the advocacy process and/or a lack of perceived behavioral control over their involvement.

**Personal factors.** There is a fair amount of literature that addresses the well-being of families with children on the autism spectrum. Many of the common issues that

parents of children with autism face would be understandable barriers to substantial parental involvement. However, there is a void in research that draws empirical links between family issues and parental advocacy. These factors, reviewed here, would be easily elicited through the TPB model. Namely, many of these issues may impact a parent's perceived behavioral control.

Silos and Kerns (2006) reported that 93% of parents of children with autism ( $N = 56$ ) indicated that they were not receiving adequate financial support for their child's therapies. Although this study was conducted outside of the United States, these concerns are abundant in the literature. Kogan, et al. (2008) used data from the 2005-2006 National Survey of Children with Special Health Care Needs to compare children with autism ( $N = 2088$ ) to children with "other emotional, developmental, or behavioral problems" ( $N = 9534$ ) and other children with special health care needs ( $N = 26,751$ ). Overall, results reported that "the financial and time impacts on the family from ASD seemed to be significantly greater" than impacts on families of children with other disabilities (p. 1151). These results held true after a logistic regression controlling for sociodemographic differences, the child's level of functioning, and health insurance coverage. Financial and time burdens in families of children with autism are consistent throughout the literature (e.g., Sperry, Shaw, & Brame, 1999; Mulick & Butter, 2002; McCabe, 2007; Bennett, 2012; Solomon & Chung, 2012).

Additionally, Gray (1994) reported financial burdens on families that were unique to children with autism. For example, according to interviews, one family designated an area of the house as a "wrecking corner" for their daughter because of her destructive

tendencies. The mother “wished for a larger house in which her daughter could have a room to damage unchecked, but the family's limited finances made this impossible” (p. 282). Other families reported spending “a substantial amount of their financial resources on obtaining care” (p. 294).

These factors may influence involvement. For example, Mandell and Salzer (2007) surveyed 1,005 caregivers of children with autism to determine what factors were associated with participation in support groups. They found that “support group participants are more likely than non-participants to be middle income and well educated,” which might reflect “greater resources and time” for such involvement (pp. 116-117). This may translate to other types of involvement, including increased advocacy. Benson et al. (2008) conducted a study specifically to determine what factors contributed to the early intervention involvement of 95 mothers of children with autism. Some mothers reported they did not have the time or energy to be involved in their child’s education at home, which suggests that additional advocacy efforts would be unlikely.

In addition to financial and time constraints, families of children with autism also experience higher levels of stress and burden than parents of children without disabilities (Allik et al., 2006; Woodgate, Ateah, & Secco, 2008; Schaaf, et al., 2011). In fact, a great deal of literature specifically examines stress in parents of children with autism. Many times, this stress is directly related to certain behaviors or symptoms common to autism and the severity of those symptoms (Tomanik, Harris, & Hawkins, 2004; Lee, et al., 2009; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). In some cases, parents

of children with autism may even experience negative outcomes to a greater extent than parents of children with other disabilities (Mandell & Salzer, 2007).

In sum, the literature suggests that children with autism and their families face exceptional issues that make parental advocacy simultaneously more necessary and more difficult (Landau, 1996; Dunlap & Fox, 1999; National Research Council, 2001; Allik, Larsson, & Smedge, 2006; Schieve, et al., 2007; Schaaf, et al., 2011). For example, Kogan and his colleagues reported that, “Children with special health care needs with autism spectrum disorder are significantly more likely to have problems regarding access to care and unmet needs, and their families have greater financial, employment, and time burdens compared with other children with special health care needs” (2008, p. 1149).

As a result, the importance of what specific factors might determine whether a parent chooses to take on the additional responsibility of advocating for his or her child cannot be overstated. Although research has acknowledged that explicit determinants may impact if and in what ways a caregiver is involved in the autism community (e.g., Mandell & Salzer, 2007; Bennett, 2012), this body of literature is largely unexplored. In fact, Benson et al. (2008) found no research examining the factors that play a role in how involved parents of children with autism are in the early intervention plan.

Thus, identifying specific factors that determine whether a parent advocates for their child and/or in the autism community is a critical but underdeveloped area of research. The TPB allows for a quantitative examination of the themes that have surfaced in existing literature as potential barriers to parental advocacy. Furthermore, the efficacy

of the TPB in guiding interventions holds potential for addressing concerns on a practical level.

### **Theory of Planned Behavior**

This section will provide an overview of the theory of planned behavior (TPB; Ajzen, 1985; 1991) and its components, as well as a review of literature that has used TPB as a theoretical framework. The theory of reasoned action (TRA; Fishbein & Ajzen, 1975) and theory of planned behavior are thorough, longstanding theories of persuasion which are designed both to predict and causally explain individuals' behaviors in given contexts. Researchers have been applying these theories both academically and practically with success since they were introduced, particularly in the health communication field.

**Overview of the theory.** To understand the role of the TPB in health communication, we need to first examine the general model proposed within the theory. Fishbein and Ajzen (1975) developed the theory of reasoned action amidst research that was failing to find strong correlations between general attitudes and behaviors. Fishbein and Ajzen (1975) suggested that an individual's behavior is best predicted not by attitudes, but by his or her intention to perform that behavior. According to the theory, these intentions can be predicted by an individual's attitude toward the behavior and by the perceived social norms (how relevant, important others would want him or her to behave). The TPB includes perceived behavioral control as an additional predictor of intentions, as well as a direct predictor of actual behavior. In combination, these three components lead to the formation of a behavioral intention.

Importantly, the TPB accounts for the relative weight of each of these determinants, which allows researchers and practitioners to understand what information is most important in influencing a given population's intentions to perform a certain behavior or set of behaviors. According to Ajzen (1991, p. 188), "The relative importance of attitude, subjective norm, and perceived behavioral control in the prediction of intention is expected to vary across behaviors and situations." The relative importance or weights of each component are calculated using regression analyses. When a multiple regression analysis is conducted, the standardized regression coefficients associated with each predictor reflect the relative importance of each determinant on intention to behave.

Within the TPB, these three components "follow spontaneously and reasonably" from relevant beliefs (Ajzen, 2011, p. 77). Although the components and relevant beliefs were overviewed earlier, they will be discussed in more depth here. Attitude toward the behavior is a function of beliefs about the likelihood of potential outcomes of the behavior and an evaluation (positive or negative) of those outcomes. According to Ajzen (2011), "The positive or negative valence of each outcome contributes to the overall attitude in direct proportion to the subjective probability that the behavior will produce the outcome in question" (p. 76). For example, a parent might believe it unlikely (subjective probability) that requesting additional services for his or her child (the behavior) will enhance the child's educational experience (a positive outcome). The same parent may believe it's extremely likely that requesting those services would result in conflict with the school (a negative outcome). Following from Fishbein and Ajzen's (1975) Expectancy-Value Model, this parent would hold a slightly negative attitude of

requesting services from the school. In brief, the sum of the value of each belief about the behavioral consequences multiplied by the value of its evaluations reflects an individual's overall attitude.

$$A \propto \sum_{i=1}^N b_i e_i$$

where  $A$  is the attitude toward performing the behavior;  $b$  is the belief that performing the behavior leads to outcome  $i$ ;  $e$  is the person's evaluation of outcome  $i$ ; and  $N$  is the number of beliefs the person holds about performing the behavior.

Subjective norms are quantified in a parallel fashion. Normative beliefs reflect a person's estimation of the likelihood that a certain individual or group would approve or disapprove of performance of the behavior. These beliefs are considered in conjunction with the individual's motivation to comply with a given referent (i.e., how important or unimportant the referent's opinion is to the individual). Thus, if the people with whom a person is motivated to comply evaluate the behavior negatively, the individual in question will likely be less inclined to perform the behavior.

Many researchers have questioned the strength of the normative component (e.g., Armitage and Conner, 2001), and others have adapted the measure (e.g., including moral norms or group norms). This study will measure subjective norms using two types of items: what important people *think* a person should do (*injunctive* norms) or what important people *actually* do (*descriptive* norms). Ajzen (2002) posited that these measures can "offer a 'snap shot' of perceived normative pressures in a given population" (p. 12). In brief, the sum of the value of normative beliefs multiplied by the value of motivation to comply reflects an individual's overall subjective norm.

$$SN \propto \sum_{i=1}^N n_i m_i$$

where SN is subjective norms;  $n$  is the normative belief (i.e., the person's belief that reference group or individual  $i$  thinks he should or should not perform the behavior);  $m$  is the motivation to comply with referent  $i$ ; and  $N$  is the number relevant referents.

Finally, perceived behavioral control is based on control beliefs, which are concerned with factors that can either help or hurt the individual's ability to perform the behavior in question. According to Ajzen (2011), "Control factors include required skills and abilities, availability or lack of time and money, cooperation by other people, and so forth" (p. 77). As the autism literature will demonstrate, these are likely to be especially relevant factors in determining a parent's intention to advocate for his or her child. Control beliefs reflect the perceived likelihood that a factor – either facilitating or inhibiting – will be present. Each belief contributes to perceived behavioral control "in direct proportion to the factor's perceived power to facilitate or impede performance of the behavior" (Ajzen, 2011, p. 78). Further discussion of the quantification of TPB constructs will be included in the discussion of this study's methods. In brief, the sum of the value of each control belief multiplied by the value of its power reflects an individual's overall perceived behavioral control.

$$PBC \propto \sum_{i=1}^N c_i p_i$$

where PBC is perceived behavioral control;  $c$  is the belief that control factor  $i$  will be present;  $p$  is the power of factor  $i$  to facilitate or impede performance of the behavior; and  $N$  is the number of control factors.

**Efficacy of the theory.** There is a great deal of empirical support for the predictive power of the model outlined above. In the most recent meta-analysis of the TPB (McEachan, et al., 2011), the three components of the theory accounted for 44 percent of the variance in intentions within 206 studies (237 tests) included in the analysis. Another recent meta-analysis examined 185 independent studies and found that the TPB accounted for 27 percent of the variance in actual behavior and 39 percent of the variance in intentions (Armitage & Conner, 2001). Other reviews have reported similar results (e.g., Hagger et al., 2002; Rivas & Sheeran, 2003a; Schulze & Whittmann, 2003; Sheeran & Taylor, 1999; Trafimow et al., 2002). Although reviews have addressed various theoretical and methodological concerns of the theory (e.g., self-report measures), the consensus remains that TPB is at least “an adequate predictor of intention and behavior” (McEachan, et al., 2011, p. 98).

Additionally, Armitage and Conner’s (2001) analysis demonstrated the strength of the relationship between belief-based measures and their corresponding components. Their analysis reported strong correlations ( $r = .50$ ) between behavioral beliefs and attitudes, between normative beliefs and subjective norms ( $r = .50$ ), and between control beliefs and perceived behavioral control ( $r = .52$ ). According to Cohen (1992), these correlations represent “medium” to “large” effect sizes.

There are several studies that compare subgroups in order to substantiate further the role of beliefs within the overall model. For example, in the second of their two studies, Conner, Sherlock, and Orbell (1998) divided their sample into two groups: those who intended to use ecstasy in the next two months and those who did not. Comparing

the behavioral, normative, and control beliefs of those within the two groups revealed significant differences. Those who intended to use the drug believed that it “would be exciting” and “make them sociable,” as opposed to “lead to physical side effects,” for example (Ajzen, 2011, p. 83).

Beliefs are important in a practical sense in that behavioral intention can be changed through interventions that “target the beliefs that underlie the component we wish to change” (Fishbein & Ajzen, 2010, p. 332). These beliefs, known as “target beliefs,” should reflect the strongest and most salient beliefs in a population, which can be identified through formative elicitation research (Fishbein & Ajzen, 2010; Middlestadt, Bhattacharyya, Rosenbaum, & Fishbein, 1996). As such, TPB serves as a basis for formative research of a target population, as well as a blueprint for designing interventions.

**Applications of the theory.** The TPB has been applied in some contexts that may be relevant to the current study. For example, some existing research has successfully used TRA or TPB to predict general pro-social behaviors, such as donating time or money to “charities or community organizations” (e.g., Smith & McSweeney, 2007). Sander van der Linden (2011) also successfully examined charitable intent through a TPB framework. Similarly, there are studies that have examined general volunteering behavior through a reasoned action framework (e.g., Warburton & Terry, 2000). Hyde and White (2009) used the TPB as the basis for a study predicting individuals’ intention to posthumously donate their organs. Recently, several studies have used a TPB framework to examine intentions to donate blood (Robinson, et al., 2008; Masser, et al., 2009; 2012).

This literature is more closely related to the current study than the majority of the health-related TPB literature in that it examines behaviors which benefit an “other” as opposed to the self.

Andrews, Silk, and Eneli (2010) tested the components of the TPB in a study examining parents as health promoters for their children. The study included 201 mothers of young children (ages 2-5) who were recruited via flyers at a pediatric health care clinic. The behaviors addressed the intention of the parents to, “provide fruits and vegetables, limit the intake of sweetened drinks, and control their children’s eating behavior” (p. 101). Independent of the other variables included (e.g., actual weight of the parent), all three components of the TPB “were substantial predictors of behavioral intention, which was a substantial predictor of behavior” (p. 103). This study suggests that the TPB may be a good fit in determining parents’ intentions to behave a certain way on behalf of their children.

Further, the TPB serves as blueprint in creating an intervention designed to change behavior in that it details the process of changing each relevant component. For example, according to Fishbein and Ajzen (1975), “Each belief links the object to some attribute; the person’s attitude toward the object is a function of his evaluations of these attributes” (p. 216). Therefore, in order to change attitudes toward a behavior, the message must (a) change the belief strength of those salient beliefs, (b) create new salient beliefs, and/or (c) change the evaluation of the outcomes of that behavior. Similarly detailed processes are explained for changing subjective norms and perceived behavioral control, both of which are also functions of beliefs – normative and control beliefs,

respectively. In this way, by understanding what factors serve as barriers to parental advocacy, those in the autism community can design messages to address those concerns in parents.

The TPB (and TRA) has found great empirical success when applied to formative research and intervention design within health communication. Ajzen and Fishbein (1980) tested TRA against the health-belief model in an attempt to change the behavior of alcoholics. Overall, Ajzen and Fishbein found that the negative and positive appeals based on TRA significantly increased the behavior (signing up for the ATU); while the traditional appeal based on the health-belief model significantly reduced this behavior.

Researchers have also applied TPB to more general behaviors or goals. Schifter and Ajzen (1985) applied TPB to predict weight loss – which is an outcome that could include a variety of specific behaviors (e.g., eating less, exercising more, hiring a trainer, taking a dietary supplement). Although this particular study was designed to test additional variables, Schifter and Ajzen found that TPB largely predicted intention to lose weight and moderately predicted actual weight loss.

Although intervention design is a less common application of TPB, it has been done. Researchers have applied the theory in studies involving samples of university students, inner-city adolescents (Jemmott, Jemmott & Fong, 1998), weight-loss candidates (Rodgers & Brawley, 1993), unemployed adults (Caplan, Vinokur, Price, & van Ryn, 1989), drug users (Bowen, 1996), and so on. The targeted behaviors have been equally diverse. Brubaker and Fowler (1990) designed an intervention based on TRA that aimed to persuade male college students to perform testicular self-examination and found

positive changes in intention. Murphy and Brubaker (1990) found similar success using a high school population.

### **Hypotheses and Research Questions**

As discussed, a great deal of literature exists demonstrating the efficacy of the theory of planned behavior in predicting intentions to behave. This includes some literature examining performing behaviors that concern another person. Thus, the following central hypothesis can be advanced:

H1: A parent's attitude toward the behavior, perceived behavioral control, and social norms will be directly related to his or her intention to advocate, both individually and in the community.

The majority of existing research surrounding parental advocacy for children with autism is qualitative in nature. Relevant studies that utilized a quantitative approach developed surveys based on extant autism literature, but in the absence of a guiding theory or model. Although a review of relevant literature suggests that attitudes, perceived behavior control, and social norms are likely to play a part in determining intentions, which component might be most important is not clear. The weighting of the components of the TPB is a strength of the model and has important implications for future research and applications. As such, the following question will be examined:

RQ1: Which component of the theory of planned behavior will be most heavily weighted in predicting a parent's intention to advocate for his or her child with autism?

There is no literature that explicitly examines attitudes, subjective norms, or perceived behavioral control in relation to autism advocacy. However, several studies

have highlighted the importance of self-efficacy, empowerment, and related constructs in parents' advocacy or involvement. According to Ajzen (1991), self-efficacy and perceived behavioral control are interchangeable constructs. Similarly, empowerment is a concept that encompasses "the individual's set of beliefs about their control, self-efficacy, and perceived competence" (Nachsen, 2005, pp. 68-69).

As discussed, several studies explicitly examined autism and parental self-efficacy in some sense (Sofronoff & Farbotko, 2002; Hastings & Brown, 2002; Kuhn & Carter, 2006). More specifically, self-efficacy was consistently found to be negatively related to stress, which is a major issue in parents of children with autism. According to Kohler (1999), the stresses of securing services for their children are magnified for parents of children with autism. This is partially because parents must "interact with multiple providers," including the education team. Kohler further noted that "time demands on the family" and "communication difficulties among agencies, providers, and the family" are magnified in families of children with autism. This is echoed throughout the literature.

Bickman and colleagues (1998) evaluated the effects of an empowerment training program in 250 caregivers of children with mental health issues. The results of this study indicated that empowerment training was effective in increasing parent's sense of self-efficacy in working with mental health services, which reiterates the similarity of the constructs. Furthermore, Koren et al. (1992) found that parents' level of empowerment was related to whether the parent was involved in advocacy-related activities. The

presence of these constructs in autism literature suggests that it will likely play an important role in predicting parents' intentions to advocate.

Furthermore, in existing studies using the TPB, resources such as time and money often surfaced as salient control beliefs (e.g., Knowles, Hyde, & White, 2012). The autism literature suggests that these are consistent issues for parents of children with autism. According to Gray (1994, p. 275), "Family members are stressed by the time and resources demanded." Solomon and Chung (2012, p. 255) noted that parents of children with autism struggle with the "precious resources like time and money" in the context of everything from therapy to date nights. According to Brobst, Clopton, and Hendrick (2008, p. 38), "Parents of children with special needs may have to offer not only more time, energy, and resources for their child's well-being."

This is unsurprising considering the lived experience of parenting a child with autism. Autism is often characterized by communication difficulties, rapid mood swings, shrieking or screaming, tantrums, self-stimulatory behaviors, noncompliance, self-injury, and aggression (Benson, 2006). Lee and colleagues (2009) conducted a study addressing the health-related quality of life of 40 parents of children with high-functioning autism. Almost half of the parents reported deteriorated health to "lack of time to recuperate from providing basic and medical care for their children, lack of control over the challenges they faced, and decreased energy" (p. 228). This drain on time and energy is reiterated throughout the literature (e.g., Sperry et al., 1999; Stoner & Angell, 2006; Blackledge & Hayes, 2008). Thus, something that seems rudimentary, such as communicating with

your child's teacher or attending an event, can be exceptionally difficult for parents of children with autism. Thus:

H2: A parent's control beliefs about advocating, both at the individual and community level, will be directly related to his or her intention to advocate at that level.

In addition to direct and belief-based measures about attitudes, perceived behavioral control, and social norms, the TPB questionnaires also elicit basic demographic information, including income and education level. Previous research indicates that these items may play a particularly important role in predicting a parent's intention to advocate for his or her child with autism. More specifically, those of higher socioeconomic status are more likely to have additional resources (i.e., time and money) to aid in advocating for his or her child. This suggests:

H3: There will be a direct relationship between a person's income and his or her likelihood to advocate for his or her child.

H4: There will be a direct relationship between a person's level of education and his or her likelihood to advocate for his or her child.

This study includes an individual and a community level advocacy behavior. As noted, the limited literature available suggests that parents are more likely to be concerned with their own children than with the entire school or community (Zaretsky, 2004). More specifically, communicating with teachers and service providers on a weekly basis will likely be easier for parents than attending a scheduled advocacy event. This is because common issues within the autism community (e.g., securing appropriate childcare) are more likely to inhibit the latter behavior. As such:

H5: Overall, more parents will intend to advocate on the individual level than on the community level.

Finally, the literature suggests additional factors may influence a parent's intention to advocate, and, thus, may serve as moderators. For example, symptom severity was frequently linked with higher parental stress (Tomanik, Harris, & Hawkins, 2004; Lee, et al., 2009; Schaaf, Toth-Cohen, Johnson, Outten, & Benevides, 2011). According to Bennett (2012), "Stress is the main reason for lack of parental involvement alongside a child who is enrolled in an early intervention program" (p. 23). Similarly, Brobst, Clopton, and Hendrick (2008) reported that parental stress was positively related to the intensity of the children's behavioral problems ( $r = .54, p < .01$  for mothers;  $r = .44, p < .05$  for fathers) and to the perceived severity of the children's disabilities ( $r = .47$  for mothers,  $r = .51$  for fathers;  $ps < .05$  for both). Thus, the severity of a child's autism diagnosis may also indirectly impact a parent's intention to advocate.

Additionally, the literature suggests that many parents have a negative perception of communication with educators (Lake & Billingsley, 2000; Fish, 2000; Stoner, et al., 2005). Usually, this perception is based on a negative past experience. Thus, this study will include a marker variable asking whether a parent has had past experience in advocating for his or her child, as well as whether that experience was positive or negative. This may impact attitude, thereby impacting intentions. However, there is not enough research in these areas to justify hypotheses. Instead, this study will consider the following research question:

RQ2: What additional factors will influence a parent's intention to advocate for his or her child?

## Chapter 2

### **METHOD**

#### **Participants**

The research population for this study is parents (or caregivers) of children with autism. As such, the sample for this study was parents or caregivers of children enrolled in the Delaware Autism Program. The Delaware Autism Program has a variety of educational models, ranging from a separate school for those with specific needs (i.e., Brennen School) to full inclusion in mainstream schools (Winterling, 2013). There are approximately 400 total students enrolled in the program, ranging from age two to age 21.

#### **Measures**

**Behaviors.** According to Fishbein and Ajzen (1975, 2010), the first step in conducting a study is to define the behavior in question. This study will examine two behaviors. The first is concerned with individual advocacy: “Communicating with your child’s teacher(s) and/or service team within the next week.” The other is concerned with community advocacy: “Attending an event sponsored by an autism advocacy organization (e.g., Autism Delaware) within the next three months.” The TPB requires that a very specific behavior or behaviors be identified by the researcher. After all,

parents may feel positively about communicating with teachers, but find it difficult to make time to do so within the next week.

Fishbein & Ajzen (1975, 2010) argue that specificity correspondence is the most important factor that influences that magnitude of the relationship between intention and behavior. They stress that it is imperative that the level of specificity between the intention being measured and the behavior being predicted correspond. For an exaggerated example, I should not ask someone if they intend to go the mall and expect to predict whether that person will meet a friend for lunch at the mall's food court on Saturday afternoon. More generally, persuasive communication is more successful at changing specific behaviors, such as running three days per week, as opposed to a behavioral set like "exercise" (Fishbein & Yzer, 2003). This study defines "advocacy" in specific and consistent terms, guided by the literature, to elicit the most successful results. Intention to perform each behavior acts as a dependent variable.

**Predictor variables.** The theoretical constructs within the TPB are hypothetical variables that must be inferred by participant responses (Ajzen, 2002). All predictors in the theory of planned behavior (i.e., attitude toward the behavior, subjective norm, and perceived behavioral control) can be assessed directly by using bipolar adjective scales, which is discussed in more detail later. In addition, each predictor can also be measured indirectly, on the basis of the corresponding beliefs, which are particularly useful in informing future behavior change communication campaigns. Salient beliefs of the target population were elicited through a pilot questionnaire, which is discussed in the next section.

## **Procedure**

**Pilot Questionnaire.** First, a pilot survey was used to elicit a representative sample's salient beliefs about the two behaviors. The pilot questionnaire was formatted after one used by Fishbein and Ajzen (2010), who provide specific instructions for designing the survey. The results from this pilot questionnaire were then used to design a standard questionnaire, which was distributed to the total sample of parents and caregivers at Brennen School (N = 390).

The pilot questionnaire (see Appendix A) included 18 direct measure items, which are used to “assess each of the major constructs” in the model: attitudes, perceived norms, perceived behavior control, and intention to behave (Fishbein & Ajzen, 2010, p. 449). This portion of the questionnaire also included a direct measure of past behavior. Each of the constructs was assessed using bipolar adjective scales that are compatible with specificity of the defined behavior and are self-directed.

In addition to these direct measure items, the pilot questionnaire included nine free response questions for each of the two behaviors; designed to elicit salient beliefs about the behavior in question, as well as normative and control beliefs. The open-ended questions allowed participants to list as many thoughts that came to mind as possible about each behavior, providing an unlimited range of responses. For example, one free response question eliciting control beliefs read, “Please list any factors or circumstances that might make it easy or enable you to attend an event sponsored by an autism advocacy organization (e.g., Autism Delaware) within the next three months.”

The pilot study – along with an introductory letter (see Appendix B) and self-addressed, stamped return envelope – was sent home with 70 students enrolled in the Delaware Autism Program. A random number generator using the school’s comprehensive transportation list chose the families that received the survey. Parents were asked to return the survey within one week of receiving it. After three weeks, only nine questionnaires were returned – eight females and one male. Time constraints did not allow for a follow-up letter or additional surveys to be distributed.

The initial surveys were analyzed for content and frequencies of the responses were tallied by hand. Responses that were very closely related were considered to be one belief category. A summary of the responses and the corresponding categories for the individual behavior is included in Appendix C. Community behavior responses and categories are summarized in Appendix D. A great deal of consistency and overlap between the nine questionnaires suggested the modal salient beliefs were representative of the population, despite the small sample. Most of the responses to the third question (“What else comes to mind?”) were categorized in related topics (e.g., advantages, disadvantages, barriers). Other responses were vague or irrelevant to the research; thus they were not considered for use in the second survey.

One particularly important theme emerged in the pilot questionnaires that significantly impacted the creation of the second questionnaire. Traditionally, the subjective normative component of the TPB is comprised of two types of beliefs. Injunctive normative beliefs address whether salient others approve of the behavior, while descriptive normative beliefs reflect how other people normally behave. Only one

of nine participants provided any free responses concerning descriptive norms. Other respondents left the item blank or indicated confusion with a question mark (“?”). As such, no belief-based items concerning descriptive norms were included in the final questionnaire. However, the direct measure items concerning descriptive norms (“Most other parents at this school will communicate with their child’s teacher(s) and/or service team within the next week;” “Most other parents at this school will attend an event hosted by an autism organization within the next three months”) yielded the most normally distributed responses of any quantifiable item on the pilot study. As such, the same direct measure items were included in the final questionnaire.

The results from the direct measure items determined what question wording was most appropriate to include in the final questionnaire. For example, eight of nine parents responded, “Definitely true” to this statement: “I am confident that I can communicate with my child’s teacher(s) and/or service team within the next week” However, responses to an item measuring the same belief (i.e., control beliefs), “My communicating with my child’s teacher(s) and/or service team within the next week is entirely up to me” were much more evenly dispersed.

Table 1 includes a table of means and standard deviations for the quantifiable items, where “1” is the most negative evaluation (e.g., “extremely bad,” “extremely useless,” “definitely false”) and a “7” is the most positive evaluation (e.g., “extremely good,” “extremely valuable,” “definitely true”).

Table 1

*Means and Standard Deviations for Pilot Study Measures*

Scale	Behavior			
	Communicate		Attend an Event	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
To _____ would be extremely bad/good	6.78	0.44	6.22	0.97
To _____ would be extremely useless/valuable	6.56	0.73	6.33	1.12
Most people who are important to me approve of my _____	6.67	0.71	6.44	1.13
Most other parents at this school will _____	5.25	1.17	4.56	0.73
It is expected of me that I _____	6.67	0.71	4.13	0.84
I am confident that I can _____	6.67	1.00	3.89	2.52
My _____ is entirely up to me	6.00	1.22	5.11	2.57
I intend to _____	6.56	1.01	5.11	2.32
I have _____ in the past week	6.56	1.01	3.78	3.07

**Standard Questionnaire.** Instructions for the standard questionnaire are also outlined in Ajzen and Fishbein (1980) and in Fishbein and Ajzen (2010). The standard questionnaire (See Appendix E) addressed behavioral outcomes (as determined by the pilot questionnaire), and a corresponding evaluation of this outcome. These outcomes are based directly on the response categories created by analyzing the pilot study. Next, the questionnaire included items relating to normative beliefs. Injunctive normative beliefs – whether salient others approve of a behavior – were included, as well as a measure of

motivation to comply with that referent. Next, items of perceived behavioral control and the power of those control factors were measured. This portion of the questionnaire involved how likely it is that a specific control factor will be present, as well as “the factor’s power to facilitate or impede performance of the behavior” (Fishbein & Ajzen, 2010, p. 455)

Additionally, the standard questionnaire included “direct measures developed on the basis of the pilot data to assess attitudes, perceived norm, perceived behavioral control, and intentions,” as well as past behavior measures (Fishbein & Ajzen, 2010, p. 455). There were several items for each component to ensure validity. Table 2 includes a table of means and standard deviations for the direct measure items, where “1” is the most negative evaluation (e.g., “extremely bad,” “extremely useless,” “definitely false”) and a “7” is the most positive evaluation (e.g., “extremely good,” “extremely valuable,” “definitely true”).

Finally, the literature suggests that demographic variables (particularly education level and income) may have serious implications on responses. Thus, several demographic items were included in the standard questionnaire. Furthermore, for this study, other background factors were included that may be particularly relevant to the sample. For example, parents were asked the age of his or her child with autism, the severity of the diagnosis, past experiences with advocacy, etc.

Table 2

*Means and Standard Deviations for Direct Measures in the Final Questionnaire*

Scale	Behavior			
	Communicate		Attend an Event	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
To _____ would be extremely bad/good	6.37	0.94	6.00	1.29
To _____ would be extremely useless/valuable	6.31	1.19	5.82	1.27
My _____ would be extremely unpleasant/pleasant	6.38	0.98	5.80	1.22
Most people who are important to me think I should _____	4.64	1.92	4.45	1.69
Most people whose opinions I value would approve of my _____	5.90	1.51	5.37	1.70
Most other parents at this school will _____	4.52	1.59	4.12	1.52
My _____ is entirely up to me	5.37	1.68	5.74	1.58
My _____ is under my control	5.84	1.55	5.56	1.65
I intend to _____	5.76	1.59	4.81	1.83
I have _____ in the past week	5.87	1.56	4.59	1.89

The questionnaire was distributed to all parents of children enrolled in the Brennen School, including those who were invited to participate in the pilot study ( $N \approx 390$ ). Attempts to extend the sample to other schools in the area were met with resistance and were ultimately unsuccessful. Brennen School does not have comprehensive e-mail lists for their parents, so letters including a shortened survey link was sent to each parent.

E-mail lists that are available (e.g., parents involved in the Parent Teacher Association) were used in addition to the letters to encourage participation wherever possible.

Two reminder letters – for a total of three letters – were distributed (See Appendix F) over the course of two months. As of June 7, 70 parents had opened the survey, 67 had completed it, and 61 had answered every question. Additionally, hard copy surveys were distributed to 25 families via a PTA event; 19 were returned completed. The final sample included 86 parents or guardians (N=86), 22% males and 78% females. Three respondents did not complete the gender question. This satisfied the required sample size (N=59) for adequate statistical power established in the proposal for this project.

**Analysis.** A multiple regression equation was used to determine the relative contributions of attitudes, subjective norms, and perceived behavioral control on participants' intentions to perform specific behaviors (Fishbein & Ajzen, 2010). This analysis will yield results for Hypotheses 1 and Research Question 1. Hypothesis 2 specifically predicted a relationship between parents' control beliefs and their intention to behave at the individual and community level, which was examined using a Pearson correlation test.

Hypotheses 3 and 4 and Research Question 2 examined relationships between parents' intention to advocate and factors that are not part of the TPB predictive model. This is not to suggest that these factors would account for *additional* variance in intention to behave, but that they would have a direct relationship with intentions. Thus, correlation was also used to examine these relationships. A paired t-test, which assumes repeated

measures, was used to compare parental intention to advocate at the individual versus the community level.

## Chapter 3

### RESULTS

#### Reliability

Reliability was tested for sets of scales that directly measured participants' attitudes, subjective norms, perceived behavioral control, and intentions. At the individual level, the three 7-point Likert scales used to measure attitude were found to be highly reliable ( $\alpha = .85$ ). The two 7-point scales used to assess perceived behavioral control were sufficiently reliable ( $\alpha = .73$ ). The three 7-point scales intended to measure subjective norms were less reliable ( $\alpha = .66$ ), but highly predictive.

The same scales were used at the community level, with the exception of the behavior in question. Scales for each component were found to be at least sufficiently reliable: attitude ( $\alpha = .92$ ), perceived behavioral control ( $\alpha = .86$ ), subjective norm ( $\alpha = .71$ ). The two 7-point scales used to measure the dependent variable (i.e., intention) were highly reliable ( $\alpha = .93$ ) at both the individual level and at the community level.

#### Hypothesis 1

Hypothesis 1 stated that the TPB model – attitude toward the behavior, perceived behavioral control, and subjective norms – would predict intention to advocate at both the individual and community levels. A multiple regression analysis assessing the overall fit of the TPB model to the two advocacy behaviors yielded support for Hypothesis 1.

At the individual level, the three main predictor variables (i.e., attitude toward the behavior, subjective norm, and perceived behavioral control) collectively explained 41% of the variance in intention to communicate with the child’s teacher(s) and/or service team,  $F(3, 73) = 16.64, p < .0001, R^2=.41$ . Table 3 presents the results of the initial multiple regression of intention to communicate with the child’s teacher(s) and/or service team.

Table 3

*Multiple Regression of Intention to Communicate*

Intention	<i>b</i>	<i>S.E.</i>	Sig. ( <i>p</i> )
Attitude toward Behavior	.14	.13	n.s.
Subjective Norm	.39	.09	.0011
Perceived Behavioral Control	.33	.10	.0007
Model Fit: $R^2 = .406$			

When including past behavior as a predictor variable, the model explains 49% of the variance in intention to communicate,  $F(4, 72) = 17.40, p < .0001, R^2=.49$ . Table 4 presents the results from the regression equation that includes past behavior.

Table 4

*Multiple Regression of Intention to Communicate (Including Past Behavior)*

Intention	<i>b</i>	<i>S.E.</i>	Sig. ( <i>p</i> )
Attitude toward Behavior	.04	.10	n.s.
Subjective Norm	.32	.11	.0042
Perceived Behavioral Control	.22	.09	.0202
Past Behavior	.35	.10	.0009
Model Fit: $R^2 = .492$			

At the community level, the three predictor variables collectively explained 53% of the variance in intention to attend an event hosted by an autism advocacy organization,  $F(3, 73) = 27.92, p < .0001, R^2=.53$ . Table 5 presents the results of the multiple regression of intention to attend an event hosted by an advocacy organization.

Table 5

*Multiple Regression of Intention to Attend an Event*

Intention	<i>b</i>	<i>S.E.</i>	Sig. ( <i>p</i> )
Attitude toward Behavior	.35	.10	.0010
Subjective Norm	.34	.09	.0008
Perceived Behavioral Control	.27	.11	.0017
Model Fit: $R^2 = .534$			

When including past behavior as a predictor variable, the model explains 64% of the variance in intention to communicate,  $F(4, 72) = 32.32, p < .0001, R^2=.64$ . Table 6 presents the results from the regression equation that includes past behavior.

Table 6

*Multiple Regression of Intention to Attend an Event (Including Past Behavior)*

Intention	<i>b</i>	<i>S.E.</i>	Sig. ( <i>p</i> )
Attitude toward Behavior	.35	.09	.0002
Subjective Norm	.28	.09	.0019
Perceived Behavioral Control	.18	.08	.0233
Past Behavior	.35	.07	<.0001
Model Fit: $R^2 = .642$			

## Research Question 1

One strength of the TPB is its ability to uncover the relative strength of each component in predicting intention. Research Question 2 asked which component of the TPB would be the most heavily weighted in predicting a parent's intention to advocate at the individual level and which would be most important at the community level.

Although the overall TPB model predicted intention to advocate at both levels, the significance and strengths of each predictor varied. At the individual level, attitude toward the behavior was not a significant predictor of intention to tan,  $\beta = .14$ ,  $t(1) = 1.25$ , *n.s.*. Subjective norms were the strongest predictor,  $\beta = .39$ ,  $t(1) = 3.39$ ,  $p = .001$ , while perceived behavioral control predicted intention to a slightly lesser degree,  $\beta = .33$ ,  $t(1) = 3.56$ ,  $p < .001$ .

At the community level, all three components predicted intention to attend an event hosted by an advocacy organization. In this case, attitude was the strongest predictor,  $\beta = .35$ ,  $t(1) = 3.42$ ,  $p = .001$ . Subjective norms were the next strongest predictor of intention,  $\beta = .34$ ,  $t(1) = 3.48$ ,  $p < .001$ , followed by perceived behavioral control,  $\beta = .27$ ,  $t(1) = 3.25$ ,  $p < .01$ .

## Hypothesis 2

Several Pearson correlations revealed partial support for Hypothesis 2, which predicted that control beliefs about advocating would be directly related to intention at the individual and community levels. Direct measures of perceived behavioral control were directly related to intention at the individual and at the community level, but only a

few specific beliefs were significantly correlated. The results are reported for each item measuring intention, some of which used the wording, “I intend...” and some of which used the wording, “I will...”

At the individual level, there was a significant positive correlation between “communicating via e-mail” and a parent’s intention to communicate with the teacher(s) and/or service team. (“I intend”:  $r = .25, n = 81, p < .05$ ), (“I will”:  $r = .32, n = 81, p < .01$ ). When measures of power were multiplied by control beliefs, the same item was even more strongly correlated with intention to communicate. (“I intend”:  $r = .42, n = 81, p < .0001$ ) (“I will”:  $r = .44, n = 81, p < .0001$ ). In other words, parents who indicated that communicating via e-mail made it easier to communicate were more likely to perform that behavior. Parents who indicated that e-mail was easier **and** that they had regular access to that type of communication were even more likely to perform the behavior. No other control beliefs were significantly correlated with intention at the individual level.

At the community level, no control beliefs were significantly correlated with intention to attend an event hosted by an autism organization. However, when control beliefs were multiplied by measures of power, two items were positively correlated with intention attend. First, there was a positive relationship between the item, “childcare and/or respite was available” and intention to attend an event hosted by an advocacy organization (“I intend”:  $r = .27, n = 79, p = .02$ ), (“I will”:  $r = .24, n = 80, p = .03$ ). Accordingly, the more likely a parent was to have access to childcare or respite, the more likely that parent was to attend an event hosted by an autism organization.

There was also a significant relationship between the time of day and intention to attend the event (“I intend”:  $r = .28, n = 89, p = .01$ ), (“I will”:  $r = .34, n = 79, p = .002$ ), such that parents who were more likely to have evenings free were also more likely to attend events hosted by autism organizations.

### **Hypotheses 3 and 4**

Hypothesis 3 predicted a relationship between intention to advocate and income while Hypothesis 4 predicted a relationship between intention to advocate and education level. Although the literature suggests income and education level impact advocacy, a Pearson correlation found no significant relationship between intention to advocate and either demographic variable. Education level was not significantly correlated with intention to communicate with a child’s teacher and/or service team, (“I intend”:  $r = .08, n = 81, n.s.$ ), (“I will”:  $r = .01, n = 82, n.s.$ ), nor was it significantly correlated with intention to attend an autism organization’s event (“I intend”:  $r = -.03, n = 79, n.s.$ ), (“I will”:  $r = -.13, n = 80, n.s.$ ).

Similarly, income level was not significantly correlated with intention to communicate with a child’s teacher and/or service team, (“I intend”:  $r = -.08, n = 79, n.s.$ ), (“I will”:  $r = -.07, n = 80, n.s.$ ), nor was it significantly correlated with intention to attend an autism organization’s event (“I intend”:  $r = .12, n = 77, n.s.$ ), (“I will”:  $r = .07, n = 78, n.s.$ ). Neither income ( $M = 4.44, SD = 1.65$ ) nor education ( $M = 3.87, SD = 1.06$ ) had skewed distributions such that statistical tests involving them would be influenced.

## Hypothesis 5

Hypothesis 5 predicted that, in line with the literature, more parents would advocate at the individual level than at the community level. The mean response for each item measuring intention suggested this was the case. At the individual level, parents responded to two items measuring intention: “I intend to communicate with my child’s teacher(s) and/or service team within the next week” ( $M = 5.8, SD = 1.6$ ) and “I will communicate with my child’s teacher(s) and/or service team within the next week” ( $M = 5.9, SD = 1.6$ ). At the community level, mean responses for each item were significantly lower: “I intend to attend an event hosted by an autism organization within the next three months” ( $M = 4.8, SD = 1.8$ ) and “I will communicate with my child’s teacher(s) and/or service team within the next week” ( $M = 4.6, SD = 1.9$ ).

A paired t-test analysis also indicated support for Hypothesis 5. The mean intention to advocate at the individual level was significantly higher than at the community level in every scenario. When comparing the direct measures, “I will communicate with my child’s teacher(s) and/or service team within the next week” and “I will attend an event hosted by an autism organization in the next three months,” the results were as follows:  $t(79) = 5.83, p < .0001$ .

When comparing the direct measures using the wording “I intend to communicate...” and “I intend to attend...,” the results were similar:  $t(77) = 4.70, p < .0001$ . When comparing “I intend to communicate...” and “I will attend...,” the results were:  $t(78) = 5.69, p < .0001$ . When comparing intention between “I will communicate...” and “I intend to attend...,” the results were:  $t(78) = 5.06, p < .0001$ .

## Research Question 2

Pearson correlations were used to examine relationships between intention to advocate and several other variables of interest: parental stress level, severity of the child's autism and the concurrent symptoms, and an evaluation (extremely negative to extremely positive) of a past advocacy experience. There were no significant relationships among any of the variables.

However, an additional correlation examining the relationship between past advocacy experience and *attitudes* toward advocacy revealed some significant relationships. Specifically, past experience with advocating was directly related to a parent's evaluation of the behavior as useless/valuable,  $r = .26, n = 65, p = .04$ , or unpleasant/pleasant,  $r = .30, n = 66, p = .01$ . In other words, the more positive a past advocacy experience was, the more "valuable" and "pleasant" a parent perceived interactions with his or her child's teachers to be, and vice-versa.

## Chapter 4

### **DISCUSSION**

The current study laid the groundwork for the use of the TPB model in studying advocacy among parents of children with autism. Despite several limitations, which will be discussed in the next section, the results of this study were important for several theoretical and practical reasons. In general, the results suggest support for a more systematic, quantitative approach to studying advocacy among parents of children with autism, specifically using the TPB model. The current study also brought to light a few specific factors that may be influencing advocacy intentions, which could be useful in designing future studies or in communication within the autism community.

The overall model fit to both behaviors is encouraging for the application of the TPB in future studies of this nature. However, we need to recall that this study is the first of its kind in many respects. Thus, there are several details and additional questions that should be examined further in future research. This section serves to discuss potential implications of the reported results, as well as the limitations of the current study and some directions for future research.

#### **Results and Implications**

**Results summary.** The current study primarily predicted that the TPB model – attitude toward the behavior, perceived behavioral control, and subjective norms – would predict intention to advocate at the individual and community levels. A multiple

regression equation revealed support for this hypothesis, and the model explained 41% of variance in intention to communicate and 53% of variance in intention to attend an event.

More specifically, the analyses revealed that subjective norms were the strongest predictor of intention to communicate with teachers, while perceived behavioral control predicted intention to a slightly lesser degree. Subjective norms and perceived behavioral control were also significant predictors of intention to attend an event hosted by an autism organization. Thus, understanding who parents look to when making decisions about their children's education is important, as well as what factors make these types of advocacy easier for parents to participate in.

Attitude toward the behavior was not a significant predictor of intention at the individual level, but was the strongest predictor of intention to attend an event hosted by an autism organization. Thus, a parent who perceives attending an event as "good," "valuable," or "pleasant" is more likely to attend, but these evaluations aren't as important when determining whether a parent intends to communicate with his child's teachers.

When past behavior was included in the model, the variance explained increased to 49% for the individual behavior and 64% for the community behavior. This indicates that parents who have advocated in these ways in the past are highly likely to do so again. This is promising insofar as crafting messages that encourage parents to engage in these behaviors may result in lasting involvement and advocacy by those parents. Although this finding is important, this study focuses mostly on the results of the initial TPB model. This is because the inclusion of past behaviors dilutes the strength and significance of the

other predictors, which are the factors that have practical implications. Past behavior cannot be changed, so future campaigns involving advocacy should focus on attitude, subjunctive norms, and perceived behavioral control as a means of increasing parental intention to advocate.

Another aim of the current study was to delve deeper into the relationship between parents' specific control beliefs and their intention to advocate at each level. Hypothesis 2 predicted that there would be a direct relationship between control beliefs and intention, but the results revealed only partial support. The existing literature suggested that certain barriers might play a role in determining advocacy among parents, but those barriers did not clearly emerge in the current study. There are several reasons this might be true, including question wording, sample issues, and the behaviors in questions – all of which are discussed in the limitations section.

These results did suggest that e-mail correspondence makes communicating with teachers and service staff easier for parents and, as such, is directly related to intention to communicate. When it came to attending an event hosted by an autism organization, the results revealed that availability of childcare and free evening hours were directly related to intention to attend. Childcare and respite issues, as well as strained time resources were both themes in existing autism research.

Previous research also suggested that education level and income level are often related to advocacy behaviors. Additionally, previous research cited relationships between parental involvement and other factors, such as stress, symptom severity, placement on the spectrum, or past advocacy experience. The current study did not find

support for any of those relationships. However, the results did fall in line with autism research that suggested parents are more likely to advocate for their own children than for autism as a more general cause.

**Overall model fit.** As discussed earlier, the TPB has been applied primarily in the context of health-related behaviors, such as getting a mammogram, exercising, or tanning. The results of this study suggest support for a smaller body of research, which applies the TPB to behaviors that benefit an “other” as opposed to the self. Previously, research in this vein has been about fairly general behaviors such as blood donation, organ donation, volunteerism, or charitable donations (Warburton & Terry, 2000; Smith & McSweeney, 2007; Hyde & White, 2009; Sander van der Linden, 2011).

This study suggests that the model can be just as (if not more) effective in predicting and explaining more specific behaviors of this type. Smith and McSweeney (2007) applied the TPB to charitable giving behaviors and explained 30% of the variance in intention to donate money. Similarly, Sander van der Linden (2011) explained 33% of the variance in charitable intent using the standard TPB model. This study explained 41% of the variance in intention to communicate with a child’s teacher or service team and more than half of the variance (53%) in intention to attend an advocacy event. This may be because the TPB is most effectively applied when the behaviors are defined with great specificity – a guideline this author took great care to follow.

Additionally, this study joins the ranks of Andrews, Silk, and Eneli’s (2010) research, which successfully predicted a parents’ intention to behave on behalf of his or her child. If this is the case, the TPB could potentially be used to understand parental

behaviors involving other decisions made on behalf of their children (e.g., nutrition, vaccines, car safety). If consistently successful, this research could shape future health communication campaigns involving these parental behaviors.

**Determinants and intention to advocate.** The ability to explain advocacy behavior yields high potential to target the things most important to parents. For example, if parents perceive or experience a certain barrier, the autism community can work to address that barrier. More specifically, if a lack of childcare is preventing parents from attending advocacy events, providing respite at the event site would logically increase attendance. Thus, what determines intention and behavior should be understood to the most specific degree possible.

The results of the current study suggest that intention to advocate is influenced by different things at different levels. This is in line with the TPB, which assumes that the importance of the three main determinants varies across behaviors and situations (Ajzen, 2001). When defining advocacy in terms of communicating with support staff at the school, subjective norms have the greatest impact on parents' intention. In other words, if parents perceive that people whose opinion they value (e.g., teachers) think that they should communicate with school staff, they are more likely to do so. This suggests that those inviting parents to be involved should stress the value these important others place on this type of advocacy. This study did not examine the relationship between intention and the specific normative beliefs, so which opinions matter most to parents is speculative at best. Because the results suggested social norms are the strongest predictor,

future research should take care to uncover whose opinions resonate with parents regarding their child's education.

Additionally, the easier parents perceive communicating with their child's education team to be, the more likely they are to do it. The results for correlations between control beliefs and intention to communicate indicated that communicating via e-mail would make it significantly easier for parents to communicate, and thus, more likely that they would. Currently, the school from which our sample was derived uses a "communication log" notebook that is sent back and forth with the student each day. These results suggest that an electronic version of this system may yield higher participation. Because consistency and communication is so important for the success of children with autism, this should be taken under serious consideration.

When defining advocacy in terms of attending an event hosted by an advocacy organization, all three determinants played a part. Attitude was the strongest predictor for intention to perform this behavior. Thus, the more favorable a parent's evaluations of the outcomes of attending an event are, the more likely they are to attend. In promoting these events, organizations such as Autism Delaware would be most successful in persuading parents that the outcomes of attending are positive. In order to do this most effectively, further research examining what parents perceive about specific outcomes is necessary. For example, parents evaluated the outcome, "Hearing information that pertains to my child" as the most positive ( $M = 6.7$ ), but many parents thought it was unlikely such an event would yield that outcome ( $M = 5.5$ ). Thus, in promoting the event, persuading parents that they would take away relevant information by attending would be useful.

Similar inferences and implications apply to subjective norms as a significant predictor of intention.

On a conceptual level, it is interesting to consider why attitude was heavily weighted in predicting intention to attend an event, but did not surface as a significant predictor for intention to communicate with teacher(s) and/or service staff at the school. This may be because the outcomes of communicating with a teacher are more immediate and personally valuable to a parent because it is in the specific interest of his or her child. On the other hand, advocating for the autism community in general may or may not have an impact on that parent or child, and that impact may or may not be a positive one. This speaks to the challenges of promoting traditional advocacy in general: it is difficult to cultivate positive attitudes toward advocating because it is an ongoing and complex process without guaranteed and/or immediate gratification as an outcome.

More formal analyses were used to examine control beliefs as they related to intention to attend an advocacy event. These are important to examine since perceived behavioral control is a significant predictor of intention to attend an advocacy event, even though it impacts intention to a lesser degree than the other two determinants. The results of Pearson correlations used to address Hypothesis 2 revealed that parents who are more likely to have access to childcare or respite are more likely to attend an event hosted by an autism advocacy organization. This makes sense in terms of previous research, which continuously highlights the impact of limited resources (including respite) on parents of children with autism. (Boyd, 2002; Benson, 2006). There are practical implications for

this finding, in that organizations such as Autism Delaware may experience higher parental turnout if they provided and promoted on-site childcare.

Similarly, correlation results suggested that parents who were more likely to have evenings free were also more likely to attend events hosted by autism organizations. Although this may be related to parental concerns about childcare, providing daytime or weekend options for events and meetings may also increase attendance. Moreover, other specific factors could be uncovered in future research, as will be discussed in the following section.

**Additional factors.** Existing research suggested that education and income levels might be related to advocacy, but the current study found no such relationship. This could be because there is a mediating variable, such as stress, that wasn't accounted for in the present study's analyses. Another possible explanation is that the present study's operational definitions of advocacy are simply not significantly related to income or education level as other conceptualizations might be. For example, Mandell and Salzer (2007) examined factors that determined participation in a support group, which is more time-intensive than the behaviors defined in the current study.

The current study did find a relationship between previous experience with advocacy and attitude toward the behavior, such that the more positive a past advocacy experience was, the more "valuable" and "pleasant" a parent perceived interactions with his or her child's teachers to be. This finding suggests that cultivating trust and valuable communication between parents and educators becomes particularly important when the parent has had a negative experience advocating in the past. If teachers and support staff

know what type of questions to ask parents about their personal experiences, they may be able to forge a better connection with them, thus increasing their involvement in the child's education.

### **Limitations**

Although the overall model fit for the current study was impressive for both behaviors, there were several limitations to the study. First, the control belief components included in the study were not adequate predictors of the determinant they are meant to represent (i.e., perceived behavioral control). A regression was used to analyze the relative contributions of the behavioral, normative, and control components in predicting their corresponding determinants (attitude toward the behavior, subjective norm, and perceived behavioral control).

At the individual level, the belief-based control components only explained 15% of the variance in perceived behavioral control,  $F(5, 75) = 2.60, p < .05, R^2 = .15$ . At the community level, the regression did not even yield a significant relationship,  $F(5, 73) = 1.73, n.s., R^2 = .11$ . This issue is likely a result of limited pilot study responses, which hindered the ability to choose truly modal salient beliefs for the population.

In addition to limited pilot study responses, the study experienced other limitations in terms of its sample. First, common sense suggests that parents who take the time to complete a voluntary survey are likely to be the same parents who exhibit involvement in other ways; namely, communicating with their child's teachers and/or attending an advocacy event. As such, the sample may well be skewed toward those who are more likely to advocate. Although this is a limitation, it does not negate the results

reported. It is still useful to know why parents who do advocate intend to do so, so that the autism community can enhance and promote these attitudes, norms, or control factors.

Furthermore, the pilot and final questionnaire are self-report measures addressing an issue that may be sensitive. In other words, a parent might be inclined to inflate his or her measure of intention or attitude because it is what he or she “should” do. The study took all available opportunities to assure parents of total anonymity, but self-report bias may still be an issue, as has been mentioned in previous advocacy literature and TPB literature.

Lastly and perhaps most importantly in terms of sample, the current study surveyed parents whose children were enrolled in the Delaware Autism Program, which is a highly specialized program dedicated exclusively to educating those on the autism spectrum. According to the Encyclopedia of Autism Spectrum Disorders, “In 2010, it served more than 800 students between 2 and 21 years of age, in the full range of settings (residential programs, separate schools and settings, and integrated school and community sites) in six affiliated school districts. DAP sites employ than 450 staff, including teachers, assistants, specialists (psychologists, speech language pathologists, occupational therapists, nurses, etc.)” (Winterling, 2013, para. 1).

Parents and children within the DAP community likely enjoy services that those in a more standardized school environment would not. Much of the existing research on autism advocacy involves parents who are pleading with public school districts to provide the care that their children need, such as speech therapists or respite care, but DAP has these in-house. Although the current results are still useful, future research may be able to

gain a richer and more representative understanding of intention to advocate by using a more typical sample.

### **Directions for Future Research**

The current study is unique in its application of the TPB to autism advocacy behaviors, and a neophyte in its attempt to operationalize and quantify advocacy within the autism community. Because the study is a foray into new territory, the results are largely big-picture, surface-level findings, which left many stones left unturned. Thus, there are countless directions that future research could take to build upon the present study.

Most importantly, practical applications of results can most effectively be applied within the autism community when the specific beliefs that influence intention to advocate are pinpointed. As such, future research should take care to implement a larger-scale pilot study that more fully and accurately elicits the salient beliefs of the target sample, and thus, population. Furthermore, future studies should analyze the available data in such a way that uncovers more potential relationships between the specific beliefs and intention. The present study examined control beliefs in depth to satisfy Hypothesis 2, but many questions remain about what behavioral beliefs and which important others are influencing intention to advocate.

In order to properly address other “Why?” questions, future researchers should also examine additional variables. The present study included measures of stress, symptom severity, and so on, but little was found in relation to these items. Some yielded no results and others were not tested in-depth. For example, although the sample was

overwhelmingly female (78%), gender was not included as a variable in any analyses. Thus, future research may want to consider the possibility of a gender effect on parental behaviors. Future research should examine the unique impact of these factors on intention to advocate, as well as their potential place as moderating or mediating variables within the overall TPB model.

Research that builds upon the use of the TPB to examine advocacy within any population should fine-tune the working definition of advocacy and be meticulous in choosing behaviors that represent that definition. The current study chose behaviors meant to represent a moderate level of involvement among parents of children with autism, but their place under the umbrella of “advocacy” may be questionable. Also, “advocacy” takes on a very different meaning within the autism community, but the successful application of the TPB to the behavior, “attend an event hosted by an advocacy organization,” suggests potential for using the theory to predict advocacy in various and specific samples (e.g., lung cancer, heart disease, etc.).

Finally, once research has been conducted to build upon the results reported here, the findings should be practically applied within the autism community. Although the TPB is a theory of human behavior, it has found much success in applications to communication research and campaigns. Thus, once there is an understanding of the factors that truly predict intention to advocate among parents of children with autism, schools and organizations can incorporate those factors into communication with parents and increase their involvement and advocacy.

## **Conclusion**

The purpose of the present study was to understand what factors influence a parent's decision to advocate for his or her child with autism. This was a first attempt at applying the TPB to advocacy within the autism community. Advocacy is particularly important within this population, and there had not been a significant amount of research on the subject to date, particularly using quantitative methods. A qualitative approach makes sense in understanding such a nuanced concept and specialized sample, but the current study found some success in numbers. Thus, it successfully added to a body of research examining advocacy in the autism community, as well as research using the TPB to understand "other"-focused behaviors.

This research should serve as a stepping-stone for future studies to apply the TPB to advocacy-related behaviors. Understanding what influences a person to participate in advocacy for a particular issue opens doors for launching more successful advocacy campaigns and increasing involvement in countless worthy causes.

## REFERENCES

- Ajzen, I. (1991). The theory of planned behavior. *Organizational Behavior and Human Decision Processes*, 50, 179–211.
- Ajzen, I. (2002). Constructing a TpB questionnaire : Conceptual and methodological considerations. Retrieved from [http://people.umass.edu/~ajzen/pdf/tpb\\_measurement.pdf](http://people.umass.edu/~ajzen/pdf/tpb_measurement.pdf)
- Ajzen, I. (2011). The theory of planned behaviour: reactions and reflections. *Psychology & Health*, 26(9), 1113–27.
- Ajzen, I. (2012). The theory of planned behavior. *Handbook of Theories of Social Psychology*, 1, 438–459.
- Ajzen, Icek, Joyce, N., Sheikh, S., & Cote, N. G. (2011). Knowledge and the prediction of behavior: The role of information accuracy in the theory of planned behavior. *Basic and Applied Social Psychology*, 33(2), 101–117.
- Andrews, K. R., Silk, K. S., & Eneli, I. U. (2010). Parents as health promoters: a theory of planned behavior perspective on the prevention of childhood obesity. *Journal of Health Communication*, 15(1), 95–107.
- Armitage, C J, & Conner, M. (2001). Efficacy of the theory of planned behaviour: A meta-analytic review. *The British Journal of Social Psychology*, 40(4), 471–99.
- Armitage, C.J., Conner, M., Loach, J., & Willetts, D. (2010). Different perceptions of control : Applying an extended theory of planned behavior to legal and illegal drug use. *Basic and Applied Social Psychology*, (October 2012), 37–41.
- Armitage, C.J., & Christian, J. (2003). From attitudes to behaviour: Basic and applied research on the theory of planned behaviour. *Current Psychology*, 22(3), 187–195.
- Autism speaks*. (2012). Retrieved from <http://www.autismspeaks.org/>
- Autism spectrum disorder*. (2011, January 26). Retrieved from <http://www.dsm5.org>
- Bennett, A. (2012). Parental involvement in early intervention programs for children with autism. *Master of Social Work Clinical Research Papers*. Paper 113. Retrieved from [http://sophia.stkate.edu/msw\\_papers/113](http://sophia.stkate.edu/msw_papers/113).

- Benson, P., Karlof, K. L., & Siperstein, G. N. (2008). Maternal involvement in the education of young children with autism spectrum disorders. *Autism : The International Journal of Research and Practice*, 12(1), 47–63.
- Benson, P. R. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: the mediating role of stress proliferation. *Journal of Autism and Developmental Disorders*, 36(5), 685–95.
- Blackledge, J. T., & Hayes, S. C. (2008). Child & family behavior therapy using acceptance and commitment training in the support of parents of children diagnosed with autism. *Child & Family Behavior Therapy*, (October 2012), 37–41.
- Booth-Butterfield, S., & Reger, B. (2004). The message changes belief and the rest is theory: the “1% or less” milk campaign and reasoned action. *Preventive Medicine*, 39(3), 581–8.
- Bouma, R., & Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: a comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46(6), 722–30.
- Boyd, B. a. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities*, 17(4), 208–215.
- Bradford, K. (2010). Supporting families dealing with autism and Asperger’s disorders. *Journal of Family Psychotherapy*, 21(2), 149–156.
- Brobst, J. B., Clopton, J. R., & Hendrick, S. S. (2008). Parenting children with Autism Spectrum Disorders: The couple’s relationship. *Focus on Autism and Other Developmental Disabilities*, 24(1), 38–49.
- Bromley, J., Hare, D. J., Davison, K., & Emerson, E. (2004). Mothers supporting children with autistic spectrum disorders: social support, mental health status and satisfaction with services. *Autism :The International Journal of Research and Practice*, 8(4), 409–23.
- Brouwer, S., Krol, B., Reneman, M. F., Bültmann, U., Franche, R.-L., Van der Klink, J. J. L., & Groothoff, J. W. (2009). Behavioral determinants as predictors of return to work after long-term sickness absence: an application of the theory of planned behavior. *Journal of occupational rehabilitation*, 19(2), 166–74.

- Brunel, F. F. & Nelson, M.R. (2000). Explaining gendered responses to “help-self” and “help-others” charity ad appeals: The mediating role of world-views. *Journal of Advertising*, 29(3), 15-28.
- Carpenter, B. (2003). Sustaining the family: Meeting the needs of families of children with disabilities. *British Journal of Special Education*, 27(3), 135–144.
- Center for Disease Control (2012). New data on Autism Spectrum Disorders. In CDC Features. Retrieved from [http://www.cdc.gov/media/releases/2012/p0329\\_autism\\_disorder.html](http://www.cdc.gov/media/releases/2012/p0329_autism_disorder.html)
- Conner, M., & Armitage, C. J. (1998). Extending the theory of planned behavior: A review and avenues for further research. *Journal of Applied Social Psychology*, 28(15), 1429–1464.
- Dabkowski, D. M. (2004). Encouraging active parent participation in IEP team meetings. *Teaching Exceptional Children*, 36(3), 34–39.
- Dennis, B.S., Buccholtz, A.K. & Butts, M.M. (2007). The nature of giving: A theory of planned behavior examination of corporate philanthropy. *Business & Society*, 48(3), 360-384.
- Doll, J., & Ajzen, I. (1992). Accessibility and stability of predictors in the theory of planned behavior. *Journal of Personality and Social Psychology*, 63(5), 754–765.
- Dunlap, G., & Fox, L. (1999). Supporting families of young children with autism. *Infants and Young Children*, 12(2), 48–54.
- Bergeson, T., Davidson, C., Harmon, B., Gill, D.H., & Colwell, M. (2008). The educational aspects of autism spectrum disorders. *Special Education*. Retrieved from the Office of Superintendent of Public Instruction.
- Elliott, M. a, Armitage, C. J., & Baughan, C. J. (2003). Drivers’ compliance with speed limits: an application of the theory of planned behavior. *The Journal of Applied Psychology*, 88(5), 964–72.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.-H., & Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism : The International Journal of Research and Practice*, 13(4), 375–87.

- Fazil, Q., Wallace, L. M., Singh, G., Ali, Z., & Bywaters, P. (2004). Empowerment and advocacy: reflections on action research with Bangladeshi and Pakistani families who have children with severe disabilities. *Health & Social Care in the Community*, 12(5), 389–97.
- Finke, E. H., McNaughton, D. B., & Drager, K. D. R. (2009). “All children can and should have the opportunity to learn”: general education teachers’ perspectives on including children with autism spectrum disorder who require AAC. *Augmentative and Alternative Communication*, 25(2), 110–22.
- Fish, W. (2000). Perceptions of parents of students with autism towards the IEP meeting: A case study of one family support group chapter. *Education*, 127(1), 56–69.
- Fishbein, M. & Ajzen, I. (1975). *Belief, attitude, intention, behavior: An introduction to theory and research*. Reading, Mass.: Addison-Wesley.
- Fishbein, M., & Ajzen, I. (2010). *Predicting and changing behavior: The reasoned action approach*. New York: Psychology Press (Taylor & Francis).
- Flippin, M., & Crais, E. R. (2011). The needs for more effective father involvement in early autism intervention: A systematic review and recommendations. *Journal of Early Intervention*, 33(1), 24–50.
- Fraser, R., Ajzen, I., Johnson, K., Herbert, J., & Chan, F. (2011). Understanding employers’ hiring intention in relation to qualified workers with disabilities. *Journal of Vocational Rehabilitation*, 35, 1–11.
- Gavaldá, J. M. S., & Qinyi, T. (2012). Improving the Process of Inclusive Education in Children with ASD in Mainstream Schools. *Procedia - Social and Behavioral Sciences*, 46, 4072–4076.
- Gray, D. E. (1993). Perceptions of stigma: the parents of autistic children. *Sociology of Health and Illness*, 15(1), 102–120.
- Gray, D. E. (1994). Coping with autism: stresses and strategies. *Sociology of Health and Illness*, 16(3), 275–300.
- Gray, D. (2002). Ten years on : a longitudinal study of families of children with autism. *Journal of Intellectual & Developmental Disability*, 27(3), 215–222.
- Greenspan, I., Handy, F., & Katz-Gerro, T. (2012). Environmental philanthropy: Is it similar to other types of environmental behavior? *Organization & Environment*, 25(2), 111–130.

- Greenwood, G. E., & Hickman, C. W. (1991). Research and practice in parent involvement: Implications for teacher education. *The Elementary School Journal*, 91(3), 279–288.
- Hamilton, K., & White, K. M. (2008). Extending the theory of planned behavior: the role of self and social influences in predicting adolescent regular moderate-to-vigorous physical activity. *Journal of Sport and Exercise Psychology*, 30(1), 56–74.
- Hartley, S. L., Barker, E. T., Seltzer, M. M., Floyd, F., Greenberg, J., Orsmond, G., & Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449–57.
- Hillman, J. (2006). Supporting and treating families with children on the autistic spectrum: The unique role of the generalist psychologist. *Psychotherapy*, 43(3), 349–58.
- Hoagwood, K. E. (2005). Family-based services in children's mental health: a research review and synthesis. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 46(7), 690–713.
- Huchting, K., Lac, A., & LaBrie, J. W. (2008). An application of the theory of planned behavior to sorority alcohol consumption. *Addictive behaviors*, 33(4), 538–51.
- Hyde, M. K., & White, K. M. (2009). To be a donor or not to be? Applying an extended theory of planned behavior to predict posthumous organ donation intentions. *Journal of Applied Social Psychology*, 39(4), 880–900.
- Jenkins, J. C. (1987). Nonprofit organizations and policy advocacy. In W. Powell (Ed.), *The Nonprofit Sector: A Research Handbook*, (pp. 296–320). New Haven, CT: Yale University Press.
- Johnston, K. L., & White, K. M. (2003). Binge-drinking: A test of the role of group norms in the theory of planned behaviour. *Psychology & Health*, 18(1), 63–77.
- Jones, T. L., & Prinz, R. J. (2005). Potential roles of parental self-efficacy in parent and child adjustment: a review. *Clinical Psychology Review*, 25(3), 341–63.
- Kasari, C., & Rotheram-Fuller, E. (2005). Current trends in psychological research on children with high- functioning autism and Asperger disorder. *Current Opinion in Psychiatry*, 18, 497–501.

- Knowles, S. R., Hyde, M. K., & White, K. M. (2012). Predictors of you people's charitable intentions to donate money : An extended theory of planned behavior perspective. *Journal of Applied Social Psychology, 42*(9), 2096–2110.
- Koegel, R. L., Schreibman, L., Loos, L. M., Dirlich-Wilhelm, H., Dunlap, G., Robbins, F. R., & Plienis, a J. (1992). Consistent stress profiles in mothers of children with autism. *Journal of Autism and Developmental Disorders, 22*(2), 205–16.
- Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & Van Dyck, P. C. (2008). A national profile of the health care experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. *Pediatrics, 122*(6), 1149–58.
- Kohler, F. W. (1999). Examining the services received by young children with autism and their families: A survey of parent responses. *Focus on Autism and Other Developmental Disabilities, 14*(3), 150–158.
- Konstantareas, M. M., & Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry, and Allied Disciplines, 30*(3), 459–70.
- Koren, P. E., Dechillo, N., & Friesen, B. J. (1992). Measuring empowerment in families whose children have emotional disabilities : A brief questionnaire. *Rehabilitation Psychology, 37*(4), 305–321.
- Kuhn, J. C., & Carter, A. S. (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with Autism. *American Journal of Orthopsychiatry, 76*(4), 564-575.
- Lake, J. F., & Billingsley, B. S. (2000). An analysis of factors that contribute to parent/school conflict in special education. *Remedial and Special Education, 21*(4), 240–251.
- Landau R.J. (1996). Professional advocacy and legal issues. In Jacobson, J., & Mulick, J. (Eds.), *Manual of Diagnosis and Professional Practice in Mental Retardation* (pp. 413-420). Washington, DC: American Psychological Association.
- Lee, G. K., Lopata, C., Volker, M. a., Thomeer, M. L., Nida, R. E., Toomey, J. a., Chow, S. Y., et al. (2009). Health-related quality of life of parents of children with high-functioning autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities, 24*(4), 227–239.

- Leong, S. M., Tiong, C., & Cheong, K. (1995). A theory of reasoned action perspective of voting behavior : Model and empirical test. *Psychology and Marketing, 12*(1), 37-51.
- Linden, S. (2011). Charitable intent: A moral or social construct? A revised theory of planned behavior model. *Current Psychology, 30*(4), 355–374.
- Mandell, D. S., & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism : The International Journal of Research and Practice, 11*(2), 111–22.
- Manstead, A. S. R., & Parker, D. (1995). Evaluating and extending the theory of planned behaviour. *European Review of Social Psychology, 6*(1), 69–95.
- Masser, B. M., Bednall, T. C., White, K. M., & Terry, D. (2012). Predicting the retention of first-time donors using an extended theory of planned behavior. *Transfusion, 52*(6), 1303–10.
- Masser, B. M., White, K. M., Hyde, M. K., Terry, D. J., & Robinson, N. G. (2009). Predicting blood donation intentions and behavior among Australian blood donors: testing an extended theory of planned behavior model. *Transfusion, 49*(2), 320–329.
- McCabe, H. (2007). Parent advocacy in the face of adversity: autism and families in the People’s Republic of China. *Focus on Autism and Other Developmental Disabilities, 22*(1), 39–50.
- McEachan, R. R. C., Conner, M., Taylor, N. J., & Lawton, R. J. (2011). Prospective prediction of health-related behaviours with the Theory of Planned Behaviour: a meta-analysis. *Health Psychology Review, 5*(2), 97–144.
- McGuire, A. (2011). Representing autism : A sociological examination of autism advocacy. *Atlantis: A Women’s Studies Journal, 35*(2), 62-71.
- Michel, G. & Rienier, S. (2012). Nonprofit brand image and typicality influences on charitable giving. *Journal of Business Research, 65*(5), 701-707.
- Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Childcare, Health and Development, 35*(2), 250–256.
- Muckian, J. (2007). Influencing policy development: the whirling dervish of the autism in-home program. *Journal of Pediatric Nursing, 22*(3), 223–230.

- Mulick, J. a., & Butter, E. M. (2002). Educational advocacy for children with autism. *Behavioral Interventions*, *17*(2), 57–74.
- Nachshen, J. (2005). Empowerment and families: Building bridges between parents and professionals, theory and research. *Journal on Developmental Disabilities*, *11*(1), 67-76.
- National Cancer Institute at the National Institutes of Health (2012). The nation's investment in cancer research : Cancer, changing the conversation. *An Annual Plan and Budget Proposal for Fiscal Year 2012*. Retrieved 9 March 2012.
- National Institute of Health (2010). Diseases and conditions: Autism. In U.S. National Library of Medicine. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmedhealth/PMH0002494>.
- National Research Council. (2001). Educating children with autism. Washington, DC: National Academy Press.
- Osborne, L. a., & Reed, P. (2010). Stress and self-perceived parenting behaviors of parents of children with autistic spectrum conditions. *Research in Autism Spectrum Disorders*, *4*(3), 405–414.
- Rise, J., Sheeran, P., & Hukkelberg, S. (2010). The Role of self-identity in the theory of planned behavior: A meta-analysis. *Journal of Applied Social Psychology*, *40*(5), 1085–1105.
- Rivis, A., Sheeran, P., & Armitage, C. J. (2009). Expanding the affective and normative components of the theory of planned behavior: A meta-analysis of anticipated affect and moral norms. *Journal of Applied Social Psychology*, *39*(12), 2985–3019.
- Robinson, N. G., Masser, B. M., White, K. M., Hyde, M. K., & Terry, D. J. (2008). Predicting intentions to donate blood among non-donors in Australia: an extended theory of planned behavior. *Transfusion*, *48*(12), 2559–67.
- Salmon, C.T., Reid, L.N., Pokrywczynski, J. & Willett, R.W. (1985). The effectiveness of advocacy advertising relative to news coverage. *Communication Research*, *12*(4), 546-567.
- Schaaf, R. C., Toth-Cohen, S., Johnson, S. L., Outten, G., & Benevides, T. W. (2011). The everyday routines of families of children with autism: examining the impact of sensory processing difficulties on the family. *Autism : The International Journal of Research and Practice*, *15*(3), 373–389.

- Schieve, L. a, Blumberg, S. J., Rice, C., Visser, S. N., & Boyle, C. (2007). The relationship between autism and parenting stress. *Pediatrics*, *119*, 114–121.
- Siklos, S., & Kerns, K. a. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders*, *36*(7), 921–33.
- Smith, J.R. & McSweeney, A. (2007). Charitable giving: The effectiveness of a revised theory of planned behavior model in predicting donating intentions and behavior. *Journal of Community & Applied Social Psychology*, *17*, 363-386.
- Sofronoff, K., & Farbotko, M. (2002). The effectiveness of parent management training to increase self-efficacy in parents of children with Asperger syndrome. *Autism : The International Journal of Research and Practice*, *6*(3), 271–86.
- Solomon, A. H., & Chung, B. (2012). Understanding autism: how family therapists can support parents of children with autism spectrum disorders. *Family process*, *51*(2), 250–64.
- Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, *18*(4), 228–237.
- Sperry, L. A., Whaley, K. T., Shaw, E., & Brame, K. (1999). Services for young children with Autism Spectrum Disorder: Voices of parents and providers. *Infants and Young Children*, *11*(4), 17–33.
- Stead, M., Tagg, S., MacKintosh, A. M., & Eadie, D. (2005). Development and evaluation of a mass media Theory of Planned Behaviour intervention to reduce speeding. *Health education research*, *20*(1), 36–50.
- Stoner, J. B., & Angell, M. E. (2006). Parent perspectives on role engagement: An investigation of parents of children with ASD and their self-reported roles with education professionals. *Focus on Autism and Other Developmental Disabilities*, *21*(3), 177–189.
- Stoner, J. B., Bock, S. J., Thompson, J. R., Angell, M. E., Heyl, B. S., & Crowley, E. P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, *20*(1), 39–51.

- Sukhodolsky, D. G., Scahill, L., Gadow, K. D., Arnold, L. E., Aman, M. G., McDougle, C. J., McCracken, J. T., et al. (2008). Parent-rated anxiety symptoms in children with pervasive developmental disorders: Frequency and association with core autism symptoms and cognitive functioning. *Journal of Abnormal Child Psychology*, *36*(1), 117–28.
- The Susan G. Komen Breast Cancer Foundation, Inc. (2010). *Consolidated statements of activities*. Consolidated Financial Statements and Supplemental Schedules. Retrieved 15 June 2012.
- Tobing, L. E., & Glenwick, D. S. (2002). Relation of the childhood autism rating scale-parent version to diagnosis, stress, and age. *Research in developmental disabilities*, *23*(3), 211–23. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/12102589>
- Tomanik, S., Harris, G. E., & Hawkins, J. (2004). The relationship between behaviours exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability*, *29*(1), 16–26.
- Villarrubia, A. (2006). *Understanding parents' decisions about serving vegetables to their children*. Retrieved from Louisiana State University Electronic Thesis and Dissertation Collection.
- Wallack L., Dorfman L., Jernigan D., Themba, M. (1993). *Media advocacy and public health: Power for prevention*. Newbury Park, CA: Sage.
- Warburton, J., & Terry, D. J. (2000). Volunteer decision-making by older people: A test of a revised theory of planned behavior. *Basic and Applied Social Psychology*, *22*, 245–257.
- Weiss, M. J. (2002). Hardiness and social support as predictors of stress in mothers of typical children, children with autism, and children with mental retardation. *Autism*, *6*(1), 115–130.
- Winterling, V. (2013). Delaware Autism Program. In *Encyclopedia of Autism Spectrum Disorders online*. Retrieved from <http://www.springerreference.com/docs/html/chapterdbid/334315.html>.
- Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative health research*, *18*(8), 1075–83.
- Zaretsky, L. (2004). Advocacy and administration: from conflict to collaboration. *Journal of Educational Administration*, *42*(2), 270–286.

## **Appendix A**

### **PILOT QUESTIONNAIRE**

We are conducting a study of parents of children with autism in the Delaware Autism Program. We are interested in parents' communication with the teachers and other service providers at the school, as well as parents' involvement with other autism organizations. We would appreciate your responses to some questions about this. There are no right or wrong answers; we are just interested in your personal opinions.

To begin, are you **MALE** or **FEMALE**? (Please circle one).

First, please take a few minutes to tell us what you think about the possibility of communicating with your child's teacher(s) and/or service team within the next week. In response to the questions or prompts that follow, please list as many thoughts as come immediately to mind. Write each thought on a separate line. (Five lines are provided for each question).

- What do you see as the advantages of you communicating with your child's teacher(s) and/or service team within the next week?
- What do you see as the disadvantages of you communicating with your child's teacher(s) and/or service team within the next week?
- What else comes to mind when you think about communicating with your child's teacher(s) and/or service team within the next week?
- Please list any factors or circumstances that would make it easy or enable you to communicate with your child's teacher(s) and/or service team within the next week.
- Please list any factors or circumstances that would make it difficult or prevent you from communicating with your child's teacher(s) and/or service team within the next week.

When it comes to your communicating with your child's teacher(s) and/or service team within the next week, there might be other individuals or groups who come to mind. In response to the prompts that follow, please list the thoughts that come immediately to mind. Write each thought

on a separate line. (Five or six lines are provided for each question). We're interested in general roles (ex: "my sister" or "my colleagues"), not in the names of specific individuals.

- Please list the individuals or groups who would approve or think you should communicate with your child's teacher(s) and/or service team within the next week.
- Please list the individuals or groups who would disapprove or think you should not communicate with your child's teacher(s) and/or service team within the next week.
- Please list the individuals or groups who are most likely to communicate with their child(ren)'s teacher(s) and/or service teams within the next week.
- Please list the individuals or groups who are least likely to communicate with their child(ren)'s teacher(s) and/or service teams within the next week.

Please answer each of the following questions by circling the number that best describes your opinion. Some of the questions may appear to be similar, but they do address somewhat different issues. Please read each question carefully.

For me to communicate with my child's teacher(s) and/or service team within the next week would be

*Extremely bad* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Extremely good*

Communicating with my child's teacher(s) and/or service team within the next week would be

*Extremely useless* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Extremely valuable*

Most people who are important to me approve of my communicating with my child's teacher(s) and/or service team within the next week.

*Strongly disagree* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Strongly agree*

Most other parents at this school will communicate with their child's teacher(s) and/or service team within the next week.

*Extremely unlikely* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Extremely likely*

It is expected of me that I communicate with my child's teacher(s) and/or service team within the next week.

*Definitely false* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Definitely true*

I am confident that I can communicate with my child's teacher(s) and/or service team within the next week.

*Definitely false* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Definitely true*

My communicating with my child’s teacher(s) and/or service team within the next week is entirely up to me.

*Strongly disagree* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Strongly agree*

I intend to communicate with my child’s teacher(s) and/or service team within the next week.

*Extremely unlikely* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Extremely likely*

In the past week, I have communicated with my child’s teacher(s) and/or service team.

*Definitely false* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Definitely true*

Next, please take a few minutes to tell us what you think about the possibility of attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months. In response to the questions that follow, please list the thoughts that come immediately to mind. Write each thought on a separate line. (Five lines are provided for each question).

- What do you see as the advantages of you attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months?
- What do you see as the disadvantages of you attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months?
- What else comes to mind when you think about attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months?
- Please list any factors or circumstances that would make it easy or enable you to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.
- Please list any factors or circumstances that would make it difficult or prevent you from attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

When it comes to your attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months, there might be other individuals or groups who come to mind. In response to the prompts that follow, please list the thoughts that come immediately to mind. Write each thought on a separate line. (Five or six lines are provided for each question). We’re interested in general roles (ex: “my sister” or “my colleagues”), not in the names of specific individuals.

- Please list the individuals or groups who would approve or think you should attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

- Please list the individuals or groups who would disapprove or think you should not attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.
- Please list the individuals or groups who are most likely to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.
- Please list the individuals or groups who are least likely to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

Please answer each of the following questions by circling the number that best describes your opinion. Some of the questions may appear to be similar, but they do address somewhat different issues. Please read each question carefully.

For me to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months would be

*Extremely bad* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely good*

Attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months would be

*Extremely useless* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely valuable*

Most people who are important to me approve of my attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

Most other parents at this school will attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Extremely unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely likely*

It is expected of me that I attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Definitely false* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely true*

I am confident that I can attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Definitely false* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely true*

My attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months is entirely up to me.

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

I intend to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Extremely unlikely* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Extremely likely*

In the past three months, I have attended an event hosted by an autism advocacy organization (e.g., Autism Delaware).

*Definitely false* :   1   :   2   :   3   :   4   :   5   :   6   :   7   : *Definitely true*

***Thank you so much for your participation!***

You have made a valuable contribution to my research and to the autism community!

If you'd like, take a moment to give us any feedback you have about filling out this questionnaire:

## **Appendix B**

### **PARENT LETTER – PILOT STUDY**

Dear Parent and/or Guardian:

My name is Dacey McGinty, and I am a second year Master's student in the Department of Communication at the University of Delaware. As part of my graduation requirements, I am conducting a survey that will eventually be the subject matter of my Masters' thesis. For this project, I wish to examine the type and extent of advocacy exhibited by parents of children with autism. I am hoping to understand the factors that predict parental advocacy so that I might further our knowledge about advocacy in general, as well as to provide important information to the autism community.

The purpose of this letter is to acquaint you with this study and invite you to participate by completing the enclosed survey. This should take no more than 20 minutes of your time and is completely anonymous. Your responses are valuable, so please return the questionnaire via the enclosed self-addressed, stamped envelope within one week of receiving it.

Please be assured that Brennen School and the Delaware Autism Program has not and will not release any information about you or your child(ren), including your names. Your participation will be totally and completely anonymous. The only information collected will be that which is provided voluntarily by you through the survey.

The enclosed questionnaire provides a further introduction and explanation of the survey items, but please feel free to contact me before, during, or after the process if you have any questions. My contact information is listed below.

I have included an autism awareness pen as a small token of my appreciation in advance for your time and valuable input. I hope that you will be a part of my project, which I am confident has the potential to make an important contribution to the autism community. Thank you!

Sincerely,

Dacey McGinty  
Dept. of Communication  
University of Delaware  
[dmcginty@udel.edu](mailto:dmcginty@udel.edu)  
(412)-952-4165

## Appendix C

### CONTENT ANALYSIS TABLES: INDIVIDUAL BEHAVIOR

Original Responses (Frequency)	Categories
School and home can support each other Reinforce learning Enhance consistency Ideas about what to work on at home Helpful suggestions	Consistency between home and school
To learn what goes on daily Know about my son's day (nonverbal) Daily progress	Knowing what happens during my child's school day
Insight of changing strengths Communicating milestones To see how my child is doing Staying informed Know about my son's mood (nonverbal) Behavior changes Behavioral changes	Learning about changes in my child (Behavior, mood, strengths, etc.)
Progress toward IEP goals Changes to work goals Staying on top of our child's progress	Tracking progress toward my child's goals
Being part of the team Working together to make sure my child gets the best education Lines of communication remain open Keep lines of communication open Keeping in contact with teachers	Feeling like a part of my child's support team

Making the right decisions in my child's process	No categorization created
Schedule runs smoothly	
The only way teachers learn about my child's evenings and weekends	

*Table 1: Individual behavior; Advantages*

<b>Original Responses (Frequency)</b>	<b>Categories</b>
Mother Sister-in-law Brother-in-law Brother Family (3)	Members of my immediate family
Spouse (3)	Spouse
Teachers (2)	My child's teachers
My child's doctors Pediatrician OT (occupational therapist)	My child's doctors
Friends (2)	No categorization created
Myself	
DVR (Division of Vocational Rehabilitation)	
POWER (Autism Delaware's self-advocacy group)	

*Table 2: Individual behavior; Those who would approve*

<b>Original Responses (Frequency)</b>	<b>Categories</b>
E-mail communication (6) Having access to ALL team members' e-mail addresses	Email communication
Phone calls (4)	Phone calls
Comfort with teacher	Comfort with teacher
Progress Sheet	No categorization created
Picking my child up at school	
Communication log	

*Table 3: Individual behavior; Make is easy*

<b>Original Responses (Frequency)</b>	<b>Categories</b>
Not having time Time of day Work schedule Meeting during the work day	Spare time
Face-to-face meetings Meeting up	Face-to-face meetings
None	No categorization created
When teacher comments aren't helpful	

*Table 4: Individual behavior; Make it difficult*

<b>Original Responses (Frequency)</b>	<b>Categories</b>
Parents who care about their children Parents with minimally verbal children	No categorization created

*Table 5: Individual behavior; Likely to perform behavior themselves\**

Original Responses (Frequency)	Categories
Parents who don't care about their children Parents of kids capable of communicating the events of the day Parents who don't have free time	No categorization created

*Table 6: Individual behavior; Unlikely to perform behavior themselves\**

\*These categories were not included in the standard questionnaire because responses came from only one respondent. Other participants left the prompts blank or indicated confusion with question marks (“?”). The standard questionnaire will include a direct measure item for descriptive beliefs, but not belief-based items.

## Appendix D

### CONTENT ANALYSIS TABLES: COMMUNITY BEHAVIOR

Original responses (Frequency)	Categories
Learning ways to help my son Information to help navigate issues for my son New information Educational	Getting information that pertains to my child
Updates and new techniques (2) Learning about new autism finds	Knowing about updates and new techniques in the autism community
Interacting with others who have been there/done that and understand Interacting Communicating with other parents Networking with other parents (2) Soundboard General kinship Seeing my friends	Interacting with other parents of children with autism  --AND –  Having a support system
Friendly environment Welcoming	Welcoming environment

*Table 1: Community behavior; Advantages*

<b>Original responses (Frequency)</b>	<b>Categories</b>
Hours in line with working families Evening hours because I work full-time Evening hours (3) Weekend hours Daytime hours because my child is in school	Evening hours
If child care/respice was provided (4)	Child care/respice
If it's close by	No category created
Advance notice	

*Table 2: Community behavior; Make it easy*

<b>Original responses (Frequency)</b>	<b>Categories</b>
Hours conflicting with working families Daytime hours Nighttime events	Evening hours
Child care/respice is not provided/available (4)	Child care/respice
The day Scheduling conflicts Work schedule Family issues	Scheduling conflicts or difficulties
My health	Health issues
It's far away	No category created
If the event has multiple sessions	

*Table 3: Community behavior; Make it difficult*

## Appendix E

### FINAL QUESTIONNAIRE

Q1 Please select the description that best fits your opinion of the following items.

- Knowing what happens during my child's school day is
- Learning about changes in my child (behavior, mood, strengths, etc.) is
- Tracking progress toward my child's goals is
- Consistency between home and school is
- Feeling like a part of my child's support team is

*Extremely bad* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely good*

Q2 If I communicate with my child's teacher(s) and/or service team within the next week, I will:

- Know what happens during my child's school day
- Learn about changes in my child (behavior, mood, strengths, etc.)
- Track progress toward my child's goals
- Maintain consistency between home and school
- Feel like a part of my child's support team

*Extremely unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely likely*

Q3 When it comes to matters pertaining to my child,

- I want to do what my spouse or partner thinks I should do
- I want to do what members of my immediate family think I should do
- I want to do what my child's teachers think I should do
- I want to do what my child's doctors think I should do

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

Q4 The following people or groups of people think I should communicate with my child's teacher(s) and/or service team within the next week.

- My spouse or partner
- Members of my immediate family
- My child's teachers
- My child's doctors

*Highly improbable* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Highly probable*

Q5 The following things would enable or make it easy for me to communicate with my child's teacher(s) and/or service team within the next week.

- Having spare time
- Meeting up face-to-face
- Communicating via e-mail
- If we talked over the phone
- Feeling comfortable with my child's teacher(s) and/or service team

*Strongly disagree* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Strongly agree*

Q6 In the following week, how likely is it that the following statements will be true?

- I will have spare time
- I will have a face-to-face meeting with my child's teacher(s) and/or service team
- I will communicate via e-mail with my child's teacher(s) and/or service team
- I will have a phone conversation with my child's teacher(s) and/or service team
- I will feel comfortable with my child's teacher(s) and/or service team

*Highly unlikely* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Highly likely*

Q7 To communicate with my child's teacher(s) and/or service team within the next week would be

*Very bad* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Very good*

Q8 My communicating with my child's teacher(s) and/or service team within the next week would be

*Extremely useless* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Extremely valuable*

Q9 Communicating with my child's teacher(s) and/or service team within the next week would be

*Very unpleasant* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Very pleasant*

Q10 Most people who are important to me think that I should communicate with my child's teacher(s) and/or service team within the next week.

*Strongly disagree* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Strongly agree*

Q11 Most people whose opinions I value would approve of my communicating with my child's teacher(s) and/or service team within the next week.

*Definitely false* :  1 :  2 :  3 :  4 :  5 :  6 :  7 : *Definitely true*

Q12 Most other parents at this school will communicate with their child's teacher(s) and/or service team within the next week.

*Extremely unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely likely*

Q13 Communicating with my child's teacher(s) and/or service team within the next week is entirely up to me.

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

Q14 To communicate with my child's teacher(s) and/or service team within the next week is under my control.

*Not at all* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Completely*

Q15 I intend to communicate with my child's teacher(s) and/or service team within the next week

*Definitely do not* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely do*

Q16 I will communicate with my child's teacher(s) and/or service team within the next week:

*Very unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Very likely*

Q17 I have communicated with my child's teacher(s) and/or service team within the past week.

*Definitely false* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely true*

Q18 Please select the description that best fits your opinion of the following items.

- Getting information that pertains to my child is
- Knowing about updates and new techniques in the autism community is
- Interacting with other parents of children with autism is
- Having a support system is
- Being in a welcoming environment is

*Extremely bad* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely good*

Q19 If I attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months, I will:

- Hear information that pertains to my child
- Get updates and new techniques in the autism community
- Interact with other parents of children with autism
- Have a support system
- Experience a welcoming environment

*Extremely unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely likely*

Q20 The following people or groups of people think I should attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

- My spouse or partner
- Members of my immediate family
- My child's teachers

- My child's doctors

*Highly improbable* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Highly probable*

Q21 The following things would make it easier for me to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

- Having spare time
- If childcare or respite was available
- If the event took place during evening hours
- If I experienced scheduling conflicts or difficulties
- If I experienced health issues

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

Q22 In the following three months, how likely is it that the following statements will be true?

- I will have spare time
- Childcare and respite will be readily available
- My evenings will be free
- I will experience scheduling conflicts and difficulties
- I will have health issues

*Extremely unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely likely*

Q23 To attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months would be

*Very bad* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Very good*

Q24 My attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months would be

*Extremely useless* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely valuable*

Q25 Attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months would be

*Very unpleasant* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Very pleasant*

Q26 Most people who are important to me think that I should attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

Q27 Most people whose opinions I value would approve of my attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Definitely false* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely true*

Q28 Most other parents at this school will attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Extremely unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Extremely likely*

Q29 Attending an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months is entirely up to me.

*Strongly disagree* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Strongly agree*

Q30 To attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months is under my control.

*Not at all* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Completely*

Q31 I intend to attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months.

*Definitely do not* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely do*

Q32 I will attend an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the next three months

*Very unlikely* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Very likely*

Q33 I have attended an event hosted by an autism advocacy organization (e.g., Autism Delaware) within the past three months

*Definitely false* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Definitely true*

Q34 Are you male or female?

Male (1)

Female (2)

Q35 What is your marital status?

Single (1)

Married (2)

Divorced (3)

Widowed (4)

Other (5)

Q36 How many children do you have?

Q37 How old is your child (who is enrolled in the Delaware Autism Program)?

Q38 Where do you feel your child with autism falls on the spectrum?

*Very low functioning* :  1 : 2 : 3 : 4 : 5 : 6 : 7  : *Very high functioning*

Q39 How would you rate the severity of your child's autism, in terms of symptoms and impact on your child?

Severe (1)

Moderate (2)

Mild (3)

Q40 In the past, I have advocated to get additional and/or improved services for my child with autism.

True (1)

False (2)

Q40a My past experience advocating to get additional and/or improved services for my child with autism was:

*Extremely negative* : 1 : 2 : 3 : 4 : 5 : 6 : 7 : *Extremely positive*

Q41 How would you rate your average stress level? "1" being "Not stressed at all" and "10" being "Extremely overwhelmed"

Q42 What is your highest level of education?

- Less than High School/GED (1)
- High School Diploma/GED (2)
- Some College (3)
- Bachelor's Degree (4)
- Master's Degree (5)
- Doctoral Degree (6)

Q43 What is your average annual household income?

- Less than \$20,000 (1)
- \$20,000 to \$39,999 (2)
- \$40,000 to \$59,999 (3)
- \$60,000 to \$79,999 (4)
- \$80,000 to \$99,999 (5)
- \$100,000 to \$150,000 (6)
- More than \$150,000 (7)

## Appendix F

### PARENT LETTERS – FINAL STUDY

*(Original Letter)*

Dear Parent and/or Guardian:

My name is Dacey McGinty, and – with your help – I am graduating this spring with a Master’s degree in Communication from the University of Delaware. As part of my graduation requirements, I’m conducting a survey that will be the primary subject matter of my Master’s thesis. For this project, I’m examining the type and extent of advocacy exhibited by parents of children with autism. I’m hoping to understand the things that affect your experience as a parent of a child with autism so that the autism community can better appreciate your needs.

Some of you may have helped build this project by filling out my initial, free-response questionnaire. I want to thank you and invite you to continue to be a part of this important research. If this is your first letter, I hope it acquaints you with the study and that you, too, will participate by entering the link below:

<http://tinyurl.com/DAPsurvey>

Entering the link will provide you with additional directions for the survey, which should take no more than 15 minutes of your time and is completely anonymous. Your responses are valuable and this project is time-sensitive, so **please complete the survey within two weeks of receiving this letter.**

Please be assured that the Delaware Autism Program has not and will not release any information about you or your child(ren), including your names. Your participation will be totally and completely anonymous. The only information collected will be that which is provided voluntarily by you through this survey.

If you have any questions or concerns before, during, or after your survey experience, please feel free to contact me. My contact information is listed below. I truly appreciate your time and valuable input, which has the potential to make an important contribution to the autism community and is essential for my graduation this spring.

Sincerely,  
Dacey McGinty

*(Reminder Letter 1)*

Dear Parent and/or Guardian,

If you have already taken the time to fill out the autism advocacy survey that I introduced in my letter a few weeks ago, please consider this my sincerest “thank you” for your valuable input.

If you haven’t had a chance to take part yet, please follow the link below to answer a few questions about your experiences. The parents who have participated so far have needed an average of **8 minutes** to finish the survey. You can even pause and come back to it if something comes up!

<http://tinyurl.com/DAPsurvey>

I realize your time is precious, but so is your unique insight on caring for a child with autism. This project has been a year in the making, and your involvement is essential for its success. In addition to being a graduation requirement for me, I truly believe this research will make an important impact in the autism community. I hope you’ll be a part of it. If you choose to participate, **please complete the survey by May 1, 2013.**

In honor of Autism Awareness Month, I thank you in advance for your distinctive contribution to the cause! As always, please don’t hesitate to contact me with any questions, comments, or concerns.

Kindest Regards,

Dacey McGinty  
[dmcginty@udel.edu](mailto:dmcginty@udel.edu)  
(412) 952-4165

*(Reminder Letter 2)*

Dear Parent and/or Guardian,

This is my final plea for your participation in my research project, which depends on your valuable input concerning your experiences. My first letter went home with 400 students on March 25<sup>th</sup>, but I have only gotten 35 responses since then. I would like to extend my sincerest appreciation to those individuals, and ask the rest of you to please consider participating.

Without at least 30 more responses, I will need to abandon the project and further delay my graduation. Beyond its significance as a graduation requirement, this project has come to mean a lot to me and I'd really like to see it through to the end.

I understand how precious your spare time is, and I have designed the survey as such: it should take you **less than 10 minutes** to complete.

If you haven't had a chance to take part yet, please follow the link below to answer a few questions about your experiences and make an important contribution to this project and to the autism community!

<http://tinyurl.com/DAPsurvey>

If you choose to participate, please complete the survey as soon as possible, preferably **within one week** of receiving this letter. Thank you in advance for your involvement!

As always, please don't hesitate to contact me with any questions, comments, or concerns.

Very Sincerely,

Dacey McGinty  
[dmcginty@udel.edu](mailto:dmcginty@udel.edu)  
(412) 952-4165

## **Appendix G**

### **IRB APPROVAL LETTER – PILOT STUDY**

DATE: January 14, 2013

TO: Dacey McGinty

FROM: University of Delaware IRB

  

STUDY TITLE: [417521-1] M.A. Thesis: Parental Advocacy in the Autism Community

  

SUBMISSION TYPE: New Project

  

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: January 14, 2013

REVIEW CATEGORY: Exemption category # 2

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will put a copy of this correspondence on file in our office. Please remember to notify us if you make any substantial changes to the project.

If you have any questions, please contact Jody-Lynn Berg at (302) 831-1119 or [jlberg@udel.edu](mailto:jlberg@udel.edu). Please include your study title and reference number in all correspondence with this office.

## Appendix H

### IRB APPROVAL LETTER – FINAL STUDY

DATE: March 22, 2013  
TO: Dacey McGinty  
FROM: University of Delaware IRB

STUDY TITLE: [445968-1] M.A. Thesis: Parental Advocacy and Autism

SUBMISSION TYPE: New Project

ACTION: DETERMINATION OF EXEMPT STATUS

DECISION DATE: March 22, 2013

REVIEW CATEGORY: Exemption category # 2

Thank you for your submission of New Project materials for this research study. The University of Delaware IRB has determined this project is EXEMPT FROM IRB REVIEW according to federal regulations.

We will put a copy of this correspondence on file in our office. Please remember to notify us if you make any substantial changes to the project.

If you have any questions, please contact Jody-Lynn Berg at (302) 831-1119 or [jlberg@udel.edu](mailto:jlberg@udel.edu). Please include your study title and reference number in all correspondence with this office.