

EVALUATING PATTERNS OF TREATMENT ACCESS AND INTEREST IN  
PARENTS AND TYPICALLY DEVELOPING SIBLINGS OF INDIVIDUALS WITH  
ASD

By

LAUREN A. PEPA

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## ABSTRACT OF THE DISSERTATION

Evaluating Patterns of Treatment Access and Interest in Parents and Typically

Developing Siblings of Individuals with ASD

By LAUREN A. PEPA

Dissertation Director:

Sandra L. Harris, Ph.D.

A diagnosis of autism spectrum disorder (ASD) has a significant and pervasive effect on the family unit. Research on parents suggests that both mothers and fathers experience more stress than parents of typically developing individuals and those with other developmental disabilities. This places parents at risk for negative psychosocial outcomes, including depression, anxiety, and marital dissatisfaction. Research on typically developing siblings is much more mixed, however the literature converges to suggest that siblings experience multiple stressors that can place them at risk for a negative outcome as well. Together, these findings indicate that families require high quality support services to address their needs. Over the past several decades, researchers and clinicians have investigated several support options for families, however there have been significant limitations in the ability to disseminate these valuable services to families in need. As such, it is important to measure service access and interest in families of individuals with ASD, and to investigate the factors that facilitate and limit engagement. The present study used an online survey to access 158 families from across the United States who had a child with ASD as well as one typically developing child.

The questionnaires included information about family demographics, service engagement variables for parents and siblings, as well as psychosocial variables about the parent and the child with ASD. Parent psychosocial variables included measures of parent stress, psychiatric symptoms, and social support. Symptom severity for the child with ASD was also measured. Results indicated that service engagement varied considerably by demographic variables, including parent and child gender, race, parent education, and child age. Parent interest and perception of services did not correspond to service engagement in this sample. Instead, high ratings of perceived ASD symptom severity, higher levels of parent stress, greater social support, lower endorsement of psychiatric symptoms, and greater perception of parent finances all predicted engagement for both parents and siblings. This study yielded important information about the service needs of families of individuals with ASD, and factors that may contribute to their decision making. The implications of the present findings, limitations, and future directions are also discussed.

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## TABLE OF CONTENTS

|   | PAGE |
|---|------|
| ABSTRACT.....   | ii   |
| ACKNOWLEDGEMENTS.....                                     | iv   |
| TABLE OF CONTENTS.....                                    | vi   |
| LIST OF TABLES.....                                       | vii  |
| INTRODUCTION.....   | 1    |
| METHOD.....   | 30   |
| RESULTS.....  | 37   |
| DISCUSSION.....   | 89   |
| REFERENCES.....   | 113  |
| APPENDICES  |      |
| A: Demographics and Family Profile Questionnaire.....     | 118  |
| B: Family Support Questionnaire (FSQ).....                | 122  |
| C: Inventory of Socially Supportive Behaviors (ISSB)..... | 143  |

## LIST OF TABLES

| Table   | Page |
|---|------|
| 1. Demographics of Parents.....   | 39   |
| 2. Family Demographics.....   | 40   |
| 3. Means and Standard Deviations of<br>Dependent Measures.....                                  | 45   |
| 4. Pearson Correlations among<br>Dependent Variables- Whole Sample.....                         | 47   |
| 5. Pearson Correlations among<br>Dependent Variables- Screen Pass Sample.....                   | 49   |
| 6. Pearson Correlations among<br>Dependent Variables- Screen Fail Sample.....                   | 51   |
| 7. Means and Standard Deviations of Service Engagement for<br>Parents and Siblings.....         | 54   |
| 8. Endorsement of Past Parent Service Access by Service Type.....                               | 55   |
| 9. Endorsement of Future Parent Service Access by Service Type.....                             | 56   |
| 10. Endorsement of Past Sibling Service Access by Service Type.....                             | 57   |
| 11. Endorsement of Future Parent Service Access by Service Type.....                            | 58   |
| 12. Means and Standard Deviations of Service Access/Interest Factors.....                       | 61   |
| 13. Means and Standard Deviations of Demographics by<br>Service Access-Whole Sample.....        | 65   |
| 14. Means and Standard Deviations of Demographics by<br>Service Access- Screen Pass Sample..... | 66   |
| 15. Means and Standard Deviations of Demographics by<br>Service Access-Screen Fail.....         | 67   |
| 16. Means and Standard Deviations of Service Access<br>Factors by Gender.....                   | 68   |

|  |    |
|--|----|
| 17. Means and Standard Deviations of Service Access<br>Factors by Race.....                                    | 69 |
| 18. Correlations between Service Access and<br>Access Factors- Whole Sample.....                               | 72 |
| 19. Correlations between Service Access and<br>Access Factors- Screen Pass Sample.....                         | 73 |
| 20. Correlations between Service Access and<br>Access Factors- Screen Fail Sample.....                         | 74 |
| 21. Correlations between Service Access/Interest Variables and<br>Dependent Variables- Whole Sample.....       | 79 |
| 22. Correlations between Service Access/Interest Variables and<br>Dependent Variables- Screen Pass Sample..... | 80 |
| 23. Correlations between Service Access/Interest Variables and<br>Dependent Variables- Screen Fail Sample..... | 81 |
| 24. Hierarchical Regression of Predictors of Past Parent<br>Service Access- Whole Sample.....                  | 83 |
| 25. Hierarchical Regression of Predictors of Past Sibling<br>Service Access- Whole Sample.....                 | 85 |
| 26. Hierarchical Regression of Predictors of Future Parent<br>Service Access- Whole Sample.....                | 87 |
| 27. Hierarchical Regression of Predictors of Future Sibling<br>Access- Whole Sample.....                       | 89 |



## Introduction

Autism spectrum disorders (ASD) have a profound influence on the day-to-day functioning of affected individuals. This includes difficulties with effective communication and social functioning, as well as the presence of restricted interests and repetitive behaviors (APA, 2014). Further, individuals with ASD often exhibit high rates of intellectual disability, and maladaptive behaviors, including aggression, self-injury, and property disruption (Shattuck et al., 2007). Research has shown that all of these cumulative difficulties hold significant functional implications for the individual with ASD. This includes the disruption of age-appropriate social relationships, as well as impairments in learning and acquisition of important academic skills (Klin et al., 2007). Further, the presence of this constellation of symptoms is evident throughout the lifespan, and therefore introduces novel challenges as the individual with ASD ages (Gotham et al., 2015; Moss, Howlin, Savage, Bolton, & Rutter, 2015; Taylor, Henninger, & Malick, 2015).

Given these well-documented stressors, researchers and clinicians alike have dedicated significant resources to the assessment and treatment of individuals with ASD. These efforts span professional disciplines and range from single-case design studies to genetics collections containing tens of thousands of participants. Further, significant amounts of federal and private funding are allocated to autism-specific research each year. For example, the signing of the Autism CARES Act in 2014 dedicated \$1.3 billion in federal funds to ASD research over the next five years, and pledges to continue the prioritization of the ASD clinical and research community.

## Impact of ASD on Parent Stress

While this allocation of funding is essential for the assistance of affected individuals, the impact of ASD does not stop at the child. Instead, it has been repeatedly demonstrated that autism spectrum disorders (ASD) introduce significant and pervasive stress into the family unit as a whole (Baker-Ericzen et al., 2005; Conway & Meyer, 2008; Hastings & Brown, 2002). Research in this area has largely focused on parents, and the effect of having a child with ASD on parent stress and psychosocial functioning. The literature unequivocally demonstrates that parents of children with ASD experience levels of distress that are distinct from the stresses of parenting a typically-developing child (Conway & Meyer, 2008; Olsson & Hwang, 2001). Parents of children with disabilities, such as ASD, experience the psychological loss of an idealized child, or a change in expectations of their child's future following a disability diagnosis (Glasberg, 2000). This adjustment can result in great amounts of parent stress over time. However, it appears that parents of a child with ASD experience stress that is distinct even from parents of children with other developmental disabilities or Down Syndrome (Conway & Meyer, 2008; Glasberg, 2000).

Researchers speculate that this unique effect of ASD on parents can be attributed to the core symptom domains and the pervasiveness of the ASD diagnosis (Abbeduto et al., 2004; Hastings, 2003). However, this global distress is moderated by several child and parent factors. Most conclusively, research indicates that symptom severity of core ASD characteristics can positively predict parent adaptation and adjustment (Hastings, 2003; Hayes & Watson, 2013). Specifically, across symptom presentations, those parents who have a child who is only mildly affected by ASD symptoms will have improved

adaptation and adjustment. Researchers have also investigated each core symptom in isolation and found similar results. Looking first at the communication domain, children who have more difficulties with effective functional communication will likely have parents with more distress (Frey, Fewell, & Vadasy, 1989). This is related to child difficulties communicating wants and needs, and subsequent parent difficulty interpreting their children's efforts. This miscommunication can lead to increases in problem-behavior among children, and increased levels of frustration and helplessness among parents. Further, difficulties with communication can also negatively impact social communication, and particularly social and emotional reciprocity with parents. In this way, children are not able to communicate their thoughts and feelings to parents, which can be a profound emotional stressor.

Similarly, impairments in social functioning cause children to have difficulty forming social connections, including friendships and other significant relationships. This can increase parent concern about their child's immediate social isolation, as well as concerns about their future care (Frey et al., 1989). While parents of typically-developing children may worry about their maturing child finding friendships and romantic relationships in the future, the impairments in fundamental social skills and social awareness can heighten these fears in the parent of a child with ASD. This is particularly true if the child with ASD has significant impairments or delays in this area (Frey et al, 1989; Pozo & Sarria, 2015).

Lastly, the presence of high rates of stereotyped or repetitive behaviors is associated with increased parent stress and difficulties with adaptation (Gabriels, Cuccaro, Hill, Ivers, & Goldson, 2004). Similar to concerns about more general social

functioning, parents of children with high rates of these behaviors may express worry about social stigmatization and isolation for their child. In addition to social feedback, these interests may also result in behavioral difficulties for the child with ASD. For example, it may be difficult for the child to deviate from highly preferred interests, and this can result in significant problem behavior (Gabriels et al., 2004). Further, repetitive or stereotyped behavior may negatively influence a child's acquisition of skills, and academic progression. The presence of maladaptive behaviors, including aggression and self-injury also bring along the same concerns (Baker et al., 2003). In addition to social stigma, parents also have to be concerned about keeping their child safe. Witnessing children hurting themselves, or others, is incredibly distressing to parents, and as such, high rates of this behavior significantly increases difficulty with parent adjustment.

In addition to core autism features, other moderators of parent stress include gender and age of the affected child. Specifically, research suggests that parents adjust more easily to having a female child with ASD than a male child. This is particularly true for fathers of these children, which may be related to gender-specific parent expectations of male children (Frey et al., 1989). The research on the effects of child age on parent stress is much less clear. Some longitudinal research suggests that early childhood is the most stressful period for parents, citing a number of shifting concerns over time (Lounds, Seltzer, Greenberg, & Shattuck, 2007). For example, parents of young children are required to secure diagnostic and intervention services as early as possible in order to achieve optimal outcomes for their children later in life. Further, the same longitudinal studies cite the research on the trajectory of ASD symptoms over time, noting that both ASD symptom severity and behavior problems generally are found to decrease over time

(Shattuck et al., 2007). As such, this decrease in general psychopathology can improve the overall wellbeing of parents (Pozo & Sarria, 2015). However, other studies would suggest that late adolescence and early adulthood are the more stressful times for parents (Scorgie et al., 1998). In this period, parents are coming to terms with the reality of the pervasiveness of their child's difficulties, and are beginning to plan for their adulthood. Further, parents and their adult children may face the difficulties with securing vocational placements, or adult day programs, which place a strain on a parent's physical and emotional resources (Shattuck et al., 2012). While the results on age are varied, taken together they suggest that parents experience significant stress across their child's lifespan as new challenges are introduced.

#### Parent Psychosocial Adjustment

Taken together, this research suggests that parents of children with ASD are susceptible to tremendous amounts of stress stemming from a constellation of areas. It is therefore unmistakable that parents of children with ASD are placed at greater risk for negative psychosocial outcomes than parents of typically developing children. This includes several negative health outcomes, including depression, marital dissatisfaction, and decreased perception of parenting competence (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). Specifically, higher rates of depression are reported among both mothers and fathers of individuals with ASD (Olsson & Hwang, 2001). This is also true of other mental health problems (Abbeduto et al., 2004; Kuhlthau et al., 2014). Further, parents of individuals with ASD report generally lower marital satisfaction and family cohesion as compared to typical families, or families of individuals with other disabilities (Gau et al., 2012; Higgins, Bailey, & Pearce, 2005).

This body of literature suggests that symptom severity and ASD characteristics are the primary predictors of parent outcomes. However, there are some individual parent characteristics that can moderate adaptation and psychosocial wellbeing (Lyons, Leon, Roecke Phelps, & Dunleavy, 2010). Specifically, parent appraisal of stressful situations, and individual coping strategies, can greatly moderate parent adaption (Dunn et al., 2001; Packenham, Sofronoff, & Samios, 2005). Looking first at appraisal, it has been said that a sense of efficacy and optimism greatly facilitate parent adaptation. With regard to efficacy, parents who feel more competent raising their child with ASD are reported to have better psychosocial outcomes (Hastings & Brown, 2002). Specifically, mothers with higher endorsement of efficacy reported lower rates of depression than those with low efficacy, while fathers with high efficacy scores reported lower levels of anxiety than fathers with low efficacy. Parent perspective on their child's disability was also shown to influence resilience and adaptation (Baker, Blacher, & Olsson, 2005). Parents who have higher levels of optimism, or positive feelings about their child's disability report significantly less stress than parents with less optimism. Further, those who can attribute a broader meaning to a diagnosis of ASD were found to have better adaptation than those parents who struggle with those issues (Packenham, Sofronoff, & Samios, 2005).

Additionally, parent coping strategies have also been shown to greatly moderate parent stress. Specifically, those parents who can more effectively manage their individual stress by using internal and external resources are less likely to have negative outcomes than those who lack such resources (Dunn et al., 2001). Looking first at external resources, financial and social supports are primary coping strategies for parents. For example, having a child with ASD poses several practical challenges that greatly

impact family resources. This includes the importance of securing assessment and treatment services, which can be financially demanding in addition to requiring a substantial time commitment. As such, research has suggested that parents with greater financial resources are less stressed (Yau & Li-Tsang, 1999). Having the ability to better manage the financial requirement, or to secure outside assistance, has proven to be a significant buffer for families. Similarly, higher levels of social support facilitate parent adjustment in the same way (Pozo & Sarria, 2014a; Yau & Li-Tsang, 1999). Families that have individuals in their social network who can assist with daily tasks, or even provide emotional support, are highly valued to an already-stressed family unit.

Looking at internal resources for parents, it has largely been found that task-oriented coping is more adaptive than emotion-oriented coping (Lyons, Leon, Phelps, & Dunleavy, 2010). Emotion-oriented coping focuses on relieving or changing one's negative emotions, while task-oriented coping involves using behaviorally or cognitively active strategies to alleviate stress. This suggests that parents will respond more positively to learning skills that focus on eliminating stress. However, it has largely been found that parents who rate their child's symptom severity the highest, or the parents who are most stressed, are more likely to practice emotion-focused coping strategies such as distraction or avoidance. This places the most vulnerable parents at greater risk for poor outcomes (Lyons et al., 2010).

Taken together, research unmistakably suggests that having a child with ASD has a significant effect on parents. The specific symptom profile of ASD, as well as the practical challenges it introduces into the family, can all impact the psychosocial adjustment of caregivers. However, there is also evidence that these stressors can be

moderated by parent factors, such as coping and perspective, and support factors, such as finances and social support, which may be amendable to intervention.

### Sibling Psychosocial Adjustment

While receiving less research attention, it is clear that siblings of children with ASD are also impacted by their affected brother or sister (Verte, Roeyers, & Buysse, 2003). The sibling relationship has been found to have a unique and significant role in very valuable developmental areas. First, the relationship between siblings typically outlasts any other relationship in one's life (Conway & Meyer, 2008; Kaminsky & Dewey, 2001). Siblings are commonly introduced early in childhood, predating friendships and romantic partners, and remain late into adulthood, often outlasting parents and other family members. Given this shared history, siblings can be an integral source of mutual social support (Kaminsky & Dewey, 2001; Orsmond & Seltzer, 2007a). Siblings also share an important environmental context. Resources within the home, such as the time, financial, and emotional resources of parents and other family members are split among siblings. Given this shared environment as very young children, siblings have a crucial role in the development of social skills (Abramovitch, Pepler, & Corter, 1982; Kaminsky & Dewey, 2001). Brothers or sisters serve as a child's first play partner, and provide ample opportunities for their sibling to learn important social rules through play. Interactions with siblings can then provide valuable opportunities to learn appropriate prosocial behaviors and social norms through direct behavioral feedback (Kaminsky & Dewey, 2001; Ross & Cuskelly, 2006). This feedback, and subsequent opportunity to learn and practice these important skills, contributes to the overall adjustment and psychosocial wellbeing of children (Ross & Cuskelly, 2006).



However, much like the parent-child relationship, the sibling dyad is significantly affected when one member is diagnosed with ASD as a result of the specific pattern of symptoms intrinsic in the diagnosis itself (Kaminsky & Dewey, 2001). On a most basic level, siblings of children with ASD largely share the same genetic predispositions as their affected brother or sister (Benson & Karlof, 2008). As such, this genetic risk may inherently leave siblings more at risk for developing psychosocial and medical difficulties over the course of their lifetime. Further, a host of behavioral and developmental differences have an effect on the sibling dyad.

Inherent in social and communication deficits are the limited use of eye contact, fewer spontaneous play bids, and limited reciprocal interaction (Celiberti & Harris, 1993; Knott, Lewis, & Williams, 1995). Together, these behaviors make it especially challenging for typically developing children to interact and play with their brother or sister, and may negatively impact the sibling relationship (Celiberti & Harris, 1993). Several research studies have evaluated these differences in sibling interaction by comparing ASD dyads to neurotypical pairs, and sibling dyads that included a child with Down Syndrome (Kaminsky & Dewey, 2001; Knott et al., 1995). These studies revealed that play behavior in the ASD dyads was generally below age level, and often relied on more developmentally immature behaviors, such as imitation. Fewer prosocial behaviors were recorded on the part of the child with ASD, and initiations for play for both members of the dyad were lower than those in the Down Syndrome group (Kaminsky & Dewey, 2001; Knott et al., 1995). This is further corroborated by self-report data of neurotypical siblings. Siblings of individuals with ASD reported less prosocial behavior, less intimacy and less nurturance than siblings of those with Down Syndrome or

neurotypical children.

In addition to discouraging play behavior, research has shown that siblings are particularly sensitive to the presence of externalizing behaviors in ASD. When siblings are asked to provide a description of ASD, children of all ages first mention external characteristics, such as motor stereotypy, impairments in effective communication and maladaptive behavior, such as tantrums (Glasberg, 2000). Siblings specifically express concern about the destruction of their personal items, as well as feeling embarrassed by their brother or sister's behavior (Bagenholm & Gillberg, 1991). Concern with peer judgment increases with age, with children in late childhood and adolescence expressing more negative responses to these stigmatizing behaviors (Glasberg, 2000). This unease may therefore limit the peer interaction of neurotypical siblings, particularly within the home environment.

The environment and family context that siblings share are also altered by an ASD diagnosis. While neurotypical siblings are generally of equivalent status within the family unit, the increased needs of the child with ASD can tip the balance away from the neurotypical child (Meyer, Ingersoll, & Hambrick, 2011). As previously mentioned in the parent section, caring for a child with ASD requires a significant allocation of family resources. Parents particularly are tasked with coordinating diagnosis and therapies for the child, attending to their daily living skills, and implementing behavior plans in the home. Therefore, the already limited resources of the parent are differentially allocated to the child with ASD out of necessity (Giallo & Gavidia-Payne, 2006). This has a profound impact on the day-to-day functioning of the neurotypical child, as some studies report increases in household and caretaking

responsibilities compared to families without ASD (Bagenholm & Gillberg, 1991; Meyer et al., 2011). The decrease in parental resources may consequently result in more expected functional independence on the part of the typical child, as well as an increased delegation of responsibilities at home. Despite positive global ratings of the sibling relationship, this increased responsibility at home may be considered a burden by neurotypical children (Bagenholm & Gillberg, 1991). This suggests that children can be negatively affected by disruptions in family context.

This shift in role responsibility within the sibling relationship parallels a parent-child bond, with some studies suggesting that siblings of children with ASD experience much of the same distress as their parents (Conway & Meyer, 2008). A study by Bagenholm and Gillberg (1991) reveals that siblings of children with ASD voiced more concerns about their sibling's future than siblings of children with intellectual disabilities. While one may posit that these negative feelings can be accounted for by sibling variables, such as symptom severity, research shows that this relationship is largely mediated by environmental variables, such as family functioning (Meyer et al., 2011; Taylor, Fuggle, & Charman, 2001). Meyer, Ingersoll and Hambrick (2011) found exactly this relationship in a study measuring the factors that contribute to neurotypical sibling adjustment. The authors conducted a study with mothers who have both a child with ASD and a typically developing child. Seventy mothers rated the severity of their child's ASD symptoms, the mother's own depression symptoms, and the behavioral adjustment of the neurotypical child. Preliminary results suggested that symptom severity was directly related to sibling adjustment, with higher severity leading to poorer adjustment. However, further analysis revealed that 91% of the relationship between ASD severity and sibling

adjustment was mediated by maternal endorsement of depression symptoms. This suggests that severe ASD impairments have a direct effect on the depression endorsement of mothers. Adjustment problems in neurotypical siblings were directly affected by maternal depression, with higher depression endorsement negatively related to sibling adjustment. Thus, ASD symptom severity does not influence the adjustment difficulties of siblings directly, but rather acts through environmental family variables. This provides further evidence for the relationship between the global stress of ASD on the family unit, and the impact on siblings individually. Specifically, siblings experience many of the same detrimental effects of ASD as parents, but may be particularly affected by family factors. Similar to the research conducted on parent adjustment, this suggests that sibling adjustment can be improved by addressing their greater environmental stress.

#### Sibling Psychosocial Outcomes

Despite these qualitative changes in the sibling relationship, and the sensitivity to environmental changes within the family environment, research on the psychosocial outcomes of siblings is more mixed than the data on parents (Tudor & Lerner, 2015). Some research suggests that children of individuals with ASD function as well as other neurotypical children (Dempsey, Llorens, Brewton, Mulchandani, & Goin-Kochel, 2012; Giallo & Gavidia-Payne, 2006; Guite, Lobato, Kao, & Plante, 2004; Verte et al., 2003), while others find significant impairments in adjustment and psychological functioning (Bagenholm & Gillberg, 1991; Benson & Karlof, 2008; Giallo & Gavidia-Payne, 2006; Meyer et al., 2011; Ross & Cuskelly, 2006).

Looking first at positive psychosocial adjustment, a study by Guite, Lobato, Kao and Plante (2004) revealed normative sibling adjustment based on the ratings of both

siblings and parents. Siblings aged 8 to 13 years and their parents rated the sibling on measures of behavioral and psychological functioning. Mean scores for the impact of disability on the family showed positive adaptive functioning and did not differ significantly between parents and children. Further, while both male and female children's scores were in the adaptive range, older female children reported less adjustment problems than younger, male children. Female siblings therefore seem to have more positive outcomes than males.

This gender effect was also found in a study by Verte, Roeyers, and Buysse (2003). This study looked at the behavior, social functioning, and self-concept of siblings of children with high functioning ASD. Parent and child report measures were used to evaluate siblings aged 6 to 16. While parents reported higher incidence of behavior problems in the 6 to 11 age group, female siblings rated themselves as having higher social competence and a more positive self-concept than controls with a typically developing sibling. This provides support for the greater adjustment of female neurotypical siblings. The ASD sample as a whole was reported to have more internalizing and externalizing problems than the control group, however these scores did not fall into the clinical or borderline ranges. This suggests overall adaptive functioning for these children despite relative elevation of scores. It is important to point out the functioning level of this group when interpreting these results, as reference siblings with ASD were on the high functioning end of the spectrum. Further, the child with ASD was in a semi-residential treatment program wherein parents and siblings received professional support. It is then likely that this group did not experience the stressors typical of other siblings, due in part to functioning level and family context variables.

In another study that emphasized the family context, Giallo and Gavidia-Payne (2006) found that daily uplifts, or positive family experiences, had a predictive effect on the neurotypical sibling's prosocial behavior. While this study largely revealed risk factors and negative outcomes of having a sibling with ASD, the authors importantly highlight the positive impact of an adaptive family context on sibling functioning. With regard to uplifts, positive family experiences served to enhance adaptive adjustment in siblings. Similarly, this study revealed that certain family factors, such as having consistent family routines and activities, had a protective effect on sibling functioning. Predictable and frequent family activities may allow children to have more regular parent contact and to receive support when needed. The adaptive functioning of families therefore serves as a protective factor for siblings, however this level of functioning may be less likely due to the increased stress that families typically experience (Kaminsky & Dewey, 2001).

While the previous studies demonstrated some positive outcomes for siblings, there is an extensive literature to suggest that these children are at risk for negative adjustment on both an individual and familial level (Tudor & Lerner, 2015). These parallel parent risk factors, with the results suggesting that internal coping skills and external resources, such as social support and security of family resources, directly moderate sibling stress.

With regard to individual adjustment, siblings of children with ASD are sometimes found to be at a higher risk for internalizing disorders. A study by Ross and Cuskelly (2006) found high rates of internalizing disorders in a sample of 25 between the ages of 8 and 15 years. Compared to the normative sample on the Child Behavior

Checklist, mean psychosocial functioning scores rated by parents were in the at-risk or clinical range. This study also measured the coping strategies endorsed by these children in the face of daily stressors. Aggression was rated as the most common stressor experienced within the sibling dyad, consistent with child reports of ASD behavior (Glasberg, 2000). Following acts of aggression by their brother or sister, children were more likely to use emotion regulation and wishful thinking to cope with these stressors, which they also ranked as being the most useful strategies. Interestingly, problem-solving and social support were among the least used, despite the extensive literature supporting their utility in buffering against psychological distress (Smith & Perry, 2005). This again demonstrates parallels between sibling and parent coping when stress is high, and suggests that siblings are in fact in need of more adaptive coping strategies.

Indeed, researchers have confirmed that there are resource effects that contribute to the psychosocial adjustment of siblings. While Guite et al. (2004) largely found adjustment within the normal range for their sibling sample, they provided important information about age trends within the data. Most parents' ratings of their child's adjustment was in accordance with the child's own ratings. However, when there were discordant data, it was found in the younger participants, with this group reporting poorer adjustment than parents had reported. This suggests that younger siblings experience more behavioral and emotional reactions to an ASD diagnosis than older children (Guite et al., 2004). This may be attributed to the lack of coping skills, and general cognitive maturity in younger samples. As children age, their network of social support increases, and they are provided with more opportunities to speak about experiences with their sibling, and to receive crucial comfort when needed. Secondly, and perhaps most

importantly, children will have a more realistic and sophisticated understanding of ASD as cognitive maturity increases, which may help to alleviate some initial distress (Glasberg, 2000).

In addition to age, sibling outcome can also be tied to more generalized risk factors for developing a psychosocial condition. For example, the broader psychological research has suggested that females are generally at greater risk than males for developing certain conditions, such as anxiety and depression (Olfson & Marcus, 2010). Given this overall risk, it is intuitive that female siblings of individuals with ASD would be at greater risk than male siblings. Further, female children are more likely to embrace a caretaking role, which may lead to increased stress over the lifespan (Seltzer et al., 2005).

Giallo and Gavidia-Payne (2006) directly measured the impact of family factors, such as communication about diagnosis, in a study including 49 siblings of children with various disabilities. This study hypothesized that family characteristics would have the most powerful influence on child behavior and psychosocial well-being. To examine this, information on daily stressors, coping skills, parent behavior, and family behavior were collected. Results showed that both parents and siblings had higher ratings on social and emotional difficulties, as well as perceived stress, compared to normative samples. Siblings also reported less prosocial behavior than the norm group. Looking at predictors of sibling stress, parent stress accounted for 44% of the variance, suggesting that family environment has a significant influence on child functioning. Family socioeconomic status was also related to sibling adjustment difficulties, but this was also mediated by parent stress. Increased environmental stress due to lack of resources therefore has an indirect effect on sibling functioning via parent functioning. Interestingly, individual



stress and coping strategies did not predict adjustment for siblings. However, the use of family communication and problem-solving was a significant predictor. Those families who were less effective at these strategies had children with more negative adjustment. This again reaffirms the importance of family variables, specifically family stress and communication, in predicting negative adjustment (Meyer et al., 2011).

Taken together, the literature suggests both positive and negative outcomes that may result from having a sibling with ASD. However, given the disruptions in the sibling relationship, and the negative effects of parent stress, neurotypical siblings are certainly at greater risk for negative psychosocial adjustment, even if this does not manifest in diagnosable internalizing or externalizing disorders. This is especially true for younger, female siblings of children with ASD (Guite et al., 2004; Seltzer, Greenberg, Orsmond, & Lounds, 2005; Verte et al., 2003). Similar to the parent sample, it is evident that there are some factors that are amenable to treatment. Specifically, in order to address current stress, and to prevent the onset of further psychosocial impairment, it is extremely important to provide siblings access to support services (Smith & Perry, 2005). Also, it is important to address the mediating variables that are elucidated in the adjustment literature: in order for children to have positive adjustment, parent and environmental resources are crucial.

#### Parent Support Services

Research on the adjustment of parents and siblings suggests that both groups could benefit from their own support services in order to buffer risk-factors inherent to having a child with ASD in the family. However, given the mediating effect of parent stress on sibling psychosocial outcomes, it is that much more important to ensure that

parents are adequately supported. Studies on support services for parents are very limited. However, available studies generally focus on two models of intervention delivery: child-focused interventions and parent-focused interventions (Ferraioli & Harris, 2013; Tonge et al., 2006). More specifically, research has split between treatments that focus on the direct emotional support of parents, versus providing parents with skills training to better address their child's behavior and measuring the indirect benefits on stress.

Looking first at child-focused interventions, research has observed indirect improvements in parent functioning as a result of including parents in their child's intervention plans. Specifically, parents who can learn to implement behavior management programs, or skill acquisition programs, with their challenging child can see subsequent reductions in overall parent stress (Ferraioli & Harris, 2013). Researchers note that this is due to a decrease in environmental stress as well as overall improvements in the parent-child relationship. For example, a study by Bristol, Gallagher, and Holt (1993) saw reductions in maternal reports of depression symptoms as a result of providing psychoeducation to parents in order to train them as co-therapists. Specifically, those parents who were able to learn behavior analytic interventions reported lower scores on a depression scale compared to a control group. However, it is unclear whether the acquisition of skills for parents can account for the decrease in parent maladjustment. Specifically, a study completed by Tonge et al. (2006) compared a parent education intervention to a behavior management intervention with parents of children with ASD. One set of parents received education in the symptomology of ASD, behavior change approaches, and resources to manage parent stress. This was compared to a group focused on discussion and educational materials, without active skills training.

Researchers found improvements in depression, stress, anxiety, and somatization in both treatment groups (Tonge et al., 2006). This suggests that while parent support and education about their child's symptoms are effective in reducing parent stress, active skills training may not be necessary to see robust improvements.

It should be noted that there is extensive literature on the inclusion of parents in child-directed interventions, such as using parents as therapists at home to teach a variety of skills. However, the literature on parent measures of self-improvement is significantly more limited. Therefore, while researchers report some gains for parents as a result of being provided with education about their child, or being directly taught skills to manage behavior, the conclusions that can be drawn from these studies are inherently limited.

In addition to child-oriented strategies, other researchers have looked at parent-oriented models of intervention. There is more substantive research in this area. These programs specifically target the clinical symptoms observed in parent populations, including stress, depression, and anxiety. Some researchers have looked at cognitive behavioral approaches that are typically used to treat anxiety and depression in typical adult populations and applied them to parents of individuals with ASD. For example, a study by Blackledge and Hayes (2006) looked at the use of Acceptance and Commitment Therapy (ACT) for parents of children diagnosed with ASD. This intervention focused on helping parents to adjust to the difficulties raising their child by looking realistically at the challenges inherent in the situation and managing those stressors using psychological strategies. This research found that symptoms of depression, as well as global health were observed for parents immediately post-treatment as well as in a three month follow-up. Another study by Ferraioli and Harris (2013) compared a mindfulness-based parent

therapy to a child-focused skills training program. In this study, one group received a mindfulness-based parent training program, which was adapted from Linehan's skills training manual. This involved the teaching of mindfulness principles, which focused on the management of distressing thoughts and feelings on the individual level. The second group received skills-based parent training, which involved strategies for increasing appropriate behavior and decreasing challenging behavior in children with ASD. The second group closely mirrors the child-directed interventions described above. Ferraioli and Harris (2013) found statistically significant differences in parent stress and global health between pre and post treatment in the mindfulness group only. However, clinically-significant improvements were seen across both groups.

Taken together, this limited literature suggests that parents can directly, and indirectly, benefit from being involved in support programs. Teaching coping skills directly, or training parents to be competent providers, can both demonstrate reductions in parent stress and mental health ratings. However, it should be noted that the research in this area is still preliminary.

#### Sibling Support Services

Research on sibling support is similarly limited, however approaches to treatment are significantly more varied (Tudor & Lerner, 2015). Most of the literature has focused on working with siblings in the context of groups. The group setting provides a unique opportunity for siblings to learn important skills, while also decreasing isolation (Conway & Meyer, 2008). Models of sibling support groups range widely from purely supportive groups, to psychoeducational groups, to skills training groups, to approaches focused more heavily on coping strategies.

Looking first at recreational studies, McLinden, Miller, and Deprey (1991) aimed to improve perceived social support in siblings using a group format. Six school-aged children were enrolled into a six-week group that met one hour per week. Siblings of group members had various disabilities including physical impairments, intellectual disabilities, or multiple handicaps. Group sessions provided a forum for discussing common experiences, and increasing acceptance of both positive and negative feelings about their sibling. Compared to wait list controls, group members had higher levels of perceived social support following the group. While some benefits were observed, purely supportive groups fail to address the primary concerns posed by the adjustment literature. While it is clear that mutual support is important, it does not fully address the needs of these siblings and more structured didactics and skills training are a crucial addition to these programs.

Knowledge about ASD, and strategies for explaining the diagnosis to others, is a crucial element to an effective support group. Research on psychosocial adjustment indicates that negative adjustment is often related to difficulty conceptualizing a sibling's disability, as well as struggle in conveying this to others (Bagenholm & Gillberg, 1991). Many sibling support groups have thus included psychoeducation as part of their curriculum, citing the collateral benefits on sibling functioning (Dyson, 1998; Evans, Jones, & Mansell, 2001; Lobato & Kao, 2002; Lobato & Kao, 2005; McCullough & Simon, 2011; McLinden et al., 1991; Smith & Perry, 2005).

In line with these concerns, McCullough and Simon (2011) created a pilot support group for siblings of children with ASD. The group aimed to provide information about ASD, as well as strategies for communicating this information to peers. The group

contained three members between the ages of 7 and 10 who each had had a brother with ASD and a comorbid intellectual disability. When defining individual goals for treatment, two group members identified learning more about ASD as a primary aim, reemphasizing the importance of this information to children. While this study had several limitations, including small sample size and qualitative outcome measures, important information about sibling knowledge and its effects on the sibling relationship is relayed.

Fostering skills that can facilitate more positive sibling interactions is another benefit of sibling support groups. In addition to teaching factual information about disabilities, Dyson (1998) targeted strategies for interacting with the disabled sibling. The study included 40 children between the ages of 7 and 12 who had a sibling with a disability. The disability group included developmental disabilities, intellectual disabilities, and physical impairments. Dyson (1998) used didactics, group discussion, and experiential activities to present information about disabilities to the sibling group. Within this context, siblings were encouraged to discuss the impairments of their disabled sibling, and strategies for improving interactions were offered. Interestingly, while these more structured activities were paired with less structured recreation and games, children ranked learning about disabilities and strategies for interacting with their brother or sister as their most preferred group activity. This emphasizes the importance that siblings themselves place on improving sibling interaction.

To this end, siblings are able to effectively learn skills to improve play interactions (Celiberti & Harris, 1993). Again, parents are typically the targets of behavioral skills training, often with the intention of generalizing skills learned at school into the home environment. However, the qualitative differences in the play relationship

of autism dyads makes it equally important to teach neurotypical siblings the skills to make these interactions more rewarding for both children (Kaminsky & Dewey, 2001). A study by Celiberti and Harris (1993) demonstrated that siblings are able to quickly master behavioral skills relevant to play, such as delivering clear instructions, providing praise, and prompting when necessary (Celiberti & Harris, 1993). With these skills, siblings have proven to be efficacious therapists, which have important implications for the functioning of both the child with ASD and the neurotypical child. The child with ASD is provided with more opportunities to learn and practice play skills with a competent therapist. The neurotypical child then feels more confident in the interactions with their sibling, and increases interest and pleasure in these interactions (Celiberti & Harris, 1993). By utilizing these skills in a group format, siblings have the opportunity to role-play and practice these skills with therapists and peers.

Support groups have also effectively improved the coping skills of siblings of children with ASD. Evans, Jones and Mansell (2001) taught problem-solving and relaxation skills to siblings, in addition to informing them about disabilities and fostering play skills. This pilot study included 29 children between the ages of 6 and 12 who had a sibling with learning disabilities and challenging behavior. Problem-solving topics included explaining disability to peers, as well as individual coping during stressful situations. Assessment pre and post group revealed significant improvements in sibling involvement, self-esteem, and the ability to relax during stressful interactions. Increased participant coping was also corroborated by parent report.

Smith and Perry (2005) found similar results in a systematic evaluation of the effects of support groups for siblings of children with ASD. Very few studies have

focused on siblings of children with ASD as a separate group, and this study evaluated the intervention with quantitative outcomes. The study included 26 siblings of children who ran through groups conducted over several years. Participating siblings were between 6 and 16 years of age and participated in an 8-week group intervention. Prior to treatment, 10 siblings scored in the borderline to clinical range on internalizing and externalizing symptoms by parent report on the Child Behavior Checklist. Nine scored in at-risk range for internalizing, five for externalizing, and four met criteria in both domains. This provides support for siblings of children with ASD experiencing negative psychosocial adjustment. Research groups focused on increasing knowledge about ASD, allowing children to speak openly about negative sibling experiences, and increasing coping skills. Following treatment, Smith and Perry (2005) found quantifiable improvements in overall self-concept and knowledge about ASD. While the generalization of this study is limited due to a lack of control group, it provides the best model for the benefits of intervention with siblings of children with ASD.

In addition to systematically evaluating support groups for siblings in isolation, research on psychosocial adjustment provides compelling evidence for including the broader family unit in these interventions (Lobato & Kao, 2002). When designing interventions for individuals with ASD, schools and therapists frequently include parents in the planning process. Including families is important as parents and siblings are responsible for extending school-based interventions into the home environment (Celiberti & Harris, 1993). If this implementation is not consistent, treatment is often less effective and progress is not sustained. The same can be said for interventions targeting children in general. Children inherently function within their family context, and this



environment exerts the most influence over their behavior. Involving parents is especially relevant for children who have a sibling with ASD. Given increased family stress, parents may be less likely to rehearse behavioral skills with their child at home (Kaminsky & Dewey, 2001). This may limit both the generalization and maintenance of skills learned in a support group. Further, as children often require prompting to complete problem-solving steps, they may require this same guidance from parents at home. If parents are unable to guide this process, the efficacy of these skills may decrease, and their use may also decrease. Therefore, group skills may be better implemented in the child's broader environment if parents are included (Bellin & Kovacs, 2006). The research in this area is even more limited, with only two documented studies utilizing parallel parent-sibling support (Lobato & Kao, 2002; 2005). These studies provided services for parents and siblings in parallel groups, tackling the same material. Results indicated significant benefits for the sibling, including increased knowledge of their sibling's disability, increased sibling connectedness, and decreased internalizing scores on internalizing and externalizing measures.

This comprehensive literature provides important information about the efficacy of sibling support groups that target knowledge about disability, skills for improving interactions with siblings, and personal coping skills. These more didactic elements should be intermixed with enjoyable activities that promote a safe, peer-supported environment (Smith & Perry, 2005). However, as mentioned within the context of the parent support literature, the information to be gained from these studies is minimal given their limited numbers.

Limitations of the Current Research

While the literature has convincingly demonstrated the need and proposed benefits of support services for both parents and siblings, there are some real limitations that are important to note when thinking about best practice for supporting families in the community. First, while there has been research focused on ways to assist both of these populations, the relative allocation of funding and research attention is significantly less than the autism-specific studies. While the Autism CARES Act allocated over a billion dollars to ASD research, there is no federal research budget carved out to explore supports for families of these individuals. Further, looking at Autism Speaks, one of the most notable private grant-funding agencies, only two grants out of sixty-eight in the last two cycles have looked at family support directly. Notably, both of these studies have focused on advocacy for underserved families, and not directly looking at models of family support. Therefore, there is significantly less research being conducted on methods of support for families relative to methods of support for the child with ASD. This inherently gives us very little information about what treatments work best for these needy families.

Further, looking at the existing data on support services for families, it appears that recruitment and group composition of these studies is inherently problematic. The vast majority of support research has focused on ASD-directed interventions, with secondary analyses that focus on parent or sibling adjustment (Bristol et al., 1993). However, these measures have been added more recently, and have not been the main focus of the analysis. Further, the smaller subset of research that does look at parents or siblings directly is typically characterized by the inclusion of non-ASD groups in the analysis. The intervention research, like the psychosocial adjustment literature, has rarely

looked at families of children with ASD in isolation. Rather, these parents and siblings are often grouped in with families of children with other developmental and physical disabilities, or those with chronic illnesses (Tudor & Lerner, 2015). As such, it is difficult to make clear conclusions about the benefits for families of children with ASD specifically, as the numbers are too few. This is especially limiting as ASD has a very particular impact on the family unit; distinct from even other developmental disabilities (Kaminsky & Dewey, 2001).

Looking at the even smaller subset of research that focuses on family members of individuals with ASD only, these studies are plagued by structural limitations such as limited sample size and difficulties with recruitment. Both the parent and sibling literature consistently reports difficulties with recruitment in their discussions, as well as difficulties with retention of parents and siblings in research projects (Ferraioli & Harris, 2013). This makes the interpretation of these already limited studies that much more difficult.

Taken together, there is a tremendous service gap that is created between the well-documented need for support services in the families of individuals with ASD and the research needed to guide best-practice treatments. Further, the involvement of families of individuals with ASD in the current research is limited, which makes interpretation of study results that much more difficult. While this problem is clear, there has been no current research that has addressed this gap and directly measured factors that may make it difficult for families to participate in research. There are certainly logical conclusions to be drawn as to why these studies are so limited, and why parents and siblings of children with ASD may be unable to participate in empirical studies. Lack of service

engagement may be accounted for by limitations on time and resources (Dunn et al., 2001), prioritization of these services within the family, or negative experiences with service providers in the past. While these factors would certainly limit researchers' ability to craft and test well-supported treatments for this population, one could reason that these same limiting factors are preventing treatment access for families in the community as well. If this is in fact the case, a large population of at-risk individuals is left without the appropriate care. This would have significant implications for the adjustment of the entire family unit, including the child with ASD. However, there are no empirical data to support these claims as it pertains to research or clinical participation.

It is therefore crucial to understand what services families members of individuals with ASD are currently accessing, and the factors that make individuals more or less likely to gain access in the future. Before the research can move forward and most appropriately address the needs of this population, we must first understand how to make these services more appealing and accessible, and thereby increase the likelihood of adaptation. Consulting with stakeholders about the future direction of research and clinical targets is a new field within psychology, and particularly within ASD (Gotham et al., 2015; Pellicano, Dinsmore, & Charman, 2014). For example, several researchers looking at the needs of adults with ASD and their family members have used large-scale surveys to poll individuals about their priorities. These studies have emphasized patient-centered care, and have found that their results lead to higher satisfaction among treatment recipients (Gotham et al., 2015; Pellicano, Dinsmore, & Charman, 2014). Moving forward, it is extremely important to consult with families of individuals with ASD about priorities for their own care in order to craft more tailored supports.

The current study investigated patterns of treatment access in parents and siblings of individuals with ASD across the United States, as well as barriers and facilitators to accessing support services in their day-to-day lives. This was completed through a series of parent report-based questionnaires, emphasizing parent perceptions and prioritizations for support services. Specifically, families were asked to indicate what, if any, support services they have accessed for themselves in the past, as well as what they would consider accessing in the future. These services spanned psychotherapy, skills training, as well as community supports for parents and siblings. Further, families were asked to indicate what factors, if any, have made treatment access more or less likely. This includes limitations on resources, time, as well as emphasis placed on the importance of these services. The treatment access questionnaire was then analyzed with common moderators of psychological adjustment, including ASD symptom severity, social support, and parent stress. Together, this aimed to create a profile of factors which make it more or less likely to access support.

While the present study is largely exploratory in nature, the current project expected to find group-based differences in service access based on psychosocial factors established in the literature. Specifically, it was hypothesized that parents who rated greater ASD symptom severity, social support, parent stress, and psychiatric symptoms would have engaged with more past support services for parents and siblings. It was also hypothesized that mothers, and those with female children, would endorse greater service engagement for parents and siblings respectively. This would also translate into a better attitude toward support services in the female group. Further, these same families were hypothesized to have more interest in future service access for both groups.

## Method

### Participants

Participants in this study were parents from across the United States who have both a child with a diagnosis of Autism Spectrum Disorder (ASD) and at least one typically developing child. A diagnosis of ASD included those children who received a diagnosis under the current DSM-5 criteria (American Psychiatric Association, 2013), as well as those children carrying diagnoses provided under previous iterations of the DSM, including those diagnosed with Autistic Disorder, Asperger's Disorder, and PDD-NOS (American Psychiatric Association, 2000). ASD diagnosis was confirmed both by parent report and completion of the Gilliam Autism Rating Scale- Third Edition, a parent-report measure that provides information about symptom severity as well as the likelihood of meeting a clinical threshold on the DSM-5. The developmental trajectory of the typically developing child was also confirmed by parent report. Exclusionary criteria for parents included a self-disclosed history of developmental delays, autism spectrum disorder, or severe psychiatric history (schizophrenia, bipolar disorder, or recurrent major depression). Further, typically developing children were excluded based on a parent reported history of developmental delay, autism spectrum disorder, significant language delay or current language impairment, or any severe past or present psychiatric diagnoses (schizophrenia, bipolar disorder, or recurrent major depression).

### Recruitment.

Participants were recruited through several referral sources. A portion of the sample was recruited through the Douglass Developmental Disabilities Center (DDDC) at Rutgers University. The DDDC has consistently provided educational, behavioral, and

therapeutic services to families of children on the autism spectrum for the last 40 years. Families currently enrolled in the school program, adult day program, and families on the wait list for services, were contacted regarding possible participation in this study. Participants were also recruited through several community-based resources throughout the United States. This included parent-support groups, sibling support programs, as well as a set of online resource networks for families of individuals with ASD (e.g., Autism New Jersey, Autism Speaks).

### Setting

Information about the study was advertised in the community and online resource networks as described, and interested parents were provided with a link and a password that allowed them to access the study questionnaires. All questionnaire data were collected via Qualtrics; a secure online survey platform that functions in partnership with Rutgers University as well as a host of other colleges and universities around the country. The questionnaire could only be accessed through a specific survey link, and was not advertised for the general population by the Qualtrics platform. Permission to complete the questionnaire was contingent upon entering a study-specific password that was granted by the study investigator.

All questionnaire data collected in the Qualtrics system was anonymous, and data were only identified through an individual participant code. Data were stored in the online Qualtrics system and could only be accessed by the study investigator through individual login. Participants received a \$5 Amazon.com giftcard in exchange for their completion of the study. They received this giftcard by providing a personal email address to the study investigator at the end of the survey, and the investigator then

emailed their compensation individually.

### Study Design

Participants completed a set of online questionnaires to assess for treatment access, demographic data, parent stress, ASD symptom severity, and social support. Participants were asked to complete the entire set of questionnaires to the best of their ability, and were permitted to start and stop the completion of the survey as needed. Questionnaire data were collected at a single time point, such that only one data point was collected per family.

### Measures

*Demographics and Family Profile Questionnaire.* Participants were asked to provide basic demographic information about themselves and their family (Appendix A). Information about the parents included their state of origin, gender, role in the family (e.g., mother, stepfather, etc.), race, ethnicity, and level of education. Parents were also asked to provide information about basic family structure, such as their marital status, family size, and the age, birth order, and gender of their children (both ASD and typically developing, individually).

In order to have a measure of psychosocial screening, parents were asked to provide information about the mental health history of themselves and their typically developing child. Specifically, parents were asked if they have ever been diagnosed with ASD, developmental disability, or a major psychiatric condition. The same were asked of their typically developing child, with parents responding on their child's behalf. If parents endorsed either of these screening questions, they were considered a Screen Fail for this project. These parents were still given the opportunity to complete the questionnaires,



however their data were considered separately.

*Family Support Questionnaire (FSQ)*. This measure was created by the present author to evaluate the treatment access of parents and siblings of individuals with ASD, as well as the factors that facilitate or impede treatment access (Appendix B). In this questionnaire, as with all questionnaires in this project, parents served as the respondents to questions about their own behavior, as well as the behavior of their typically developing children. The questionnaire was divided into four sections. The first addressed what support services, if any, parents and their typically developing child have accessed in the past. Parents were asked about 13 different support services for themselves and their child including psychotherapy, skills training groups, online resources, and community support. A short description for each service was provided in lay language. The set of 13 services presented for parents and siblings were identical, with the language tailored to fit the population addressed. For example, parents were asked if they sought support from their primary care physician or other health professional. Parents were then asked if their child had accessed support from their pediatrician or other health professional. For each service they were asked to indicate “Yes” or “No” to whether they had accessed this in the past. The second set of questions included the same set of 13 services provided in the first set, and inquired as to whether parents would access these services for themselves or their children in the future. This was again presented in a “Yes” or “No” format.

The third set of questions addressed treatment access factors that may facilitate or impede treatment access for themselves (18 statements) or their typically developing child (18 statements). These factors addressed six content areas: general attitude toward

support services (e.g., “I think support services would be helpful to me”), prioritizing support services (e.g., “Obtaining support services for my child is a priority for me”), preferences in service content (e.g., “I prefer activities that are skills based), preferences in group composition (e.g., “I think my child would be interested in accessing services with other children), preferences in time/location of support services (e.g., “I am able to participate in support services during the weekdays), and finances/childcare (e.g., “I have the finances for my child to participate in support services). Each of these statements were rated on a 5 point Likert scale (1= strongly disagree, 5= strongly agree). In the final section, parents were given free-response space to indicate any other factors that may be relevant to their access to support services.

*General Health Questionnaire-28 (GHQ-28, Goldberg, 1978).* This 28 item self-report measure assesses global health comprised of four subscales. Subscales include somatic symptoms, anxiety/insomnia, social dysfunction, and depression. Individuals were asked to rate items on a 4-point Likert scale based on how they have been feeling over the past few weeks. Low scores indicate better health and higher scores indicate worse health. In the scoring process, ratings of 0 and 1 on this measure were collapsed into a final score of 0 while scores of 2 and 3 were collapsed into a score of 1. This is the scoring method advocated by the author. Scores of four or higher for the total measure are found to be clinically significant.

*Gilliam Autism Rating Scale, Third Edition (GARS-3, Gilliam, 1995).* To achieve an objective measure of the symptom severity of the child with ASD, and to validate the likelihood of an ASD diagnosis, parents were administered the GARS-3. The GARS-3 asks parents to observe and rate their child’s behavior across a variety of domains. For

parents with children who are verbal, per parent report, they receive questions across six domains: restrictive, repetitive behaviors, social interaction, social communication, emotional responses, cognitive style, and maladaptive speech. Parents of nonverbal children receive only the first four subscales. The GARS-3 then provides a measure of the likelihood of an ASD diagnosis based on DSM-5 criteria, as well as measures of symptom severity, and an overall autism index score. All scores on the GARS-3 are normed against a population of individuals with ASD. Internal validity for this measure is very high with a Chronbach alpha of 0.85.

*Inventory of Socially Supportive Behaviors (ISSB, Barrera et al., 1981).* This 40-item self-report questionnaire measures how often individuals received different forms of social support during the previous four weeks (e.g., “Looked after a family member when you were away,” “Listened to you talk about your private feelings”) (Appendix C). Participants were asked to rank each item on a 5-point Likert scale ranging from 1=not at all to 5=about every day. The ISSB can be interpreted as a global score of social support, through a total sum of all item scores, or an average of all item scores. Total scores on the global measure range from 40 to 200, with higher scores indicating more perceived social support. The ISSB can also be broken down into factors of social support: Directive Guidance, NonDirective Support, Positive Social Exchange, and Tangible Assistance. Means scores are calculated for these individual domains. The internal consistency of this measure is consistently above 0.9.

*Parenting Stress Index- Fourth Edition- Short Form (PSI-4-SF, Abidin, 1995).*

This is a self-report measure that assesses common stressors involved in parenting children up to 12 years of age. This questionnaire includes 36 items that measure parental

distress (e.g., “I often have the feeling that I cannot handle things very well”), parent-child dysfunctional interaction (e.g., “Sometimes I feel my child doesn’t like me and doesn’t want to be close to me”) and difficult child characteristics (e.g., “My child makes more demands on me than most children.”) Items are rated on a 5-point Likert scale (1=strongly agree, 5=strongly disagree) and includes questions such as, “Most times I feel that my child does not like me and does not want to be close to me.” In addition to individual subscale scores, the PSI-4-SF yields a total stress score.

### Data Analyses

All data were analyzed with SPSS 22.0. In order to characterize the sample, means and standard deviations for all demographic measures and dependent measures were obtained. All analyses were completed for the sample as a whole, as well as two subgroups (i.e., Screen Pass and Screen Fail). Group-based differences on these measures were calculated using a Multivariate Analysis of Variance (MANOVA).

In order to investigate service engagement, means and standard deviations were described for the four service groups: the number of past services accessed (for parents and siblings), as well as the number of future services that parents are interested in accessing (for parents and siblings). In these analyses, higher numbers of services accessed corresponded to a more positive outcome. Means and standard deviations were also displayed for service access factors, such as attitude toward services and priority of services. Finally, frequencies for the endorsement of individual services (e.g., individual psychotherapy) were displayed for each of the four service groups.

In order to create service engagement profiles, ANOVAs, chi square analyses, and correlations were conducted to investigate the relationship between service access and

interest by demographic variables (e.g., parent gender, race, etc.) Pearson correlations and ANOVAS were used investigate the relationship between the four service groups and service access factors and dependent measures. Finally, a series of hierarchical linear regressions were constructed in order to identify the variables that best predict service engagement for the four service groups.

## Results

### Participant Enrollment and Demographic Information

A total of 158 responses to the study survey were received. Of these respondents, 32 participants (20%) met screening criteria in at least one domain (i.e., screening diagnosis met for the parent, or for the typically developing child). Of these 32 cases, 12 of them (38%) met Screen Fail criteria for both the parent and the sibling. The literature on parent and sibling psychosocial outcome suggests that family members are in fact at an increased risk for developing a psychiatric condition (Ingersoll, Meyer, & Becker, 2011; Micali, Chakrabarti, & Fombonne, 2004; Shivers, C.M., Deisenroth, L.K., & Taylor, J. L). As such, these participants were included in analyses for the final sample. However, in order to account for any unique statistical contribution of these families, many of the results below were analyzed in three groups: the sample as a whole sample, Screen Fail families alone, and Screen Pass families (e.g., those who did not endorse additional psychopathology for the parents and siblings).

Demographic variables for the entire sample are displayed in Table 1.

Respondents included families from 40 out of the 48 contiguous states. Looking at respondents by region, the largest proportion of families resided in the Northeast (32.3%) and the Western portion of the United States (32.9%). Respondents were predominantly

female (59.5%), in intact married relationships (94.9%), White (85.4%), and Non-Hispanic (85.4%). Further, the large majority of participants reported having a Bachelor's Degree as their highest level of education achieved (62.7%).

With regard to family level variables (displayed in Table 2), most parents endorsed having two children living in the home (77.2%), reflecting the inclusion criteria of having a family with one child with ASD and one typically developing child. With regard to the child with ASD, parents reported that the majority of these children were male (63.9%), and between the ages of 3-5 years (24.1%) or 9-11 years (23.4%). The large majority of these families reported having only one child with ASD (94.3%). With regard to the typically developing siblings, parents reported that the majority of these children were female (47.5%) and between the ages of 6-8 years (42.4%). This suggests that the typically developing child was largely split between being older (47.5%) or younger than their sibling with ASD (47.5%).

Demographic information for the families qualified as Screen Fails (i.e., Screen Fail families) are also displayed in Tables 1 and 2. A series of chi square analyses were conducted in order to identify any demographic differences between groups. Screen Fail families differed significantly from the rest of the sample (i.e., Screen Pass families) in only two demographic areas. Parents in the Screen Fail sample were significantly more diverse with regard to racial identification,  $\chi^2 (5, N=158) = 23.032, p < .01$ . Further, the typically developing siblings in the Screen Fail sample were reported to be younger than what was represented in the remaining sample,  $\chi^2 (8, N=158) = 19.625, p < .05$ .

Table 1  
*Demographics of Parents*

|   | N <sup>WS</sup> | % <sup>WS</sup> | N <sup>SP</sup> | % <sup>SP</sup> | N <sup>SF</sup> | % <sup>SF</sup> |
|---|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Region                                    |                 |                 |                 |                 |                 |                 |
| Northeast                                 | 51              | 32.3            | 42              | 33.3            | 9               | 28.1            |
| Midwest                                   | 20              | 12.7            | 18              | 14.3            | 2               | 34.4            |
| South                                     | 35              | 22.2            | 28              | 22.2            | 7               | 56.3            |
| West                                      | 52              | 32.9            | 38              | 30.2            | 14              | 43.8            |
| Gender                                    |                 |                 |                 |                 |                 |                 |
| Male                                      | 64              | 40.5            | 49              | 38.9            | 15              | 46.9            |
| Female                                    | 95              | 59.5            | 77              | 61.1            | 17              | 53.1            |
| Marital Status                            |                 |                 |                 |                 |                 |                 |
| Married                                   | 150             | 94.9            | 119             | 94.4            | 31              | 96.9            |
| Divorced                                  | 3               | 1.9             | 3               | 2.4             | 0               | 0               |
| Partnered                                 | 2               | 1.3             | 1               | 0.8             | 1               | 3.1             |
| Separated                                 | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| Widowed                                   | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| Never Married                             | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| Race                                      |                 |                 |                 |                 |                 |                 |
| White                                     | 135             | 85.4            | 114             | 90.5            | 21              | 65.6            |
| Black or African American                 | 11              | 7.0             | 5               | 4.0             | 6               | 18.8*           |
| American Indian or Alaska Native          | 8               | 5.1             | 6               | 4.8             | 2               | 6.3**           |
| Asian                                     | 1               | 0.6             | 0               | 0               | 1               | 3.1**           |
| Native Hawaiian or Other Pacific Islander | 2               | 1.3             | 0               | 0               | 2               | 6.3**           |
| Two or More Races                         | 1               | 0.6             | 1               | 0.8             | 0               | 0**             |
| Ethnicity                                 |                 |                 |                 |                 |                 |                 |
| Hispanic                                  | 20              | 12.7            | 15              | 11.9            | 5               | 15.6            |
| Non-Hispanic                              | 135             | 85.4            | 110             | 87.3            | 25              | 78.1            |
| Parent Education                          |                 |                 |                 |                 |                 |                 |
| Some High School                          | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| High School Graduate                      | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| Some College                              | 21              | 13.3            | 14              | 11.1            | 7               | 21.9            |
| Associate's Degree                        | 19              | 12.0            | 14              | 11.1            | 5               | 15.6            |
| Bachelor's Degree                         | 99              | 62.7            | 88              | 69.8            | 11              | 34.4            |
| Professional Degree                       | 9               | 5.7             | 4               | 3.2             | 5               | 15.6            |
| Some Graduate Education                   | 3               | 1.9             | 1               | 0.8             | 2               | 6.3             |
| Advanced Degree                           | 5               | 3.2             | 3               | 2.4             | 2               | 6.3             |

\* $p < .05$ , \*\* $p < .01$

Note. <sup>WS</sup>= Whole Sample, <sup>SP</sup>= Screen Pass, <sup>SF</sup>= Screen Fail

Table 2  
*Family Demographics*

|                            | N <sup>WS</sup> | % <sup>WS</sup> | N <sup>SP</sup> | % <sup>SP</sup> | N <sup>SF</sup> | % <sup>SF</sup> |
|----------------------------|-----------------|-----------------|-----------------|-----------------|-----------------|-----------------|
| Number of Children in Home |                 |                 |                 |                 |                 |                 |
| 2                          | 122             | 77.2            | 104             | 82.5            | 18              | 56.3            |
| 3                          | 28              | 17.7            | 17              | 13.5            | 11              | 34.4            |
| 4                          | 6               | 3.8             | 3               | 2.4             | 3               | 9.4             |
| 5+                         | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| More Than One Child ASD    |                 |                 |                 |                 |                 |                 |
| Yes                        | 9               | 5.7             | 5               | 4.0             | 4               | 12.5            |
| No                         | 149             | 94.3            | 121             | 96.0            | 28              | 87.5            |
| ASD Gender                 |                 |                 |                 |                 |                 |                 |
| Male                       | 101             | 63.9            | 79              | 62.7            | 22              | 68.8            |
| Female                     | 45              | 28.5            | 37              | 29.4            | 8               | 25.0            |
| ASD Age                    |                 |                 |                 |                 |                 |                 |
| 0-1 years                  | 0               | 0               | 0               | 0               | 0               | 0               |
| 1-2 years                  | 7               | 4.4             | 5               | 4.0             | 2               | 6.3             |
| 2-3 years                  | 22              | 13.9            | 19              | 15.1            | 3               | 9.4             |
| 3-5 years                  | 38              | 24.1            | 26              | 20.6            | 12              | 37.5            |
| 6-8 years                  | 24              | 15.2            | 17              | 13.5            | 7               | 21.9            |
| 9-11 years                 | 37              | 23.4            | 32              | 25.4            | 5               | 15.6            |
| 12-14 years                | 28              | 17.7            | 25              | 19.8            | 3               | 9.4             |
| 15-17 years                | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| 18+ years                  | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| TD Gender                  |                 |                 |                 |                 |                 |                 |
| Male                       | 71              | 44.9            | 61              | 48.4            | 10              | 31.3            |
| Female                     | 75              | 47.5            | 55              | 43.7            | 20              | 62.5            |
| TD Age                     |                 |                 |                 |                 |                 |                 |
| 0-1 years                  | 1               | 0.6             | 1               | 0.8             | 0               | 0               |
| 1-2 years                  | 1               | 0.6             | 0               | 0               | 1               | 3.1*            |
| 2-3 years                  | 6               | 3.8             | 2               | 1.6             | 4               | 12.5*           |
| 3-5 years                  | 36              | 22.8            | 26              | 20.6            | 10              | 31.3*           |
| 6-8 years                  | 67              | 42.4            | 53              | 42.1            | 14              | 43.8*           |
| 9-11 years                 | 35              | 22.2            | 33              | 26.2            | 2               | 6.3*            |
| 12-14 years                | 63              | 3.8             | 5               | 4.0             | 1               | 3.1             |
| 15-17 years                | 3               | 1.9             | 3               | 2.4             | 0               | 0*              |
| 18+ years                  | 3               | 1.9             | 3               | 2.4             | 0               | 0*              |

\* $p < .05$ , \*\* $p < .01$

Note. <sup>WS</sup>= Whole Sample, <sup>SP</sup>= Screen Pass, <sup>SF</sup>= Screen Fail



## Means and Standard Deviations across Dependent Measures

Means and standard deviations for all dependent measures are depicted in Table 3. In addition to the descriptive information provided for the whole sample, group-based differences between the Screen Pass and Screen Fail samples were identified by placing summary scores for the dependent variables in a multivariate analysis of variance (MANOVA). Summary scores included the Autism Index of the GARS-3, Total Score on the PSI-4-SF, GHQ-28 Total Score, and the Total Frequency score on the ISSB. Additional one-way ANOVAS were conducted in order to elucidate differences in subscale values.

### Gilliam Autism Rating Scale- Third Edition (GARS-3).

On the GARS-3, parents were asked to rate behaviors associated with their child with ASD across six different domains. For participants who described their child as being verbal, they received questions from all six domains: restricted, repetitive behaviors, social interaction, social communication, emotional responses, cognitive style, and maladaptive speech. Parents who described their child as being nonverbal only answered questions of the first four domains, as the latter two described higher order verbal behavior.

Looking first at the sample as a whole, parents reported an average Autism Index score that falls just below the 50<sup>th</sup> percentile. This suggests that the sample falls in the middle of the normative range of other individuals with ASD, per parent report. This is further substantiated by the DSM-5 Severity Score converted from the overall Autism Index. This revealed that only 2.5% of the sample fell in the lowest severity range (Level 1), while 49.4% and 43% fell in the two higher ranges (Level 2 and Level 3 respectively).

Out of the 158 total respondents, 113 (71.5%) described their child as verbal, while 45 (28.5%) described their child as nonverbal. Looking at individual subdomains, all subscale scores were found to be significantly, and positively, correlated within the measure (Table 4), with the highest scores observed in the repetitive behaviors ( $M=10.66$ ,  $SD=2.03$ ), cognitive style ( $M=11.49$ ,  $SD=1.74$ ), and maladaptive speech ( $M=11.11$ ,  $SD=1.92$ ) subscales.

The MANOVA revealed that the Autism Index score were significantly different between groups  $F(1,144)=19.80$ ,  $p<.01$ ; Wilk's  $\Lambda=0.812$ , partial  $\eta^2=.12$ . Specifically Autism Index scores in the Screen fail sample was significantly lower than the Screen Fail sample  $F(1,148)=18.46$ ,  $p<.01$ . This was also true of all the individual subdomains. Further the Screen Fail sample was found to have a significantly higher proportion of nonverbal children with ASD,  $\chi^2(1, N=158) = 4.593$ ,  $p<.05$ .

#### Parenting Stress Index- Fourth Edition- Short Form (PSI-4-SF).

The parenting stress measure was broken down into three subdomains, as well as one Total Stress Score. Looking at the whole sample, the mean Total Stress Score was found to be elevated ( $M=70.32$ ,  $SD=7.58$ ) relative to the normative sample. Further, 77.4% of the sample was found to be in the clinically significant range for overall parent stress, and an additional 3.1% was found to be in the high range. All three subdomains, parent distress ( $M=65.27$ ,  $SD=9.02$ ), parent child dysfunctional interaction ( $M=69.89$ ,  $SD=8.63$ ), and difficult child ( $M=67.87$ ,  $SD=7.70$ ), were also found to be elevated. Additionally, these subdomain scores were found to be significantly and positively correlated (See Table 4).

The Screen Fail sample yielded a similar pattern of results (see Table 4). Overall, the Total Stress score for this sample was found to be elevated ( $M=69.00$ ,  $SD=7.01$ ), as well as all three subdomains: parent distress ( $M=65.31$ ,  $SD=8.28$ ), parent child dysfunctional interaction ( $M=69.23$ ,  $SD=7.95$ ), and difficult child ( $M=66.87$ ,  $SD=6.34$ ). The MANOVA, and individual ANOVAs on subtest scores, revealed that the Screen Fail group and the Screen Pass groups did not differ significantly on any measure of parent stress.

#### General Health Questionnaire-28 item version (GHQ-28).

The GHQ-28 was used as a screening measure to detect psychiatric symptoms across four areas: somatic symptoms, anxiety/insomnia, social dysfunction, and depression. Looking first at the overall sample, parents were found to have a mean total score that was in the clinically significant range ( $M=6.01$ ,  $SD=5.57$ ). Further, 48.7% of the total sample was found to be in the clinically significant range (i.e., a total score of 4 or higher). All subdomain scores were significantly correlated within the measure (see Table 4). The anxiety/insomnia domain had the highest mean total of endorsed symptoms ( $M=1.70$ ,  $SD=1.71$ ) and was significantly more elevated than the somatic symptom domain ( $M=1.41$ ,  $SD=1.56$ )  $t(157)=-2.672$ ,  $p<.01$ , and the depression domain ( $M=1.37$ ,  $SD=1.57$ )  $t(157)=-2.767$ ,  $p<.01$ .<sup>1</sup>

As to be expected, the MANOVA suggested that the Screen Fail sample differed significantly with regard to the symptom profile on GHQ-28,  $F(1,144)=13.80$ ,  $p<.01$ ; Wilk's  $\Lambda=0.812$ , partial  $\eta^2=.09$ . The mean total score was also in the clinically significant range for the Screen Fail sample ( $M=8.56$ ,  $SD=5.45$ ), however it was

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<sup>1</sup> Groupwise alpha adjusted for 3 analyses= 0.02

significantly more elevated than the Screen Pass sample ( $M=6.01$ ,  $SD=5.57$ )

$F(1,156)=8.89$ ,  $p<.01$ . This pattern was true of the total score, as well as every subscale.

#### Inventory of Socially Supportive Behaviors (ISSB).

Total scores on the ISSB range from 40, indicating the least amount of perceived social support, to 200, indicating the most amount of perceived social support<sup>2</sup>. The total frequency score for the entire sample was slightly above average ( $M=122.09$ ,  $SD=32.27$ ), suggesting a good amount of perceived social support. Further, looking at individual subdomains, all four domains were significantly internally correlated (see Table 4).

Scores for the Screen Fail sample were significantly different than the Screen Pass sample  $F(1,144)=15.87$ ,  $p<.01$ ; Wilk's  $\Lambda=0.812$ , partial  $\eta^2=.10$ , with the Screen Fail sample endorsing significantly less social support  $F(1,156)=9.98$ ,  $p<.01$ . Looking at individual subdomains, the Screen Fail sample differed significantly from the Screen Pass sample in the Nondirective Support area,  $F(1,156)=9.98$ ,  $p<.01$ . This suggests that the difference in ISSB Total Score was driven by discrepancies in this particular subdomain.

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<sup>2</sup> Total scores for the ISSB are calculated as a frequency count. Individual subdomain scores are calculated as mean scores.

Table 3  
*Means and Standard Deviations of Dependent Measures*

|                           | Whole Sample   | Screen Pass    | Screen Fail      |
|---------------------------|----------------|----------------|------------------|
| <b>GARS-3</b>             |                |                |                  |
| Autism Index              | 95.87 (12.89)  | 98.05 (12.16)  | 87.48 (12.35)**  |
| RRB                       | 10.66 (2.03)   | 10.90 (1.89)   | 9.72 (2.33)      |
| Social Interaction        | 7.45 (1.37)    | 7.60 (1.34)    | 6.84 (1.35)      |
| Social Communication      | 7.65 (1.82)    | 7.85 (1.76)    | 6.87 (1.89)      |
| Emotional Responses       | 9.56 (1.97)    | 9.73 (1.85)    | 8.88 (2.31)      |
| Cognitive Style           | 11.49 (1.74)   | 11.73 (1.57)   | 10.22 (2.05)**   |
| Maladaptive Speech        | 11.11 (1.92)   | 11.41 (1.76)   | 9.50 (1.98)**    |
| <b>PSI-4-SF</b>           |                |                |                  |
| Total Stress Score        | 70.32 (7.58)   | 70.66 (7.70)   | 69.00 (7.01)     |
| Parental Distress         | 65.27 (9.02)   | 65.26 (9.23)   | 65.31 (8.28)     |
| Parent Child              | 69.89 (8.63)   | 70.05 (8.81)   | 69.23 (7.95)     |
| Dysfunctional Interaction |                |                |                  |
| Difficult Child           | 67.87 (7.70)   | 68.12 (8.01)   | 66.87 (6.34)     |
| <b>GHQ-28</b>             |                |                |                  |
| Total Score               | 6.01 (5.57)    | 5.36 (5.43)    | 8.56 (5.45)**    |
| Somatic Symptoms          | 1.41 (1.56)    | 1.23 (1.50)    | 2.09 (1.63)**    |
| Anxiety/Insomnia          | 1.70 (1.71)    | 1.55 (1.70)    | 2.28 (1.69)*     |
| Social Dysfunction        | 1.54 (1.53)    | 1.37 (1.45)    | 2.22 (1.68)**    |
| Depression                | 1.37 (1.57)    | 1.21 (1.51)    | 1.97 (1.66)*     |
| <b>ISSB</b>               |                |                |                  |
| Total Frequency           | 122.09 (32.27) | 126.06 (32.69) | 106.44 (25.43)** |
| Directive Guidance        | 3.06 (0.87)    | 3.12 (0.89)    | 2.84 (0.70)      |
| Nondirective Support      | 3.08 (0.83)    | 3.19 (0.81)    | 2.69 (0.77)**    |
| Positive Social Exchange  | 3.15 (0.85)    | 3.21 (0.86)    | 2.94 (0.80)      |
| Tangible Assistance       | 2.98 (0.88)    | 3.03 (0.92)    | 2.79 (0.73)      |

\* $p < 0.05$ , \*\* $p < .01$

#### Correlations between Dependent Measures

As previously stated, all subdomain scores within the GARS-3, PSI-4-SF, GHQ-28, and ISSB were all significantly and positively correlated within their broader measure.

Looking at the correlations between the four dependent measures for the whole sample (see Table 4), the Autism Index on the GARS-3 was found to be significantly and positively correlated with ISSB Total Frequency  $r(150) = .521$ ,  $p < .01$ , and Total Stress

Score  $r(146)=.344, p<.01$  on the PSI, suggesting that higher parent-reported ASD severity was related to increased parent perceptions of social support as well as increased parent stress. Further, the Autism Index Score was significantly and negatively correlated with GHQ Total Score  $r(150)=-.309, p<.01$ , suggesting that higher parent-reported ASD severity was related to decreased self-reported parent psychosocial functioning. Additionally, looking at social support, scores on the ISSB were negatively and significantly associated with the GHQ  $r(150)=-.309, p<.01$ , and positively related to Total Parent Stress  $r(150)=.393, p<.01$ . This suggests that those parents endorsing high perceived social support also rated themselves to be the least affected by psychosocial symptoms, yet more impacted by perceived parent stress. No significant relationship was found between parent psychosocial functioning on the GHQ-28 and Parent Stress on the PSI.

Results in the Screen Pass sample followed the patterns of relationship and significance endorsed by the whole group (see Table 5). However, the Screen Fail sample differed significantly. In the Screen Fail sample (see Table 6), the only significant relationship that was maintained was the negative relationship between ASD symptom severity and parent psychosocial functioning on the GHQ-28  $r(31)=-.402, p<.05$ . The other relationships were rendered nonsignificant by looking at this sample in isolation.

Table 4  
*Pearson Correlations among Dependent Variables- Whole Sample*

|                      | 1     | 2     | 3     | 4     | 5     | 6     | 7     | 8    | 9    | 10   |
|----------------------|-------|-------|-------|-------|-------|-------|-------|------|------|------|
| 1. GARS Autism Index | -     |       |       |       |       |       |       |      |      |      |
| 2. RRB               | .86*  | -     |       |       |       |       |       |      |      |      |
| 3. Social Int.       | .84*  | .75*  | -     |       |       |       |       |      |      |      |
| 4. Social Comm.      | .82*  | .64*  | .70*  | -     |       |       |       |      |      |      |
| 5. Emot. Resp.       | .86*  | .76*  | .57*  | .57*  | -     |       |       |      |      |      |
| 6. Cog. Style        | .66*  | .47*  | .36*  | .36*  | .52*  | -     |       |      |      |      |
| 7. Mal. Speech       | .78*  | .69*  | .70*  | .70*  | .56*  | .49*  | -     |      |      |      |
| 8. PSI Total Stress  | .34*  | .43*  | .43*  | .12   | .16   | .29*  | .39*  | -    |      |      |
| 9. Parental Diss.    | .16*  | .20*  | .20*  | .05   | .17*  | .14   | .21*  | .59* | -    |      |
| 10. PCDI             | .26*  | .43*  | .43*  | .09   | .04   | .22*  | .41*  | .94* | .51* | -    |
| 11. Diff. Child      | .30*  | .43*  | .43*  | .15   | .08   | .26*  | .26*  | .91* | .45* | .82* |
| 12. GHQ Total        | -.31* | -.20* | -.17* | -.18* | -.20* | -.30* | -.21* | -.09 | .01  | -.07 |
| 13. Som. Symp.       | -.28* | -.17* | -.17* | -.17* | -.16* | -.26* | -.22* | -.14 | -.04 | -.09 |
| 14. Anx./Insomnia    | -.29* | -.26* | -.25* | -.15  | .17*  | -.21* | -.32* | -.10 | .05  | -.13 |
| 15. Social Dys.      | -.18* | -.09* | -.04  | -.05  | -.11  | -.20* | 0.05  | -.03 | .00  | -.01 |
| 16. Depression       | -.33* | -.19* | -.13  | -.27* | -.27* | -.38* | -.09  | -.05 | .01  | -.02 |
| 17. ISSB Total       | .52*  | .54*  | .43*  | .34*  | .35*  | .51*  | .51*  | .39* | .18* | .36* |
| 18. Dir. Guidance    | .27*  | .27*  | .24*  | .09   | .25   | .23*  | .29*  | .28* | .20* | .27* |
| 19. Nondire. Support | .19*  | .18*  | .14   | .02   | .16*  | .23*  | .29*  | .25* | .20* | .23* |
| 20. Pos. Soc.        | .18*  | .19*  | .16*  | .06   | .20*  | .23*  | .18   | .30  | .25* | .26* |
| 21. Tangible Assist. | .22*  | .25*  | .17*  | -.02  | .20*  | .25*  | .30*  | .28* | .18* | .24* |

\* $p < .05$

Table 4

*Pearson Correlations among Dependent Variables- Whole Sample (cont.)*

|                      | 11   | 12    | 13    | 14    | 15   | 16   | 17   | 18   | 19   | 20   | 21 |
|----------------------|------|-------|-------|-------|------|------|------|------|------|------|----|
| 1. GARS Autism Index |      |       |       |       |      |      |      |      |      |      |    |
| 2. RRB               |      |       |       |       |      |      |      |      |      |      |    |
| 3. Social Int.       |      |       |       |       |      |      |      |      |      |      |    |
| 4. Social Comm.      |      |       |       |       |      |      |      |      |      |      |    |
| 5. Emot. Resp.       |      |       |       |       |      |      |      |      |      |      |    |
| 6. Cog. Style        |      |       |       |       |      |      |      |      |      |      |    |
| 7. Mal. Speech       |      |       |       |       |      |      |      |      |      |      |    |
| 8. PSI Total Stress  |      |       |       |       |      |      |      |      |      |      |    |
| 9. Parental Diss.    |      |       |       |       |      |      |      |      |      |      |    |
| 10. PCDI             |      |       |       |       |      |      |      |      |      |      |    |
| 11. Diff. Child      | -    |       |       |       |      |      |      |      |      |      |    |
| 12. GHQ Total        | -.10 | -     |       |       |      |      |      |      |      |      |    |
| 13. Som. Symp.       | -.13 | .89*  | -     |       |      |      |      |      |      |      |    |
| 14. Anx./Insomnia    | -.11 | .84*  | .65*  | -     |      |      |      |      |      |      |    |
| 15. Social Dys.      | -.04 | .90*  | .77*  | .67*  | -    |      |      |      |      |      |    |
| 16. Depression       | -.07 | .86*  | .71*  | .59*  | .72* | -    |      |      |      |      |    |
| 17. ISSB Total       | .34* | -.16* | -.13  | -.29* | -.05 | -.09 | -    |      |      |      |    |
| 18. Dir. Guidance    | .20* | -.11  | -.08  | -.16* | -.05 | -.09 | .40* | -    |      |      |    |
| 19. Nondire. Support | .17* | -.19* | -.19* | -.20* | -.16 | -.13 | .31* | .82* | -    |      |    |
| 20. Pos. Soc.        | .22* | -.12  | -.08  | -.15  | -.06 | -.13 | .34* | .85* | .74* | -    |    |
| 21. Tangible Assist. | .19* | -.11  | -.08  | -.15  | -.07 | -.07 | .37* | .90* | .79* | .74* | -  |

\* $p < .05$



Table 5  
*Pearson Correlations among Dependent Variables- Screen Pass*

|                      | 1     | 2     | 3     | 4     | 5     | 6     | 7     | 8     | 9    | 10   |
|----------------------|-------|-------|-------|-------|-------|-------|-------|-------|------|------|
| 1. GARS Autism Index | -     |       |       |       |       |       |       |       |      |      |
| 2. RRB               | .83*  | -     |       |       |       |       |       |       |      |      |
| 3. Social Int.       | .82*  | .70*  | -     |       |       |       |       |       |      |      |
| 4. Social Comm.      | .79*  | .56*  | .65*  | -     |       |       |       |       |      |      |
| 5.Emot.Resp.         | .85*  | .70*  | .51*  | .70*  | -     |       |       |       |      |      |
| 6.Cog. Style         | .79*  | .58*  | .48*  | .51*  | .62*  | -     |       |       |      |      |
| 7. Mal. Speech       | .88*  | .77*  | .70*  | .61*  | .69*  | .67*  | -     |       |      |      |
| 8. PSI Total Stress  | .41*  | .34*  | .47*  | .16   | .23*  | .33*  | .38*  | -     |      |      |
| 9. Parental Diss.    | .19*  | .14   | .20*  | .09   | .23*  | .18   | .21*  | .56*  | -    |      |
| 10. PCIDI            | .26*  | .25*  | .50*  | .18   | .14   | .28*  | .40*  | .95*  | .48* | -    |
| 11. Diff. Child      | .31*  | .21*  | .46*  | .13   | .06   | .25*  | .27*  | .92*  | .44* | .86* |
| 12. GHQ Total        | -.41* | -.30* | -.27* | -.23* | -.29* | -.31* | -.32* | -.10  | -.02 | -.10 |
| 13. Som. Symp.       | -.40* | -.30* | -.26* | -.24* | -.29* | -.33* | -.29* | -.18* | -.08 | -.14 |
| 14. Anx./Insomnia    | -.39* | -.36* | -.35* | -.20  | -.26* | -.22* | -.42* | -.09  | .05  | -.12 |
| 15. Social Dys.      | -.27* | -.17  | -.12  | -.09  | -.18* | -.20* | -.10  | -.06  | -.02 | -.04 |
| 16. Depression       | -.39* | -.24* | -.18* | -.28* | -.30* | -.31* | -.22* | -.04  | -.01 | -.03 |
| 17. ISSB Total       | .55*  | .59*  | .47*  | .37*  | .39*  | .52*  | .53*  | .40*  | .19* | .38* |
| 18. Dir. Guidance    | .27*  | .28*  | .26*  | .08   | .23*  | .13   | .36*  | .31*  | .22* | .30* |
| 19. Nondire. Support | .18*  | .19*  | .17   | .00   | .15   | .11   | .29*  | .28*  | .25* | .26* |
| 20. Pos. Soc.        | .18   | .22*  | .18*  | .05*  | .18*  | .10   | .21*  | .32*  | .26* | .28* |
| 21. Tangible Assist. | .22*  | .26*  | .18*  | -.03  | .17   | .18   | .37*  | .32*  | .20* | .27* |

\* $p < .05$

Table 5

*Pearson Correlations among Dependent Variables- Screen Pass (cont.)*

|                      | 11   | 12   | 13    | 14    | 15   | 16   | 17   | 18   | 19   | 20   | 21 |
|----------------------|------|------|-------|-------|------|------|------|------|------|------|----|
| 1. GARS Autism Index |      |      |       |       |      |      |      |      |      |      |    |
| 2. RRB               |      |      |       |       |      |      |      |      |      |      |    |
| 3. Social Int.       |      |      |       |       |      |      |      |      |      |      |    |
| 4. Social Comm.      |      |      |       |       |      |      |      |      |      |      |    |
| 5. Emot. Resp.       |      |      |       |       |      |      |      |      |      |      |    |
| 6. Cog. Style        |      |      |       |       |      |      |      |      |      |      |    |
| 7. Mal. Speech       |      |      |       |       |      |      |      |      |      |      |    |
| 8. PSI Total Stress  |      |      |       |       |      |      |      |      |      |      |    |
| 9. Parental Diss.    |      |      |       |       |      |      |      |      |      |      |    |
| 10. PCDI             |      |      |       |       |      |      |      |      |      |      |    |
| 11. Diff. Child      | -    |      |       |       |      |      |      |      |      |      |    |
| 12. GHQ Total        | -.08 | -    |       |       |      |      |      |      |      |      |    |
| 13. Som. Symp.       | -.14 | .91* | -     |       |      |      |      |      |      |      |    |
| 14. Anx./Insomnia    | -.08 | .84* | .67*  | -     |      |      |      |      |      |      |    |
| 15. Social Dys.      | -.05 | .91* | .80*  | .68*  | -    |      |      |      |      |      |    |
| 16. Depression       | -.02 | .87* | .77*  | .57*  | .75* | -    |      |      |      |      |    |
| 17. ISSB Total       | .34  | -.09 | -.09  | -.22* | .02  | .00  | -    |      |      |      |    |
| 18. Dir. Guidance    | .22  | -.08 | -.07  | -.16* | .01  | -.04 | .44* | -    |      |      |    |
| 19. Nondire. Support | .19  | -.17 | -.18* | -.19* | -.11 | -.10 | .32* | .83* | -    |      |    |
| 20. Pos. Soc.        | .22  | -.09 | -.10  | -.14  | .00  | -.07 | .37* | .84* | .74* | -    |    |
| 21. Tangible Assist. | .20  | -.09 | -.07  | -.15  | -.02 | -.05 | .41* | .90* | .80* | .74* | -  |

\* $p < .05$

Table 6  
*Pearson Correlations among Dependent Variables- Screen Fail*

|                      | 1    | 2    | 3    | 4    | 5    | 6     | 7    | 8    | 9    | 10   |
|----------------------|------|------|------|------|------|-------|------|------|------|------|
| 1. GARS Autism Index | -    |      |      |      |      |       |      |      |      |      |
| 2. RRB               | .94* | -    |      |      |      |       |      |      |      |      |
| 3. Social Int.       | .88* | .85* | -    |      |      |       |      |      |      |      |
| 4. Social Comm.      | .89* | .83* | .78* | -    |      |       |      |      |      |      |
| 5.Emot.Resp.         | .93* | .87* | .70* | .83* | -    |       |      |      |      |      |
| 6.Cog. Style         | .12  | -.02 | -.19 | -.06 | .23  | -     |      |      |      |      |
| 7. Mal. Speech       | .43  | .38  | .64* | .32  | .16  | -.49* | -    |      |      |      |
| 8. PSI Total Stress  | -.04 | -.06 | .21  | -.13 | -.14 | -.01  | .25  | -    |      |      |
| 9. Parental Diss.    | .05  | .02  | .20  | -.09 | -.02 | .01   | .27  | .76* | -    |      |
| 10. PCIDI            | -.21 | -.17 | .09  | -.30 | -.33 | -.15  | .31  | .91* | .68* | -    |
| 11. Diff. Child      | .19  | .18  | .32  | .15  | .14  | .16   | 1.00 | .83* | .52* | .60* |
| 12. GHQ Total        | .40* | .31  | .42* | .22  | .22  | .07   | .67* | .07  | .11  | .07  |
| 13. Som. Symp.       | .46* | .40* | .26* | .32  | .33  | .26   | .48* | .12  | .11  | .14  |
| 14. Anx./Insomnia    | .33  | .22  | .29  | .24  | .23  | .10   | .38  | -.08 | .08  | -.13 |
| 15. Social Dys.      | .45* | .33  | .47* | .29  | .23  | .17   | .64* | .18  | .07  | .14  |
| 16. Depression       | .07  | .08  | .24  | -.11 | -.08 | -.30  | .75* | .01  | .08  | .07  |
| 17. ISSB Total       | .07  | .21  | .06  | .01  | .03  | .20   | -.01 | .27  | .20  | .30  |
| 18. Dir. Guidance    | .10  | .11  | .01  | 0.03 | .26  | .45   | -.32 | .05  | .11  | .06  |
| 19. Nondire. Support | -.14 | -.06 | -.21 | -.19 | .04  | .29   | -.36 | .01  | .01  | .05  |
| 20. Pos. Soc.        | .04  | -.01 | -.05 | -.04 | .19  | .49   | -.26 | .19  | .21  | .16  |
| 21. Tangible Assist. | .10  | .16  | .03  | -.09 | .29  | .34   | -.32 | .02  | .06  | .04  |

\* $p < .05$

Table 6

*Pearson Correlations among Dependent Variables- Screen Fail (cont.)*

|                      | 11   | 12   | 13   | 14    | 15   | 16   | 17   | 18   | 19   | 20   | 21 |
|----------------------|------|------|------|-------|------|------|------|------|------|------|----|
| 1. GARS Autism Index |      |      |      |       |      |      |      |      |      |      |    |
| 2. RRB               |      |      |      |       |      |      |      |      |      |      |    |
| 3. Social Int.       |      |      |      |       |      |      |      |      |      |      |    |
| 4. Social Comm.      |      |      |      |       |      |      |      |      |      |      |    |
| 5.Emot.Resp.         |      |      |      |       |      |      |      |      |      |      |    |
| 6.Cog. Style         |      |      |      |       |      |      |      |      |      |      |    |
| 7. Mal. Speech       |      |      |      |       |      |      |      |      |      |      |    |
| 8. PSI Total Stress  |      |      |      |       |      |      |      |      |      |      |    |
| 9. Parental Diss.    |      |      |      |       |      |      |      |      |      |      |    |
| 10. PCDI             |      |      |      |       |      |      |      |      |      |      |    |
| 11. Diff. Child      | -    |      |      |       |      |      |      |      |      |      |    |
| 12. GHQ Total        | -.10 | -    |      |       |      |      |      |      |      |      |    |
| 13. Som. Symp.       | -.01 | .80* | -    |       |      |      |      |      |      |      |    |
| 14. Anx./Insomnia    | -.19 | .82* | .55* | -     |      |      |      |      |      |      |    |
| 15. Social Dys.      | .06  | .85* | .63* | .56*  | -    |      |      |      |      |      |    |
| 16. Depression       | -.20 | .80* | .45* | .58*  | .59* | -    |      |      |      |      |    |
| 17. ISSB Total       | .30  | -.25 | -.03 | -.47* | -.06 | -.26 | -    |      |      |      |    |
| 18. Dir. Guidance    | .07  | -.12 | .01  | -.06  | -.13 | -.19 | .01  | -    |      |      |    |
| 19. Nondire. Support | -.03 | -.06 | .01  | -.08  | -.11 | -.01 | -.01 | .78* | -    |      |    |
| 20. Pos. Soc.        | .17  | -.11 | .12  | -.05  | -.15 | -.27 | .08  | .87* | .72* | -    |    |
| 21. Tangible Assist. | .05  | -.09 | -.03 | -.05  | -.15 | -.06 | .03  | .90* | .75* | .71* | -  |

\* $p < .0$

## Endorsement of Past Service Access and Future Service Interest

In the Family Services Questionnaire (FSQ), parents were presented with a set of 13 support services, and were asked to indicate if they had ever accessed any of these services for themselves or their typically developing child in the past, and if they would consider accessing any of them in the future. Parents responded to each service individually.

Looking at the sample as a whole, parents endorsed having accessed an average of 8.23 services (out of a possible 13) for themselves following the diagnosis of their child with ASD (See Table 7). Parents reported accessing less services for their typically developing children in that same time frame ( $M=7.38$ )  $t(156)=4.777, p<.01$ . This pattern was found to be comparable in both the Screen Pass and Screen Fail samples, though statistical significance was only found to be trending in the latter group. Notably, the Screen Fail sample was found to have accessed significantly fewer services than the Screen Pass sample across both parent  $F(1,155)=81.79, p<.01$  and sibling areas  $F(1,156)=66.36, p<.05$ .<sup>3</sup>

Looking at future interest in service access, parents as a whole reported having interest in accessing more services than what was endorsed in the past. This was true both of parents  $t(156)=-5.429, p<.01$  and siblings  $t(157)=-6.573, p<.01$ .<sup>4</sup> This pattern was also endorsed by both subgroups. However, while the Screen Fail sample had a trend level increase in their interest in future services access, it should be noted that they reported significantly less interest in future parent services  $F(1,156)=25.10, p<.01$  and future sibling services than the Screen Pass sample  $F(1, 156)=16.42, p<.01$ .

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<sup>3</sup> Groupwise alpha not adjusted given the limited  $n$  for the Screen Fail sample. This is true for ongoing between group comparisons.

<sup>4</sup> Groupwise alpha adjusted for 2 analyses= 0.025

Table 7  
*Means and Standard Deviations of Service Engagement for Parents and Siblings*

|                       | Whole Sample  | Screen Pass  | Screen Fail   |
|-----------------------|---------------|--------------|---------------|
| Past Service Access   |               |              |               |
| Parents               | 8.23 (2.95)   | 8.59 (2.98)  | 6.77 (2.38)** |
| Siblings              | 7.38 (3.54)   | 7.71 (3.66)  | 6.09 (2.68)*  |
| Future Service Access |               |              |               |
| Parents               | 9.46 (3.55)** | 10.12 (3.35) | 6.84 (3.09)** |
| Siblings              | 9.05 (3.92)** | 9.66 (3.92)  | 6.66 (2.91)** |

\* $p < 0.05$ , \*\* $p < .01$

#### Endorsement of Service Access/Interest by Service Type

##### Parent Past Service Access.

Looking at the types of services that parents have accessed in the past (See Table 8), parents in the whole sample were most likely to endorse the use of individual psychotherapy as a source of support (73.8%). Individual psychotherapy was then followed by two sets of related support options: reading (72.0%) and writing posts (69.2%) on online message boards, and parent support groups, both online (70.5%) and in person (69.9%). Parents in the whole sample were least likely to endorse the use of community support organizations (e.g., Autism Speaks, Autism New Jersey) for their own use (49.0%), though this still represents roughly half of the sample.

Parents in the Screen Pass sample were also most likely to endorse individual therapy as a source of self-support (78.6%), while the Screen Fail sample more heavily accessed reading posts on online message boards (78.1%). Notably, parents in the Screen Fail sample were far less likely to access community support services specific to ASD (15.6%) than the Screen Pass sample (78.6%),  $\chi^2 (1, N=157) = 17.962, p < .01$ .

Table 8  
*Endorsement of Past Parent Service Access by Service Type*

|  | % Endorsed <sup>WS</sup> | % Endorsed <sup>SP</sup> | % Endorsed <sup>SF</sup> |
|--|--------------------------|--------------------------|--------------------------|
| Individual Psychotherapy                 | 73.8                     | 78.6                     | 75.0                     |
| Online Message Boards<br>(Reading Posts) | 72.0                     | 70.4                     | 78.1                     |
| Parent Support Group (Online)            | 70.5                     | 68.8                     | 77.4                     |
| Parent Support Group (In Person)         | 69.9                     | 71.8                     | 62.5                     |
| Online Message Boards<br>(Writing Posts) | 69.2                     | 68.5                     | 71.9                     |
| Couples Therapy                          | 65.8                     | 65.9                     | 65.6                     |
| Primary Care Physician                   | 65.6                     | 68.8                     | 53.1                     |
| Parent Skills Training Group             | 62.6                     | 66.7                     | 46.9                     |
| Religious Community                      | 59.0                     | 60.8                     | 51.6                     |
| Informal Parent Group                    | 58.3                     | 61.3                     | 46.9                     |
| Family Psychotherapy                     | 53.5                     | 53.7                     | 53.1                     |
| Group Psychotherapy                      | 53.5                     | 52.0                     | 59.4                     |
| Other Community Support                  | 49.0                     | 57.6                     | 15.6**                   |

\* $p < 0.05$ , \*\* $p < .01$

#### Parent Future Service Interest.

When parents were asked to indicate their interest in future service access (See Table 9), service preference shifted for the sample as a whole. While individual psychotherapy was the most endorsed service in the past, the preference for this in-person service was slightly edged out by online options when querying future interest; online parent support groups (80.3%) and reading posts on online message boards (78.8%). This may reflect a shift in preference to services that have more flexible access, or require less response-effort. Other community support, however, remained the least preferred support service for parents (62.0%).

Parents in the Screen Fail sample replicated this preference in online support; reading posts on online message boards (78.1%) and online parent support groups (75.0%). The Screen Pass sample, however, endorsed the most interest in parent skills

training groups (83.2%) and individual psychotherapy (82.5%), perhaps suggesting that more effortful services are not as much a deterrent for this subgroup.

Table 9

*Endorsement of Future Parent Service Interest by Service Type*

|  | % Endorsed <sup>WS</sup> | % Endorsed <sup>SP</sup> | % Endorsed <sup>SF</sup> |
|--|--------------------------|--------------------------|--------------------------|
| Parent Support Group (Online)            | 80.3                     | 81.6                     | 75.0                     |
| Online Message Boards<br>(Reading Posts) | 78.8                     | 79.0                     | 78.1                     |
| Individual Psychotherapy                 | 78.5                     | 82.5                     | 62.5                     |
| Parent Skills Training Group             | 78.3                     | 83.2                     | 59.4                     |
| Parent Support Group (In Person)         | 73.4                     | 78.6                     | 53.1                     |
| Group Psychotherapy                      | 73.2                     | 74.6                     | 67.7                     |
| Informal Parent Group                    | 72.8                     | 79.4                     | 46.9                     |
| Couples Therapy                          | 72.6                     | 80.0                     | 43.8                     |
| Online Message Boards<br>(Writing Posts) | 72.0                     | 78.4                     | 46.9                     |
| Primary Care Physician                   | 70.3                     | 71.2                     | 50.0                     |
| Family Psychotherapy                     | 69.0                     | 73.0                     | 53.1                     |
| Religious Community                      | 68.2                     | 71.2                     | 56.3                     |
| Other Community Support                  | 62.0                     | 74.6                     | 12.5                     |

\* $p < 0.05$ , \*\* $p < .01$

#### Sibling Past Service Access.

Similar to the parent sample, individual psychotherapy was the most endorsed service accessed for typically developing siblings (72.2%) (See Table 10). However, other top services differed significantly from the parent group. Parents were far more likely to access a medical professional,  $\chi^2 (1, N=157) = 10.232, p < .01$ , or members of the religious community,  $\chi^2 (1, N=157) = 26.364, p < .01$  for their child than for themselves. Teachers were also a common source of support endorsed for siblings (63.9%). Similar to parents, other community organizations were amongst the lowest endorsed for siblings (49.0%).



This pattern largely held true for the both the Screen Pass and Screen Fail samples, though siblings in the Screen Fail sample were far more likely to have participated in the reading

of online message boards (81.3%) than the Screen Pass sample (55.6%),  $\chi^2 (1, N=158) = 7.066, p<.01$  Similar to the parents, siblings in the Screen Fail sample were again far less likely to have participated in community-based support options (12.5%) than the Screen Pass Sample (47.6%),  $\chi^2 (1, N=158) = 13.060, p<.01$ .

Table 10

*Endorsement of Past Sibling Service Access by Service Type*

|  | % Endorsed <sup>WS</sup> | % Endorsed <sup>SP</sup> | % Endorsed <sup>SF</sup> |
|--|--------------------------|--------------------------|--------------------------|
| Individual Psychotherapy                 | 72.2                     | 74.6                     | 62.5                     |
| Pediatrician                             | 65.2                     | 66.7                     | 59.4                     |
| Religious Community                      | 63.9                     | 65.1                     | 59.4                     |
| Teachers at School                       | 62.0                     | 62.7                     | 59.4                     |
| Online Message Boards<br>(Reading Posts) | 60.8                     | 55.6                     | 81.3                     |
| Sibling Support Group (Online)           | 59.6                     | 57.3                     | 68.8                     |
| Sibling Skills Training Group            | 59.6                     | 61.3                     | 53.1                     |
| Online Message Boards<br>(Writing Posts) | 55.1                     | 56.3                     | 50.0                     |
| Sibling Support Group<br>(In Person)     | 52.9                     | 52.8                     | 53.1                     |
| Informal Sibling Group                   | 51.3                     | 53.6                     | 41.9                     |
| Group Psychotherapy                      | 50.0                     | 50.0                     | 50.0                     |
| Other Community Support                  | 49.0                     | 47.6                     | 12.5                     |
| Family Psychotherapy                     | 47.8                     | 44.8                     | 59.4                     |

\* $p<0.05$ , \*\* $p<.01$

Sibling Future Service Interest.

Looking ahead to services that parents were interested in accessing for their child in the future, individual psychotherapy was maintained as the most endorsed service for the whole sample (78.2%) (See Table 11). Parents were also far more likely to endorse interest in in-person services for their children than for themselves. This included group

psychotherapy  $\chi^2 (1, N=157) = 27.027, p<.01$ , and in person support groups  $\chi^2 (1, N=156) = 28.252, p<.01$ . Similar to parents, other community organizations remained amongst the lowest endorsed for siblings (61.1%). While this pattern was largely replicated in the Screen Pass sample, parents in the Screen Fail sample were far less likely to endorse a preference for individual psychotherapy,  $\chi^2 (1, N=156) = 5.826, p<.05$ , and community support-based services,  $\chi^2 (1, N=157) = 40.035, p<.01$ . Instead, their preferences were set most highly in group psychotherapy (77.4%) and reading online message boards (75.0%).

Table 11  
*Endorsement of Future Sibling Service Interest by Service Type*

|  | % Endorsed <sup>WS</sup> | % Endorsed <sup>SP</sup> | % Endorsed <sup>SF</sup> |
|--|--------------------------|--------------------------|--------------------------|
| Individual Psychotherapy                 | 78.2                     | 82.3                     | 62.5                     |
| Group Psychotherapy                      | 73.2                     | 72.2                     | 77.4                     |
| Sibling Support Group<br>(In Person)     | 73.1                     | 75.2                     | 64.5                     |
| Sibling Skills Training Group            | 72.8                     | 79.4                     | 46.9                     |
| Teachers at School                       | 72.2                     | 73.0                     | 68.8                     |
| Sibling Support Group (Online)           | 71.5                     | 71.4                     | 71.9                     |
| Pediatrician                             | 71.2                     | 75.8                     | 53.1                     |
| Online Message Boards<br>(Reading Posts) | 70.9                     | 69.8                     | 75.0                     |
| Family Psychotherapy                     | 70.5                     | 76.0                     | 48.4                     |
| Informal Sibling Group                   | 66.9                     | 72.8                     | 43.8                     |
| Religious Community                      | 66.5                     | 67.5                     | 62.5                     |
| Online Message Boards<br>(Writing Posts) | 62.0                     | 66.7                     | 43.8                     |
| Other Community Support                  | 61.1                     | 73.6                     | 12.5                     |

\* $p<0.05$ , \*\* $p<.01$

#### Ratings of Service Access/Interest Factors

##### Parent Ratings of their Own Support.

Parents were presented with a series of statements describing elements that may facilitate or impede treatment access for families. These statements were grouped into

several factors, including a parent's general attitude toward support services, the priority of services for parents, having the time/availability to participate and services, and their ability to allocate finances/childcare in order to access services. Higher ratings describe a more positive view, or more ability to access services.

Parents in the whole sample rated their attitude toward support services highly ( $M=3.27$ ,  $SD=0.67$ ), suggesting that parents are interested in these services, and think services would be helpful to them (See Table 12). Parents also endorsed having the time and flexibility in transportation to participate in services ( $M=3.14$ ,  $SD=0.33$ ), as well as having the money and childcare to arrange their access to supports ( $M=3.67$ ,  $SD=0.85$ ). Notably, parents reported the priority of services ( $M=2.68$ ,  $SD=0.58$ ) significantly lower than the other 3 factors: attitude toward services ( $M=3.27$ ,  $SD=0.67$ )  $t(157)=-10.307$ ,  $p<.01$ , time/location of services ( $M=3.14$ ,  $SD=0.33$ )  $t(157)=-8.465$ ,  $p<.01$ , and finances/childcare for services ( $M=3.67$ ,  $SD=0.85$ )  $t(157)=-11.535$ ,  $p<.01$ .<sup>5</sup> This suggests that priority of treatment services, compared to other activities and obligation in a parent's life, may be the greatest impediment to accessing their own treatment.

The Screen Pass and Screen Fail samples follow suit with the patterns endorsed by the whole sample. However, it is important to note that the Screen Fail sample reported significantly more troubles than the Screen Pass sample with finding time for services  $F(1,156)=4.540$ ,  $p<.05$  and finding finances/arranging childcare in order to access services  $F(1,156)=5.011$ ,  $p<.05$ .

#### Parent Ratings of Sibling Support.

Following a pattern similar to parent service factors, parents rated their attitude toward services for siblings highly ( $M=3.29$ ,  $SD=0.61$ ) (See Table 12). They also rated

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<sup>5</sup> Groupwise alpha adjusted for 3 analyses= 0.02

having time for these services ( $M=3.12$ ,  $SD=0.38$ ) and the ability to arrange finances and childcare in order for their typically developing child to access support for themselves ( $M=3.71$ ,  $SD=0.81$ ). Additionally, as with the parent report on their own support, parents rated the priority of securing support for siblings ( $M=2.85$   $SD=0.62$ ) significantly lower than the other 3 factors: attitude toward services ( $M=3.29$ ,  $SD=0.61$ )  $t(157)=-7.915$ ,  $p<.01$ , time/location of services ( $M=3.12$ ,  $SD=0.38$ )  $t(156)=-4.615$ ,  $p<.01$ , and finances/childcare for services ( $M=3.71$ ,  $SD=0.81$ )  $t(157)=-10.058$ ,  $p<.01$ .<sup>6</sup> Further, importantly, while parents reported priority to be the lowest factor in both the parent and sibling ratings, parents reported priority for their own services to be significantly lower than the priority for their typically developing child  $t(157)=-2.644$ ,  $p<.01$ .

Again, the Screen Pass and Screen Fail families follow the same pattern as the sample taken as a whole. However, it should be noted that parents in the Screen Fail sample rated finances to be significantly more troublesome than parents in the Screen Pass sample  $F(1,15)=6.505$ ,  $p<.05$ . This again suggests that more logistical factors, such as time and finances, are a primary factor in impeding high-risk families from accessing services for parents and siblings.

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<sup>6</sup> Groupwise alpha adjusted for 3 analyses= 0.02

Table 12

*Means and Standard Deviations of Service Access/Interest Factors*

|                           | Whole Sample  | Screen Pass   | Screen Fail   |
|---------------------------|---------------|---------------|---------------|
| Parents                   |               |               |               |
| Attitude toward Services  | 3.27 (0.67)   | 3.32 (0.62)   | 3.07 (0.85)   |
| Priority of Services      | 2.68 (0.58)** | 2.68 (0.58)** | 2.69 (0.55)** |
| Time/Location of Services | 3.14 (0.33)   | 3.17 (0.31)   | 3.03 (0.40)*  |
| Finances/Child Care       | 3.67 (0.85)   | 3.75 (0.85)   | 3.38 (0.80)*  |
| Siblings                  |               |               |               |
| Attitude toward Services  | 3.29 (0.61)   | 3.31 (0.62)   | 3.22 (0.57)   |
| Priority of Services      | 2.85 (0.62)   | 2.84 (0.63)   | 2.89 (0.57)   |
| Time/Location of Services | 3.12 (0.38)   | 3.13 (0.38)   | 3.10 (0.39)   |
| Finances/Child Care       | 3.71 (0.81)   | 3.79 (0.80)   | 3.39 (0.79)*  |

\* $p < 0.05$ , \*\* $p < 0.01$

## Relationship between Demographic Variables and Service Variables

A series of analysis of variance (ANOVA), correlations, and chi square analyses were conducted in order to elucidate relationships between demographic variables, service variables, such as the number of services accessed, and service access factors, such as attitude and priority.

No significant differences were found in the amount of support services accessed in the past, or interest in future services, by respondent region or marital status (See Table 13). This was true of both parent and sibling services. Further, no significant differences were found between men and women respondents in the amount of parent or sibling services accessed in the past, or the amount of services parents would be interested in accessing for siblings in the future. Women did report being interested in a higher number of future parent services than men  $F(1,156)=7.348, p<.01$ . Women also reported having a more positive attitude toward parent support services than men  $F(1,156)=8.151, p<.01$  (see Table 16). This was true of sibling services as well, with women reporting higher, more positive attitude scores than men  $F(1,156)=15.517, p<.01$ . Women also

reported having significantly more time for parent services than men  $F(1,156)=11.439$ ,  $p<.01$ <sup>7</sup>. The relationship between parent gender and future service interest for parents was found only in the Screen Pass sample (Table 14), while the difference in attitude toward parent services was only found in the Screen Fail sample (Table 15).

There were no differences in past service access and interest by respondent ethnicity. However, a one-way ANOVA by ethnicity revealed that those who identified as Hispanic were interested in significantly more sibling services in the future than Non-Hispanic families  $F(1,153)=4.525$ ,  $p<.05$ . This relationship was also found to be trend-level for future parent services  $F(1,153)=3.789$ ,  $p=.053$ . The differences in future service interest by ethnicity appear to be driven by the Screen Pass sample, with the Screen Fail sample not demonstrating any significant relationships to this end. Demographic variables describing race were also related to service variables. Given the small proportion of the sample that did not identify their race as White, the race variable was collapsed into a binary variable (e.g., White and Non-White). Results from the ANOVA showed that parents who identified as White endorsed interest in a higher number of future parent services  $F(1,156)=7.004$ ,  $p<.01$ , and future sibling services  $F(1,156)=9.288$ ,  $p<.01$ , than Non-White participants<sup>8</sup>. Participants who identify as White also endorsed a more positive attitude toward parent  $F(1,156)=9.288$ ,  $p<.01$ , and sibling services  $F(1,156)=3.946$ ,  $p<.05$ <sup>9</sup>, than Non-White participants (see Table 17). Given the large proportion of Non-White participants in the Screen Fail sample, an analysis of covariance (ANCOVA) was conducted to control for the effect of Screen Fails on the between group differences. In these analyses, both the number of future sibling services endorsed, and

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<sup>7</sup> Groupwise alpha adjusted for 3 analyses= 0.02

<sup>8</sup> Groupwise alpha adjusted for 2 analyses= 0.025

<sup>9</sup> Groupwise alpha adjusted for 2 analyses= 0.025

the parent's attitude toward sibling services was rendered nonsignificant when accounting for Screen Fail status. However, interest in future parent services  $F(1,157)=4.903, p<.05$ , and attitude toward parent services  $F(1,157)=6.854, p<.05$  remained significant.

Further, some effects on service access and interest was found by parent education. The large majority of the sample reported a Bachelors Degree as their highest level of education achieved (65.66%). As such, parent education was collapsed into a 3-level variable: below Bachelor's, Bachelor's Degree, and above Bachelor's. When placed into an ANOVA, results revealed that those at the Bachelor level endorsed the most past parent services,  $F(2,154)=9.087, p<.01$ , past sibling services  $F(2,155)=12.528, p<.01$ , future parent services  $F(2,155)=6.799, p<.01$ , and future sibling services  $F(2,155)=8.031, p<.01$ <sup>10</sup>. The relationship between education level and past service was replicated in the Screen Pass sample for both parents and siblings in the Screen Pass sample, and for siblings only in the Screen Fail sample. No differences in attitude toward services, or priority of services was observed by parent educational level.

Family-level variables were also related to the endorsement of parent and sibling services. A series of correlations demonstrated that the number of children living in the home was negatively and positively associated with past parent service access  $r(156)=-.198, p<.05$ , future parent service access  $r(157)=-.218, p<.01$ , and future sibling service access  $r(157)=-.223, p<.01$ . This suggests that those families with fewer children in the home have accessed more services for parents and typically developing siblings, and are interested in more future services for siblings. Child age and gender were also found to be factors in service access and interest. Parents with older children with ASD endorsed interest in fewer future support services for themselves  $r(158)=-.161, p<.05$  than parents

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<sup>10</sup> Groupwise alpha adjusted for 4 analyses= 0.0125

of younger children. Whereas, parents with older typically developing children endorsed interest in more support services for their typically developing child  $r(158)=.178, p<.05$  than parents of younger children. With regard to gender, parents of female children with ASD endorsed accessing more parent  $F(1,143)=11.183, p<.01$ , and sibling  $F(1,144)=16.082, p<.01$ <sup>11</sup>, services in the past than those parents of male children with ASD. It should be noted that the gender of the child with ASD was not significantly correlated with Autism Symptom Severity on the GARS-3; therefore increased service access in this population cannot be accounted for by ASD presentation. No other differences in service interest or access factors were found based on the gender of the child with ASD, nor the gender of the typically developing child.

When looking at the subgroups separately, all effects related to number of children in the home, child age, and gender were replicated in the Screen Pass sample, while no significant effects were found in the Screen Fail sample.

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<sup>11</sup> Groupwise alpha adjusted for 2 analyses= 0.025



Table 13

*Means and Standard Deviations of Demographics by Service Access-Whole Sample*

|                  | Parent History | Sibling History | Parent Future  | Sibling Future |
|------------------|----------------|-----------------|----------------|----------------|
| Region           |                |                 |                |                |
| Northeast        | 8.02 (2.51)    | 7.29 (3.21)     | 8.96 (3.46)    | 8.63 (3.57)    |
| Midwest          | 9.25 (2.69)    | 8.35 (3.53)     | 11.00 (2.47)   | 10.15 (4.17)   |
| South            | 8.00 (3.57)    | 6.86 (4.12)     | 9.34 (4.04)    | 8.91 (4.76)    |
| West             | 8.20 (3.00)    | 7.44 (3.46)     | 9.42 (3.56)    | 9.13 (3.56)    |
| Marital Status   |                |                 |                |                |
| Married          | 8.23 (2.96)    | 7.49 (3.49)     | 9.48 (3.55)    | 9.02 (3.96)    |
| Divorced         | 8.67 (1.53)    | 3.33 (1.53)     | 7.67 (4.93)    | 9.67 (2.89)    |
| Partnered        | 8.50 (6.36)    | 8.00 (7.07)     | 9.00 (5.66)    | 8.50 (6.36)    |
| Separated        | 9.00 (-)       | 7.00 (-)        | 11.00 (-)      | 13.00 (-)      |
| Widowed          | 9.00 (-)       | 8.00 (-)        | 11.00 (-)      | 7.00 (-)       |
| Never Married    | 4.00 (-)       | 1.00 (-)        | 9.00 (-)       | 11.00 (-)      |
| Race             |                |                 |                |                |
| White            | 8.34 (3.04)    | 7.42 (3.71)     | 9.84 (3.54)**  | 9.39 (4.01)**  |
| Non-White        | 7.57 (2.31)    | 7.13 (2.38)     | 7.22 (2.68)    | 7.09 (2.71)    |
| Ethnicity        |                |                 |                |                |
| Hispanic         | 7.65 (2.43)    | 7.65 (1.93)     | 10.90 (3.31)   | 10.80 (4.02)*  |
| Non-Hispanic     | 8.37 (3.02)    | 7.36 (3.75)     | 9.26 (3.55)    | 8.82 (3.86)    |
| Parent Gender    |                |                 |                |                |
| Male             | 7.80 (2.53)    | 7.11 (2.72)     | 8.55 (3.33)    | 8.48 (3.34)    |
| Female           | 8.53 (3.12)**  | 7.56 (4.01)**   | 10.07 (3.58)** | 9.44 (4.25)**  |
| Child ASD Gender |                |                 |                |                |
| Male             | 8.00 (2.43)    | 7.10 (3.05)     | 9.50 (3.45)    | 8.89 (3.94)    |
| Female           | 9.61 (3.17)**  | 9.36 (3.35)**   | 9.78 (3.52)    | 9.82 (3.71)    |
| Parent Education |                |                 |                |                |
| Below Bachelors  | 7.05 (2.24)    | 6.07 (2.93)     | 8.55 (3.61)    | 7.90 (3.85)    |
| Bachelors        | 8.96 (2.93)**  | 8.36 (3.50)**   | 10.19 (3.26)** | 9.94 (3.64)**  |
| Above Bachelors  | 6.82 (3.30)    | 4.88 (2.96)     | 7.41 (3.89)    | 6.71 (4.21)    |

\* $p < 0.05$ , \*\* $p < .01$

Table 14

*Means and Standard Deviations of Demographics by Service Access-Screen Pass Sample*

|                  | Parent History | Sibling History | Parent Future  | Sibling Future |
|------------------|----------------|-----------------|----------------|----------------|
| Region           | 8.29 (2.50)    | 7.62 (3.15)     | 9.31 (3.35)    | 8.90 (3.66)    |
| Northeast        | 9.61 (2.59)    | 8.67 (3.58)     | 11.50 (2.04)   | 10.83 (3.75)   |
| Midwest          | 8.00 (3.73)    | 6.75 (4.38)     | 9.93 (3.95)    | 4.83 (9.39)    |
| South            | 8.87 (2.97)    | 8.05 (3.64)     | 10.50 (3.23)   | 10.13 (3.47)   |
| West             |                |                 |                |                |
| Marital Status   |                |                 |                |                |
| Married          | 8.66 (3.00)    | 7.92 (3.62)     | 10.22 (3.33)   | 9.69 (3.96)    |
| Divorced         | 8.67 (1.53)    | 3.33 (1.53)     | 7.67 (4.93)    | 9.67 (2.89)    |
| Partnered        | 4.00 (-)       | 3.00 (-)        | 5.00 (-)       | 4.00 (-)       |
| Separated        | 9.00 (-)       | 7.00 (-)        | 11.00 (-)      | 13.00 (-)      |
| Widowed          | 9.00 (-)       | 8.00 (-)        | 11.00 (-)      | 7.00 (-)       |
| Never Married    | 4.00 (-)       | 1.00 (-)        | 9.00 (-)       | 11.00 (-)      |
| Race             |                |                 |                |                |
| White            | 8.64 (3.05)    | 7.75 (3.77)     | 10.32 (3.36)*  | 9.93 (3.91)*   |
| Non-White        | 8.08 (2.23)    | 7.33 (2.61)     | 8.17 (2.69)    | 7.08 (3.12)    |
| Ethnicity        |                |                 |                |                |
| Hispanic         | 8.27 (1.91)    | 7.93 (1.71)     | 12.67 (0.72)** | 12.93 (0.26)** |
| Non-Hispanic     | 8.64 (3.11)    | 7.66 (3.87)     | 9.75 (3.42)    | 9.18 (3.98)    |
| Parent Gender    |                |                 |                |                |
| Male             | 8.16 (2.51)    | 7.35 (2.85)     | 9.22 (3.31)    | 9.02 (3.47)    |
| Female           | 8.86 (3.23)    | 7.94 (4.01)     | 10.69 (3.27)*  | 10.06 (4.15)   |
| Child ASD        |                |                 |                |                |
| Male             | 8.29 (2.46)    | 7.35 (3.12)     | 10.34 (3.12)   | 9.59 (3.94)    |
| Female           | 10.30 (2.62)** | 9.92 (3.24)**   | 10.49 (3.25)   | 10.54 (3.46)   |
| Parent Education |                |                 |                |                |
| Below            | 7.27 (2.41)    | 6.13 (3.25)     | 9.30 (3.78)    | 8.60 (4.16)    |
| Bachelors        | 9.10 (2.92)*   | 8.47 (3.56)**   | 10.50 (3.14)   | 10.18 (3.65)   |
| Above            | 7.88 (4.09)    | 5.25 (3.77)     | 9.00 (3.59)    | 7.87 (5.03)    |

\* $p < 0.05$ , \*\* $p < .01$

Table 15

*Means and Standard Deviations of Demographics by Service Access-Screen Fail*

|                  | Parent History | Sibling History | Parent Future | Sibling Future |
|------------------|----------------|-----------------|---------------|----------------|
| Region           |                |                 |               |                |
| Northeast        | 6.78 (2.28)    | 5.78 (3.23)     | 7.33 (3.74)   | 7.33 (2.92)    |
| Midwest          | 6.00 (0.00)    | 5.50 (0.71)     | 6.50 (0.71)   | 4.00 (2.83)    |
| South            | 8.00 (3.06)    | 7.29 (3.09)     | 7.00 (3.74)   | 7.00 (4.20)    |
| West             | 6.23 (2.17)    | 5.79 (2.29)     | 6.50 (2.71)   | 6.43 (2.17)    |
| Marital Status   |                |                 |               |                |
| Married          | 6.57 (2.11)    | 5.87 (2.41)     | 6.65 (2.93)   | 6.45 (2.72)    |
| Divorced         | -              | -               | -             | -              |
| Partnered        | 13.00 (-)      | 13.00 (-)       | 13.00 (-)     | 13.00 (-)      |
| Separated        | -              | -               | -             | -              |
| Widowed          | -              | -               | -             | -              |
| Never Married    | -              | -               | -             | -              |
| Race             |                |                 |               |                |
| White            | 6.65 (2.43)    | 5.67 (2.85)     | 7.19 (3.42)   | 6.43 (3.20)    |
| Non-White        | 7.00 (2.37)    | 6.91 (2.21)     | 6.18 (2.36)   | 7.09 (2.34)    |
| Ethnicity        |                |                 |               |                |
| Hispanic         | 5.80 (3.11)    | 6.80 (2.49)     | 5.60 (1.82)   | 4.40 (2.88)    |
| Non-Hispanic     | 7.13 (2.23)    | 6.04 (2.82)     | 7.12 (3.35)   | 7.24 (2.82)    |
| Parent Gender    |                |                 |               |                |
| Male             | 6.60 (2.29)    | 6.33 (2.09)     | 6.33 (2.32)   | 6.73 (2.15)    |
| Female           | 6.94 (2.52)    | 5.88 (3.16)     | 7.29 (3.65)   | 6.59 (3.52)    |
| Child ASD Gender |                |                 |               |                |
| Male             | 6.95 (2.04)    | 6.18 (2.61)     | 6.50 (2.92)   | 6.36 (2.79)    |
| Female           | 6.00 (3.56)    | 6.75 (2.66)     | 6.50 (2.88)   | 6.50 (3.12)    |
| Parent Education |                |                 |               |                |
| Below Bachelors  | 6.45 (1.64)    | 5.92 (2.02)     | 6.67 (2.35)   | 6.17 (2.25)    |
| Bachelors        | 7.82 (2.86)    | 7.55 (3.08)*    | 7.73 (3.26)   | 8.00 (3.00)    |
| Above Bachelors  | 5.89 (2.26)    | 4.56 (2.19)     | 6.00 (3.78)   | 5.67 (3.28)    |

\* $p < 0.05$ , \*\* $p < .01$

Table 16  
*Means and Standard Deviations of Service Access Factors by Gender*

|                     | Male <sup>WS</sup> | Female <sup>WS</sup> | Male <sup>SP</sup> | Female <sup>SP</sup> | Male <sup>SF</sup> | Female <sup>SF</sup> |
|---------------------|--------------------|----------------------|--------------------|----------------------|--------------------|----------------------|
| Parents             |                    |                      |                    |                      |                    |                      |
| Attitude            | 3.09 (0.63)        | 3.39 (0.68)**        | 3.20 (0.60)        | 3.40 (0.62)          | 2.73 (0.62)        | 3.37 (0.93)*         |
| Priority            | 2.60 (0.50)        | 2.74 (0.61)          | 2.61 (0.51)        | 2.73 (0.63)          | 2.56 (0.50)        | 2.80 (0.58)          |
| Time/Location       | 3.04 (0.30)        | 3.21 (0.33)**        | 3.09 (0.26)        | 3.22 (0.32)*         | 2.87 (0.38)        | 3.17 (0.37)*         |
| Finances/Child Care | 3.59 (0.79)        | 3.72 (0.88)          | 3.64 (0.82)        | 3.81 (0.86)          | 3.43 (0.68)        | 3.23 (0.92)          |
| Siblings            |                    |                      |                    |                      |                    |                      |
| Attitude            | 3.07 (0.59)        | 3.44 (0.57)**        | 3.09 (0.61)        | 3.45 (0.59)**        | 3.00 (0.56)        | 3.41 (0.52)*         |
| Priority            | 2.83 (0.60)        | 2.87 (0.64)          | 2.78 (0.59)        | 2.89 (0.66)          | 3.01 (0.62)        | 2.78 (0.51)          |
| Time/Location       | 3.11 (0.34)        | 3.13 (0.41)          | 3.11 (0.34)        | 3.14 (0.41)          | 3.11 (0.34)        | 3.10 (0.44)          |
| Finances/Child Care | 3.61 (0.73)        | 3.78 (0.85)          | 3.67 (0.71)        | 3.87 (0.84)          | 3.40 (0.78)        | 3.38 (0.83)          |

\* $p < .05$ , \*\* $p < .01$

Note. <sup>WS</sup> = Whole Sample, <sup>SP</sup> = Screen Pass, <sup>SF</sup> = Screen Fail

Table 17  
*Means and Standard Deviations of Service Access Factors by Race*

|                     | White <sup>WS</sup> | Non-White <sup>WS</sup> | White <sup>SP</sup> | Non-White <sup>SP</sup> | White <sup>SF</sup> | Non-White <sup>SF</sup> |
|---------------------|---------------------|-------------------------|---------------------|-------------------------|---------------------|-------------------------|
| Parents             |                     |                         |                     |                         |                     |                         |
| Attitude            | 3.34 (0.67)         | 2.88 (0.65)**           | 3.35 (0.61)         | 3.03 (0.66)             | 3.25 (0.91)         | 2.73 (0.63)             |
| Priority            | 2.70 (0.58)         | 2.59 (0.58)             | 2.69 (0.60)         | 2.64 (0.46)             | 2.76 (0.45)         | 2.55 (0.70)             |
| Time/Location       | 3.17 (0.33)         | 2.98 (0.32)**           | 3.19 (0.31)*        | 3.00 (0.17)             | 3.06 (0.39)         | 2.97 (0.44)             |
| Finances/Child Care | 3.73 (0.84)         | 3.33 (0.83)**           | 3.82 (0.82)**       | 3.08 (0.87)             | 3.26 (0.83)         | 3.59 (0.74)             |
| Siblings            |                     |                         |                     |                         |                     |                         |
| Attitude            | 3.33 (0.61)         | 3.06 (0.53)**           | 3.35 (0.62)**       | 2.92 (0.49)             | 3.22 (0.60)         | 3.21 (0.54)             |
| Priority            | 2.81 (0.61)         | 3.12 (0.64)**           | 2.82 (0.63)         | 3.06 (0.69)             | 2.73 (0.49)         | 3.20 (0.60)             |
| Time/Location       | 3.13 (0.39)         | 3.08 (0.33)             | 3.14 (0.39)         | 2.98 (0.32)             | 3.06 (0.42)         | 3.19 (0.33)             |
| Finances/Child Care | 3.76 (0.79)         | 3.46 (0.88)             | 3.82 (0.80)         | 3.58 (0.73)             | 3.43 (0.65)         | 3.32 (1.03)             |

\* $p < .05$ , \*\* $p < .01$

Note. <sup>WS</sup> = Whole Sample, <sup>SP</sup> = Screen Pass, <sup>SF</sup> = Screen Fail

### Relationship between Service Access and Access Factors

Looking at the sample as a whole, a series of correlations revealed several significant relationships between access factors and service engagement for both parents and siblings (see Table 18). Results suggest that parent reports of having the financial, and childcare, means to access services for themselves (e.g., higher scores on that factor) were significantly and positively correlated with greater past access to both parent  $r(157)=.37, p<.01$  and sibling services  $r(157)=.33, p<.01$ , as well as more interest in future parent  $r(157)=.38, p<.01$  and sibling services  $r(157)=.38, p<.01$ . The same was true of parent ratings of finances to attribute to sibling services, with all four service groups yielding positive, moderate correlations with the monetary factor. In addition, higher ratings of time for sibling services was significantly, and positively correlated with interest in more future sibling services  $r(157)=.16, p<.01$ . Finally, a more positive attitude toward parent services was significantly and positively correlated with interest in more parent services in the future  $r(157)=.23, p<.01$ .

When looking at the subgroups separately, all relationships found in the whole sample were replicated in the Screen Pass sample (see Table 19). However, results were significantly different in the Screen Fail sample (see Table 20). All relationships between finances and service access and interest were rendered nonsignificant for the Screen Fail sample. It should be noted that the Screen Fail sample did report significantly less financial resources to allocate to both parent and sibling services (see Table 12). Perhaps this might suggest that decision making related to services in the Screen Fail group cannot be accounted for by these more logistical variables. However, a significant positive relationship between time for sibling services, and interest in more future sibling

services was maintained  $r(157)=.47, p<.01$ . Further, the relationship between parent attitude toward services and interest in future parent services was maintained  $r(157)=.39, p<.01$ .

Table 18  
*Correlations between Service Access and Access Factors- Whole Sample*

|                       | 1     | 2      | 3     | 4     | 5     | 6    | 7     | 8      | 9     | 10   | 11  | 12 |
|-----------------------|-------|--------|-------|-------|-------|------|-------|--------|-------|------|-----|----|
| 1. Parent History     | -     |        |       |       |       |      |       |        |       |      |     |    |
| 2. Sibling History    | .78** | -      |       |       |       |      |       |        |       |      |     |    |
| 3. Parent Future      | .62** | .51**  | -     |       |       |      |       |        |       |      |     |    |
| 4. Sibling Future     | .55** | .64**  | .78** | -     |       |      |       |        |       |      |     |    |
| 5. Attitude-Parent    | -.04  | -.23** | .23** | .16   | -     |      |       |        |       |      |     |    |
| 6. Priority- Parent   | .03   | .05    | .16   | .11   | .35** | -    |       |        |       |      |     |    |
| 7. Time-Parent        | .13   | -.06   | .10   | .06   | .14   | -.05 | -     |        |       |      |     |    |
| 8. Money-Parent       | .37** | .33**  | .38** | .38** | .13   | -.11 | .11   | -      |       |      |     |    |
| 9. Attitude-Sibling   | .18*  | .05    | .31** | .25** | .22** | .04  | .32** | .11    | -     |      |     |    |
| 10. Priority- Sibling | -.11  | -.21** | -.09  | -.09  | .16   | .09  | .04   | -.24** | .37** | -    |     |    |
| 11. Time-Sibling      | .13   | .22**  | .13   | .16*  | .13   | .00  | .19*  | .10    | .05   | -.02 | -   |    |
| 12. Money-Sibling     | .32** | .33**  | .42** | .41** | -.00  | .10  | .08   | .49**  | .23** | -.11 | .10 | -  |

\* $p < .05$ , \*\* $p < .01$



Table 19  
*Correlations between Service Access and Access Factors- Screen Pass Sample*

|                       | 1     | 2      | 3     | 4     | 5     | 6    | 7     | 8     | 9     | 10   | 11  | 12 |
|-----------------------|-------|--------|-------|-------|-------|------|-------|-------|-------|------|-----|----|
| 1. Parent History     | -     |        |       |       |       |      |       |       |       |      |     |    |
| 2. Sibling History    | .80** | -      |       |       |       |      |       |       |       |      |     |    |
| 3. Parent Future      | .58** | .54**  | -     |       |       |      |       |       |       |      |     |    |
| 4. Sibling Future     | .51** | .67**  | .76** | -     |       |      |       |       |       |      |     |    |
| 5. Attitude-Parent    | -.13  | -.24** | .13   | .09   | -     |      |       |       |       |      |     |    |
| 6. Priority- Parent   | -.01  | .06    | .14   | .09   | .37** | -    |       |       |       |      |     |    |
| 7. Time-Parent        | -.02  | -.11   | .00   | -.04  | .10   | -.10 | -     |       |       |      |     |    |
| 8. Money-Parent       | .38** | .33**  | .45** | .39** | .18*  | -.11 | .16   | -     |       |      |     |    |
| 9. Attitude-Sibling   | .19*  | .06    | .33** | .27** | .20*  | .07  | .28** | .17   | -     |      |     |    |
| 10. Priority- Sibling | -.10  | -.22*  | -.06  | -.07  | .24** | .13  | -.01  | -.21* | .38** | -    |     |    |
| 11. Time-Sibling      | .12   | .17    | .17   | .19*  | .07   | .03  | .15   | .15   | .02   | -.06 | -   |    |
| 12. Money-Sibling     | .31** | .31**  | .46** | .43** | .15   | .12  | .07   | .47** | .27** | -.07 | .22 | -  |

\* $p < .05$ , \*\* $p < .01$

Table 20  
*Correlations between Service Access and Access Factors- Screen Fail Sample*

|                       | 1     | 2     | 3     | 4    | 5    | 6    | 7     | 8     | 9    | 10   | 11  | 12 |
|-----------------------|-------|-------|-------|------|------|------|-------|-------|------|------|-----|----|
| 1. Parent History     | -     |       |       |      |      |      |       |       |      |      |     |    |
| 2. Sibling History    | .62** | -     |       |      |      |      |       |       |      |      |     |    |
| 3. Parent Future      | .67** | .19   | -     |      |      |      |       |       |      |      |     |    |
| 4. Sibling Future     | .57** | .24   | .72** | -    |      |      |       |       |      |      |     |    |
| 5. Attitude-Parent    | .13   | -.39* | .39*  | .25  | -    |      |       |       |      |      |     |    |
| 6. Priority- Parent   | .27   | -.03  | .30   | .29  | .35* | -    |       |       |      |      |     |    |
| 7. Time-Parent        | .23   | -.03  | .28   | .22  | .16  | .12  | -     |       |      |      |     |    |
| 8. Money-Parent       | .16   | .23   | -.17  | .06  | -.12 | -.10 | -.16  | -     |      |      |     |    |
| 9. Attitude-Sibling   | .10   | -.04  | .24   | .07  | .29  | -.11 | .46** | -.21  | -    |      |     |    |
| 10. Priority- Sibling | -.21  | -.15  | -.23  | -.11 | -.09 | -.11 | .24   | -.35* | .34  | -    |     |    |
| 11. Time-Sibling      | .14   | .47** | -.03  | .01  | -.24 | -.13 | .30   | -.14  | .16  | .19  | -   |    |
| 12. Money-Sibling     | .22   | .31   | .03   | .11  | -.01 | .03  | .00   | .45*  | -.01 | -.27 | .06 | -  |

\* $p < .05$ , \*\* $p < .01$

## Relationship between Service Variables and Dependent Variables

A series of correlations and ANOVAS were conducted in order to describe the relationships between service variables and the dependent variables collected. As previously reported (see Tables 4, 5 and 6), all subscales within each dependent measure were significantly and positively associated with the total score for that measure. As such, correlations are only reported for Total Scores and individual subscale scores that yielded nonsignificant results.

Looking at the sample as a whole, results revealed that all dependent variables were found to be significantly related to past service access and future service interest (see Table 21). Specifically, a higher Autism Index score on the GARS-3, representing a measure of global autism severity, was significantly and positively related to past parent service access  $r(157)=.47, p<.01$ , past sibling service access  $r(157)=.44, p<.01$ , interest in future parent services  $r(157)=.63, p<.01$ , and future sibling services  $r(157)=.58, p<.01$ . This suggests that more severe parent ratings of symptom severity in their child with ASD, the more services accessed by parents and siblings in the past, and the more interested parents are in accessing services for both family members in the future.

When looking at the Screen pass and Screen Fail sample separately, results revealed that the relationship between ASD symptom severity and service access and interest was driven by the Screen Fail sample (see Table 23). No significant results were seen in the Screen Pass sample (see Table 22). As Autism Index scores for the Screen Fail sample were found to be significantly lower than the Screen Pass sample, this relationship cannot be sufficiently accounted for by a more severe ASD presentation. Instead, this may suggest that perceptions of ASD symptoms impact a need or desire for

services more strongly in the Screen Fail sample than those parents in the Screen Pass sample.

Higher scores of social support on the ISSB were also found to be significantly and positively related to access in all four domains: past parent access  $r(157)=.50, p<.01$ , past sibling access  $r(157)=.48, p<.01$ , future parent service interest  $r(157)=.48, p<.01$ , and future sibling service interest  $r(157)=.56, p<.01$ . These moderate correlations suggest that the more perceived social support on the part of the parent, the more services are accessed in the past and the more interested parents are in accessing services in the future.

The relationship between social support and service access and interest was replicated in the Screen Fail sample. However, social support for the Screen Pass sample was only significantly related to future parent  $r(157)=-.52, p<.01$ , and sibling services  $r(157)=-.51, p<.01$ , in this group, but in the opposite direction than the other groups. Specifically, lower ratings of social support were related to more future service interest for parents and siblings. This may suggest that social support may service a different function in families with and without co-occurring psychopathology.

The PSI-4-SF yielded similar significant results. Higher total stress scores on the measure were positively associated with past service access for both parents  $r(157)=.38, p<.01$  and siblings  $r(157)=.43, p<.01$ , as well as future service interest for parents  $r(157)=.31, p<.01$  and siblings  $r(157)=.35, p<.01$ . These patterns of results suggest that parents who report higher levels of subjective stress related to parenting are accessing more services for their families, as well as being more interested in services in the future. In looking at the subscales more specifically, Parental Distress was the only subscale that

did not conform to the patterns of the Total Stress score. This subscale particularly corresponds to feelings of parenting competence. Higher reported Parental Distress was only positively related to past service access for parents  $r(157)=.25, p<.01$  and siblings  $r(157)=.26, p<.01$ . Parental distress was not associated with future service interest for either group.

Similar to relationships observed in the ISSB, it appears that the association between parent stress on the PSI-4-SF and service access and interest differed significantly by subgroup. No significant relationships were observed between parent stress and service access or interest in the Screen Pass sample. However, significant and positive relationships were found between past service access for parents  $r(157)=.38, p<.01$ , and siblings  $r(157)=.43, p<.01$ , as well as future service interest for parents  $r(157)=.31, p<.01$ , and siblings  $r(157)=.35, p<.01$  for those parents in the Screen Fail group. This again may suggest that parent stress may function differently for the Screen Fail parents than the Screen Pass parents.

Finally, scores on the GHQ-28 were placed into correlations with the service access and interest variables. Different than any other dependent measure, the Total Score on the GHQ-28 was only significantly related to future service access for parents  $r(157)=-.27, p<.05$  and siblings  $r(157)=-.20, p<.05$ , and these scores only yielded weak correlations. However, looking at the subscale scores individually yielded more robust results. The strongest relationships between parent-reported psychiatric health and service access were found in the depression domain of the GHQ-28. Specifically, parents with lower scores on the GHQ-28 depression domain (i.e., less psychiatric symptoms endorsed) had accessed more sibling services in the past  $r(157)=-.32, p<.01$ , and were

interested in more parent services  $r(157)=-.33, p<.01$  and sibling services in the future  $r(157)=-.23, p<.01$ . Similarly, lower scores on the anxiety/insomnia domain were weakly related to more past parent  $r(157)=-.17, p<.05$  and sibling access  $r(157)=-.18, p<.05$ , as well as future service interest for both parents  $r(157)=-.18, p<.05$ , and siblings  $r(157)=-.18, p<.05$ . Somatic symptoms and social dysfunction were only significantly related to future services, as was found by using the Total Score on the measure. Taken together, this suggests that less psychiatric symptoms overall is related to more service access and interest. However, depression symptoms appear to have the strongest relationship among this group of relatively modest relationships.

Similar to the results presented above for the ISSB and PSI-4-SF, the two subgroups differed significantly on the correlations between scores on the GHQ-28 and service access and interest. Specifically, no significant relationships were found between the total score, or any subscale, of the GHQ-28 and service access/interest variables for the Screen Pass group. Results seen in the whole sample were therefore carried by the Screen Fail sample. It should be noted that the Screen Fail sample reported significantly globally higher GHQ-28 scores than the Screen Pass sample (see Table 3). However, the significant relationships observed between GHQ-28 scores and service access/interest may again reflect a relationship above and beyond elevated scores.

Table 21

*Correlations between Service Access/Interest Variables and Dependent Variables- Whole Sample*

|                            | 1     | 2      | 3      | 4      | 5      | 6     | 7    | 8     | 9    | 10     | 11   | 12   | 13 |
|----------------------------|-------|--------|--------|--------|--------|-------|------|-------|------|--------|------|------|----|
| 1. Parent Service History  | -     |        |        |        |        |       |      |       |      |        |      |      |    |
| 2. Sibling Service History | .78** | -      |        |        |        |       |      |       |      |        |      |      |    |
| 3. Parent Future Interest  | .62** | .51**  | -      |        |        |       |      |       |      |        |      |      |    |
| 4. Sibling Future Interest | .55** | .64**  | .78**  | -      |        |       |      |       |      |        |      |      |    |
| 5. GARS Autism Index       | .47** | .44**  | .63**  | .58**  | -      |       |      |       |      |        |      |      |    |
| 6. PSI Total Score         | .38** | .43**  | .31**  | .35**  | .34**  | -     |      |       |      |        |      |      |    |
| 7. Parental Distress       | .25** | .26**  | .15    | .15    | .16*   | .59** | -    |       |      |        |      |      |    |
| 8. GHQ Total Score         | -.15  | -.07   | -.27** | -.20*  | -.31** | -.09  | .01  | -     |      |        |      |      |    |
| 9. Som. Symptoms           | -.13  | -.04   | -.25** | -.17*  | -.28** | -.14  | -.04 | .89*  | -    |        |      |      |    |
| 10. Anxiety/Insomnia       | -.17* | -.18*  | -.18*  | -.18*  | -.28** | -.10  | .05  | .84*  | .65* | -      |      |      |    |
| 11. Social Dys.            | -.11  | .00    | -.21** | -.11   | -.18*  | -.03  | 1.00 | .90*  | .77* | .67*   | -    |      |    |
| 12. Depression             | -.13  | -.32** | -.32** | -.23** | -.33** | -.05  | .89  | .86*  | .71* | .59*   | .72* | -    |    |
| 13. ISSB Total             | .50** | .48**  | .48**  | .56**  | .52**  | .18*  | .18* | -.16* | -.13 | -.29** | -.05 | -.09 | -  |

\* $p < .05$ , \*\* $p < .01$

Table 22

*Correlations between Service Access/Interest Variables and Dependent Variables- Screen Pass*

|                            | 1     | 2    | 3      | 4      | 5     | 6     | 7    | 8     | 9     | 10    | 11    | 12  | 13 |
|----------------------------|-------|------|--------|--------|-------|-------|------|-------|-------|-------|-------|-----|----|
| 1. Parent Service History  | -     |      |        |        |       |       |      |       |       |       |       |     |    |
| 2. Sibling Service History | .62** | -    |        |        |       |       |      |       |       |       |       |     |    |
| 3. Parent Future Interest  | .67** | .19  | -      |        |       |       |      |       |       |       |       |     |    |
| 4. Sibling Future Interest | .57** | .24  | .72**  | -      |       |       |      |       |       |       |       |     |    |
| 5. GARS Autism Index       | .26   | .07  | .28    | .10    | -     |       |      |       |       |       |       |     |    |
| 6. PSI Total Score         | .06   | .33  | -.07   | .13    | -.04  | -     |      |       |       |       |       |     |    |
| 7. Parental Distress       | .12   | .31  | -.02   | .15    | .05   | .76** | -    |       |       |       |       |     |    |
| 8. GHQ Total Score         | .26   | .09  | .25    | .15    | .40*  | .07   | .11  | -     |       |       |       |     |    |
| 9. Som. Symptoms           | .35   | .13  | .32    | .18    | .46** | .12   | .11  | .80** | -     |       |       |     |    |
| 10. Anxiety/Insomnia       | .34   | -.02 | .43    | .18    | .33   | -.08  | .087 | .82** | .67** | -     |       |     |    |
| 11. Social Dys.            | .09   | .02  | .18    | .11    | .45*  | .18   | .07  | .85** | .80** | .68** | -     |     |    |
| 12. Depression             | .06   | .15  | -.10   | .04    | .07   | .01   | .08  | .80** | .77** | .57** | .75** | -   |    |
| 13. ISSB Total             | -.33  | .03  | -.52** | -.51** | .07   | .27   | .20  | -.25  | -.09  | -.22* | .02   | .00 | -  |

\* $p < .05$ , \*\* $p < .01$



Table 23

*Correlations between Service Access/Interest Variables and Dependent Variables- Screen Fail*

|                            | 1     | 2      | 3      | 4      | 5      | 6     | 7    | 8     | 9    | 10     | 11   | 12   | 13 |
|----------------------------|-------|--------|--------|--------|--------|-------|------|-------|------|--------|------|------|----|
| 1. Parent Service History  | -     |        |        |        |        |       |      |       |      |        |      |      |    |
| 2. Sibling Service History | .78** | -      |        |        |        |       |      |       |      |        |      |      |    |
| 3. Parent Future Interest  | .62** | .51**  | -      |        |        |       |      |       |      |        |      |      |    |
| 4. Sibling Future Interest | .55** | .64**  | .77**  | -      |        |       |      |       |      |        |      |      |    |
| 5. GARS Autism Index       | .47** | .44**  | .63**  | .58**  | -      |       |      |       |      |        |      |      |    |
| 6. PSI Total Score         | .38** | .43**  | .31**  | .35**  |        | -     |      |       |      |        |      |      |    |
| 7. Parental Distress       | .25** | .26**  | .15    | .15    | .34**  | .59** | -    |       |      |        |      |      |    |
| 8. GHQ Total Score         | -.15  | -.07   | -.27** | -.20*  | .16*   | -.09  | .01  | -     |      |        |      |      |    |
| 9. Som. Symptoms           | -.13  | -.04   | -.25** | -.17*  | -.31** | -.14  | -.04 | .89*  | -    |        |      |      |    |
| 10. Anxiety/Insomnia       | -.17* | -.18*  | -.18*  | -.18*  | -.28** | -.10  | .05  | .84*  | .65* | -      |      |      |    |
| 11. Social Dys.            | -.11  | .00    | -.21** | -.11   | -.18*  | -.03  | 1.00 | .90*  | .77* | .67*   | -    |      |    |
| 12. Depression             | -.13  | -.32** | -.32** | -.23** | -.33** | -.05  | .89  | .86*  | .71* | .59*   | .72* | -    |    |
| 13. ISSB Total             | .50** | .48**  | .48**  | .56**  | .52**  | .18*  | .18* | -.16* | -.13 | -.29** | -.05 | -.09 | -  |

\* $p < .05$ , \*\* $p < .01$

### Predictors of Past Treatment Access: Multiple Regression Analysis

A three stage hierarchical multiple regression was conducted with amount of past parent services accessed as the dependent variable. Parent gender, race, ethnicity, and education were entered in block one of the regression to control for the effect of demographic variables. Family-level variables (e.g., gender of the child with ASD, etc.) were entered in block 2, and dependent variables (e.g., autism symptom severity, availability of financial support for services, etc.) were entered into the third block. Regression statistics are reported in Table 24.

The hierarchical multiple regression revealed that at block one, demographic variables contributed significantly to the regression model  $F(4, 125) = 3.046, p < .05$  and accounted for 8.9% of the variation in parent service history. Introducing family-level variables explained an additional 11.0% of the variation in parent service access and this change was significant  $F(5, 120) = 3.307, p < .01$ . Finally, the addition of dependent measures explained an additional 28.1% of the variation and this change was again significant  $F(7, 113) = 8.714, p < .01$ . All together, the three blocks explained a total of 48.0% of the variation in parent service access. With all three blocks entered into the model, only parent ratings of finances for their own support, and autism symptom severity remained significant. All other dependent measures dropped out, suggesting that these dependent measures were the best predictors of past parent access.

This model was also applied to the Screen Fail and Screen Pass samples individually. However, given the lower power associated with each model, these results are reported as exploratory, but not displayed individually. Results for the Screen Pass families followed the results of the whole sample, though only Autism Index scores

remained significant in the last block. In contrast, no dependent measures were found to predict past parent access for the Screen Fail families, with only social support reaching trend level ( $p=.07$ ). However, it should be noted that this model was significantly underpowered and should be interpreted with caution.

Table 24

*Hierarchical Regression of Predictors of Past Parent Service Access- Whole Sample*

|                      | <i>B</i> | <i>SE (B)</i> | $\beta$ | <i>F</i> | $R^2$ | $\Delta R^2$ |
|----------------------|----------|---------------|---------|----------|-------|--------------|
| Block 1              |          |               |         | 3.046    | .09   | .09*         |
| Parent Gender        | .95      | 1.73          | .17     | -        | -     | -            |
| Parent Race          | -1.26    | .72           | -1.75   | -        | -     | -            |
| Parent Ethnicity     | 1.62     | .75           | .19     | -        | -     | -            |
| Parent Education     | -.10     | .47           | -.02    | -        | -     | -            |
| Block 2              |          |               |         | 3.307    | .20   | .11**        |
| Parent Gender        | .09      | .56           | -.12    | -        | -     | -            |
| Parent Race          | -.95     | .74           | -.12    | -        | -     | -            |
| Parent Ethnicity     | 1.12     | .74           | .13     | -        | -     | -            |
| Parent Education     | .19      | .46           | .04     | -        | -     | -            |
| # Children           | -.10     | .46           | -.20    | -        | -     | -            |
| ASD Gender           | 1.72     | .55           | .28     | -        | -     | -            |
| ASD Age              | -.08     | .17           | -.04    | -        | -     | -            |
| TD Gender            | -.48     | .48           | -.09    | -        | -     | -            |
| TD Age               | .14      | .22           | .05     | -        | -     | -            |
| Block 3              |          |               |         | 8.71     | .48   | .28**        |
| Parent Gender        | -.01     | .53           | -.00    | -        | -     | -            |
| Parent Race          | .08      | .76           | .01     | -        | -     | -            |
| Parent Ethnicity     | 1.31     | .70           | .16     | -        | -     | -            |
| Parent Education     | .34      | .44           | .07     | -        | -     | -            |
| # Children           | -.47     | .48           | -.09    | -        | -     | -            |
| ASD Gender           | 1.22     | .53           | .20     | -        | -     | -            |
| ASD Age              | -.03     | .16           | -.02    | -        | -     | -            |
| TD Gender            | -.24     | .47           | -.04    | -        | -     | -            |
| TD Age               | -.02     | .21           | -.01    | -        | -     | -            |
| GHQ Depression       | -.29     | .23           | -.16    | -        | -     | -            |
| GHQ Anxiety          | .15      | .21           | .08     | -        | -     | -            |
| Parent Stress Total  | .06      | .04           | .13     | -        | -     | -            |
| Social Support Total | .03      | .01           | .31     | -        | -     | -            |
| Money-Sibling        | .28      | .35           | .07     | -        | -     | -            |
| Autism Index         | .11      | .02           | .48     | -        | -     | -            |
| Money- Parent        | .68      | .28           | .19     | -        | -     | -            |

\* $p<0.05$ , \*\* $p<.01$

The same three block model was applied to the prediction of past sibling service access (see Table 25). The hierarchical multiple regression revealed that at block one, unlike the parents, demographic variables did not contribute significantly to the regression model  $F(4, 126) = 0.953, p = .44$  and accounted for only 2.9% of the variation in sibling service history. Introducing family-level variables added significantly to the model, predicting an additional 12.6.0% of the variation in sibling service access and this change was significant  $F(5, 121) = 3.605, p < .01$ . Finally, the addition of dependent measures explained an additional 39.4% of the variation and this change was again significant  $F(7, 114) = 14.257, p < .01$ . All together, the three blocks explained a total of 55.0% of the variation in parent service access. With all three blocks entered into the model, several dependent measures remained significant. Specifically, parent ratings of ASD symptom severity, parent ratings of perceived social support, and financial support allocated to parent support services best predicted past parent access.

Results for the Screen Pass families followed the results of the whole sample, though only Autism Index scores and social support remained significant in the last block. Again, no dependent measures were found to predict past parent access for the Screen Fail families.

Table 25

*Hierarchical Regression of Predictors of Past Sibling Service Access- Whole Sample*

|                      | <i>B</i> | <i>SE (B)</i> | $\beta$ | <i>F</i> | <i>R</i> <sup>2</sup> | $\Delta R^2$ |
|----------------------|----------|---------------|---------|----------|-----------------------|--------------|
| Block 1              |          |               |         | 0.953    | .03                   | .03          |
| Parent Gender        | .71      | .61           | .11     | -        | -                     | -            |
| Parent Race          | -.91     | .86           | -.10    | -        | -                     | -            |
| Parent Ethnicity     | .80      | .89           | .08     | -        | -                     | -            |
| Parent Education     | -.08     | .55           | -.01    | -        | -                     | -            |
| Block 2              |          |               |         | 3.605    | .16                   | .13**        |
| Parent Gender        | -.36     | .66           | -.06    | -        | -                     | -            |
| Parent Race          | -1.09    | .87           | -.12    | -        | -                     | -            |
| Parent Ethnicity     | .36      | .87           | .04     | -        | -                     | -            |
| Parent Education     | .09      | .54           | .02     | -        | -                     | -            |
| # Children           | -.35     | .53           | -.06    | -        | -                     | -            |
| ASD Gender           | 2.69     | .65           | .38     | -        | -                     | -            |
| ASD Age              | -.05     | .20           | -.02    | -        | -                     | -            |
| TD Gender            | -.29     | .57           | -.04    | -        | -                     | -            |
| TD Age               | .04      | .26           | .01     | -        | -                     | -            |
| Block 3              |          |               |         | 14.257   | .55                   | .39**        |
| Parent Gender        | -.68     | .51           | -.10    | -        | -                     | -            |
| Parent Race          | .71      | .72           | .08     | -        | -                     | -            |
| Parent Ethnicity     | .86      | .69           | .09     | -        | -                     | -            |
| Parent Education     | .08      | .41           | .02     | -        | -                     | -            |
| # Children           | .69      | .46           | .12     | -        | -                     | -            |
| ASD Gender           | 1.95     | .51           | .27     | -        | -                     | -            |
| ASD Age              | .08      | .15           | .04     | -        | -                     | -            |
| TD Gender            | -.17     | .45           | -.03    | -        | -                     | -            |
| TD Age               | -.52     | .21           | -.17    | -        | -                     | -            |
| GHQ Depression       | -.15     | .22           | -.07    | -        | -                     | -            |
| GHQ Anxiety          | .18      | .20           | .08     | -        | -                     | -            |
| Parent Stress Total  | .07      | .04           | .14     | -        | -                     | -            |
| Social Support Total | .04      | .01           | .34     | -        | -                     | -            |
| Money-Sibling        | .12      | .34           | .03     | -        | -                     | -            |
| Autism Index         | .74      | .30           | .18     | -        | -                     | -            |
| Money- Parent        | .09      | .02           | .34     | -        | -                     | -            |

\* $p < 0.05$ , \*\* $p < .01$ 

## Predictors of Future Treatment Interest: Multiple Regression Analysis

The same three stage hierarchical multiple regression was conducted with amount of future parent services accessed as the dependent variable (see Table 26). The hierarchical multiple regression revealed that at block one, demographic variables

contributed significantly to the regression model  $F(4, 126) = 7.203, p < .01$  and accounted for 18.6% of the variation in future service interest for parents. Introducing family-level variables explained an additional 9.9% of the variation in parent service interest and this change was significant  $F(5, 121) = 3.355, p < .01$ . Finally, the addition of dependent measures explained an additional 30.9% of the variation and this change was again significant  $F(7, 114) = 12.380, p < .01$ . All together, the three blocks explained a total of 59.4% of the variation in parent future service interest. With all three blocks entered into the model, several dependent measures remained significant. Specifically, parent anxiety scores on the GHQ-28, social support on the ISSB, and Autism Index scores on the GARS-3 were the best predictors of parent service access in the future.

Results for the Screen Pass and Screen Fail families followed the results of the whole sample, though only Autism Index scores and social support remained significant in the last block.

Table 26

*Hierarchical Regression of Predictors of Future Parent Service Interest- Whole*

|                      | <i>B</i> | <i>SE (B)</i> | $\beta$ | <i>F</i> | <i>R</i> <sup>2</sup> | $\Delta R^2$ |
|----------------------|----------|---------------|---------|----------|-----------------------|--------------|
| Block 1              |          |               |         | 7.203    | .19                   | .19**        |
| Parent Gender        | 1.37     | .59           | .19     | -        | -                     | -            |
| Parent Race          | -2.85    | .84           | -.30    | -        | -                     | -            |
| Parent Ethnicity     | -1.37    | .87           | -.13    | -        | -                     | -            |
| Parent Education     | -.10     | .54           | -.02    | -        | -                     | -            |
| Block 2              |          |               |         | 3.355    | .29                   | .10**        |
| Parent Gender        | .77      | .65           | .11     | -        | -                     | -            |
| Parent Race          | -2.18    | .85           | -.23    | -        | -                     | -            |
| Parent Ethnicity     | -1.78    | .85           | -.17    | -        | -                     | -            |
| Parent Education     | .18      | .53           | .03     | -        | -                     | -            |
| # Children           | -.97     | .52           | -.16    | -        | -                     | -            |
| ASD Gender           | .15      | .64           | .02     | -        | -                     | -            |
| ASD Age              | -.26     | .20           | -.11    | -        | -                     | -            |
| TD Gender            | -.94     | .56           | -.13    | -        | -                     | -            |
| TD Age               | .63      | .26           | .20     | -        | -                     | -            |
| Block 3              |          |               |         | 12.380   | .59                   | .31**        |
| Parent Gender        | .11      | .52           | .02     | -        | -                     | -            |
| Parent Race          | -.63     | .73           | -.07    | -        | -                     | -            |
| Parent Ethnicity     | -1.13    | .69           | -.11    | -        | -                     | -            |
| Parent Education     | .16      | .42           | .03     | -        | -                     | -            |
| # Children           | .08      | .47           | .01     | -        | -                     | -            |
| ASD Gender           | -.35     | .51           | -.05    | -        | -                     | -            |
| ASD Age              | -.23     | .16           | -.10    | -        | -                     | -            |
| TD Gender            | -1.10    | .46           | -.16    | -        | -                     | -            |
| TD Age               | .15      | .22           | .05     | -        | -                     | -            |
| GHQ Depression       | -.41     | .22           | -.18    | -        | -                     | -            |
| GHQ Anxiety          | .66      | .20           | .28     | -        | -                     | -            |
| Parent Stress Total  | .05      | .04           | .10     | -        | -                     | -            |
| Social Support Total | .02      | .01           | .20     | -        | -                     | -            |
| Money-Sibling        | .26      | .24           | .05     | -        | -                     | -            |
| Autism Index         | .28      | .31           | .06     | -        | -                     | -            |
| Money- Parent        | .12      | .02           | .45     | -        | -                     | -            |

\* $p < 0.05$ , \*\* $p < .01$ 

When looking at this model as it applies to parent interest in accessing sibling services in the future (see Table 27), demographic variables contributed significantly to the regression model  $F(4, 126) = 4.549$   $p < .01$  and accounted for 12.6% of the variation in

future service interest for siblings. Introducing family-level variables explained an additional 10.9% of the variation in future service interest for siblings and this change was significant  $F(5, 121) = 3.461, p < .01$ . Finally, the addition of dependent measures explained an additional 33.7% of the variation and this change was again significant  $F(7, 114) = 12.820, p < .01$ . All together, the three blocks explained a total of 57.2% of the variation in future service interest for siblings. With all three blocks entered into the model, several dependent measures remained significant. Uniquely, parent total stress on the PSI-4-SF remained significant in this model and was a significant predictor of interest in sibling services in the future. Additionally, social support on the ISSB, and Autism Index scores on the GARS-3 were among the best predictors of parent service access in the future.

Results for the Screen Fail families followed the results of the whole sample. For the Screen Pass families, only social support remained significant when accounting for all other variables in lower blocks.



Table 27

*Hierarchical Regression of Predictors of Future Sibling Service Interest- Whole*

|                      | <i>B</i> | <i>SE (B)</i> | $\beta$ | <i>F</i> | $R^2$ | $\Delta R^2$ |
|----------------------|----------|---------------|---------|----------|-------|--------------|
| Block 1              |          |               |         | 4.549    | .13   | .13*         |
| Parent Gender        | .56      | .67           | .07     | -        | -     | -            |
| Parent Race          | -2.84    | .94           | -.27    | -        | -     | -            |
| Parent Ethnicity     | -1.79    | .98           | -.16    | -        | -     | -            |
| Parent Education     | -.11     | .60           | -.02    | -        | -     | -            |
| Block 2              |          |               |         | 3.461    | .24   | .11**        |
| Parent Gender        | -.48     | .73           | -.06    | -        | -     | -            |
| Parent Race          | -2.21    | .96           | -.21    | -        | -     | -            |
| Parent Ethnicity     | -2.22    | .96           | -.20    | -        | -     | -            |
| Parent Education     | .24      | .59           | .04     | -        | -     | -            |
| # Children           | -1.38    | .59           | -.20    | -        | -     | -            |
| ASD Gender           | 1.13     | .72           | .14     | -        | -     | -            |
| ASD Age              | -.31     | .22           | -.12    | -        | -     | -            |
| TD Gender            | -.26     | .62           | -.03    | -        | -     | -            |
| TD Age               | .71      | .29           | .20     | -        | -     | -            |
| Block 3              |          |               |         | 12.820   | .57   | .34**        |
| Parent Gender        | -.85     | .58           | -.11    | -        | -     | -            |
| Parent Race          | -.68     | .82           | -.07    | -        | -     | -            |
| Parent Ethnicity     | -1.91    | .77           | -.17    | -        | -     | -            |
| Parent Education     | .21      | .47           | .03     | -        | -     | -            |
| # Children           | -.42     | .52           | -.06    | -        | -     | -            |
| ASD Gender           | .18      | .57           | .02     | -        | -     | -            |
| ASD Age              | -.24     | .17           | -.10    | -        | -     | -            |
| TD Gender            | .02      | .51           | .00     | -        | -     | -            |
| TD Age               | .26      | .25           | .07     | -        | -     | -            |
| GHQ Depression       | -.06     | .25           | -.03    | -        | -     | -            |
| GHQ Anxiety          | .37      | .22           | .15     | -        | -     | -            |
| Parent Stress Total  | .11      | .04           | .19     | -        | -     | -            |
| Social Support Total | .05      | .01           | .25     | -        | -     | -            |
| Money-Sibling        | .51      | .28           | .10     | -        | -     | -            |
| Autism Index         | .55      | .34           | .11     | -        | -     | -            |
| Money- Parent        | .07      | .03           | .23     | -        | -     | -            |

\* $p < 0.05$ , \*\* $p < .01$ 

## Discussion

The present study evaluated several factors related to services that families of individuals with ASD access for their own support. The sample as a whole conveyed the valuable voices of parents from across the United States. Results from this project

revealed that several factors predicted the amount of services that parents and siblings have accessed in the past, and are willing to access in the future. These factors include demographic and logistical variables, parent functioning, and characteristics of the child with ASD. Further, it was found that attitude and priority of services was not sufficient to predict treatment access and engagement. Taken together, these patterns can ultimately inform the trajectory of research and clinical services in the future.

#### Characterization of the Sample.

The sample included a wide range of both child and parent characteristics. Among the child sample, focusing specifically on the identified child with ASD, there were a wide variety of ages and functioning levels represented. This allowed for a view of treatment access and interest across the developmental range. Parents and typically developing siblings were also found to be diverse in many important ways. First, this sample provided information by both male and female respondents. In the parent support literature, respondents are largely mothers of individuals with ASD. This study allowed for a look at the important perspective of fathers in this sample. Further, perhaps most notably, there was a significant subset of families ( $n=32$ ) who met exclusionary criteria based on a set of parent and sibling screening questions. This sample of “Screen Fail” families represented those who have a parent, or a typically developing child, who have an endorsed developmental, learning, or major psychiatric condition (e.g., schizophrenia, bipolar disorder, or recurrent major depression). As this subset of Screen Fail families reflect the portion of clinically identified families in the literature, the discussion of the results below reflects those three groups: whole sample, Screen Pass families, and Screen Fail families.

Looking at dependent measures that describe both the parent's functioning (PSI-4-SF, GHQ-28, ISSB) and the functioning of the child with ASD (GARS-3), this sample can be characterized as fairly impacted on both accounts. Despite endorsing moderate to high levels of social support on the ISSB, parents reported elevated scores of parenting stress on the PSI-4-SF and psychiatric symptoms on the GHQ-28 relative to the normative samples. Further, children were rated to have high levels of ASD behaviors, as measured by the GARS-3. Only 2.5% of the sample fell within the lowest severity range of the DSM-5 (Level 1), and the remaining 97.5% occupied the two more severe ranges (Level 2 and 3). While higher scores on the GARS-3 would suggest higher overall ASD severity, it is important to note that these scores are based on parent perceptions of their child's behavior, and have no accompanying objective data. Given the parent stress level endorsed by the sample, it is possible that scores on the GARS-3 may reflect ASD severity as well as the parent stress and wellbeing described above. Despite the influence of parent responding on all measures, the subjective experience of these parents reveals that families felt themselves to stressed, and at-risk, overall.

Looking at the Screen Pass and Screen Fail subgroups individually, families in the Screen Fail sample were found to be even more substantially at risk, reflecting differences in dependent measures as well as demographic variables. As these families had self-disclosed psychopathology in the parents or siblings, in addition to having a child with ASD, it was expected that these families would differ in many important areas. As expected, parents in the Screen Fail sample had a significantly higher endorsement of psychiatric symptoms on the GHQ-28 across all subscale areas in comparison to those in the Screen Pass sample. These families also reported significantly less perceived social

support on the ISSB, with differences being driven by lower scores in nondirective support (e.g., listening and reflecting, without providing active advice or suggestions). Additionally, the Screen Fail families reflected a higher proportion of children described as nonverbal, which may serve as its own measure of impairment, though overall Autism Index scores were significantly lower than the Screen Pass families. Finally, the Screen Fail sample was significantly more diverse with regard to the racial identification of parents. While the samples did not differ on any other demographic variables that pertain to the parents (e.g., education, marital status, etc.), public health and policy research has documented significant mental health disparities within racial and ethnic minority populations in the United States (U.S. Department of Health and Human Services, 2001). Therefore, in addition to the challenges added by having a child with ASD, and another family member with significant psychopathology, these families may inherently access fewer services, or fewer high quality services, than Caucasian families with the same stressors. Despite the challenges facing this Screen Fail sample, the groups did not differ significantly on any measure of parent stress. The lack of difference between groups may be explained by the globally high levels of stress endorsed by the sample as a whole. Therefore, this Screen Fail sample can be considered just as ‘clinically significant’ with regard to stress as the rest of the sample.

#### Endorsement of Service Access and Interest.

Overall, parents in this sample reported a generally positive view of support services as they pertain to themselves and their typically developing children. This suggests that parents viewed support services as something that could be helpful, or of value, to their families and did not carry a significant burden of stigma. This positive

attitude appeared to translate into a fairly engaged sample of parents and siblings.

Looking first at past service access, the large majority of families in this sample reported having utilized support services for both parents and siblings following the diagnosis of the child with ASD. Specifically, 98% of families reported having accessed at least one avenue of support for parents in the past, and 97% of families endorsed using at least one sibling support service in that same time frame. Further, the mean number of services accessed for each group suggests that parents and siblings have come into contact with a range of diverse support options. Parents reported having accessed an average of 8.23 services for themselves in the past, with a range spanning 0 to all 13 services offered in the array. Results indicate that parents have accessed significantly fewer services for their typically developing child, though the mean for this group still indicates a fairly wide range of supports ( $M=7.38$ , Range= 0-13).

This broad interest in support options is maintained when asking parents about their willingness to engage with services in the future. Specifically, means for both parent and sibling services were significantly higher than what was utilized in the past. This suggests that, despite having previously accessed a sampling of services, parents are interested in more supports when looking toward the future. While this could suggest that parents are merely interested in accessing more for themselves and their families, this may also reflect parents' feelings about the quality or fit of the services that they have utilized in the past. Specifically, those families who have accessed services that were deemed unsatisfactory, or required too many resources (e.g., time, financial resources), may prompt parents to endorse interest in a broader set of services in the future. This trend is further elucidated in the qualitative information reviewed in the next section.

Interestingly, the Screen Fail sample endorsed less service engagement in the past, and less interest in future support services than the Screen Pass sample. As the Screen Fail sample reported an average of 6.77 past services for parents and 6.09 services for siblings, it appears that this sample has in fact explored many options for family support. However, significant differences in future service interest may reflect a qualitatively different experience for this population. Notably, mean interest in the number of support services for parents and siblings did not increase from past access to future, as the Screen Pass sample did. This again may speak to the quality of services accessed in the past, or satisfaction with these same services. However, it is likely that these additional services could be limited by more logistical variables. In general, parents endorsed that family resources, such as time and finances, were not generally a prohibitive factor to accessing services. However, when looking at the Screen Fail Sample in isolation, these parents endorsed having significantly less time and finances to devote to supports. These limitations may significantly hinder the Screen Fail families from engaging with treatments.

However, it is also possible that crucial time and financial resources are already being allocated in these families, such that their service needs are captured within already existing connections to the support world. Specifically, these are families that have endorsed psychosocial challenges in addition to those introduced by ASD. While it is unclear whether these psychosocial factors were present prior to the diagnosis of ASD, it is possible that families have been connected to services tailored to their own individual needs (e.g., a parent with schizophrenia, or a typically developing child with a learning disability). As such, additional services to address stress specific to ASD may be captured

within these preexisting avenues, and therefore would translate into fewer endorsement of service interests.

#### Qualitative Information about Service Access/Interest.

Themes related to quality and fit of services were also reflected in qualitative information that was gathered about individual service access. Looking first at past access for parents, individual psychotherapy was the highest endorsed service option, with 73.8% of the sample endorsing past experience with one-on-one treatment or counseling. This percentage is significantly elevated in comparison to reports of outpatient psychotherapy access nationwide. Specifically, information collected from the U.S. general population survey and the Medical Expenditure Panel Surveys suggested a 3.37% point prevalence for individuals engaging in outpatient psychotherapy (Olfson & Marcus, 2010). It should however be noted that the survey data from Olfson & Marcus (2010) qualified psychotherapy access as attending more than one appointment. No such restrictions were placed on the current sample, and as such, percentages may be quite elevated.

In addition to individual counseling, parents were most likely to access supports that could be utilized online: reading and writing posts on online message boards, and parent support groups found online. This suggests that parents overall gravitate most toward services that are lower response effort, or can be accessed more flexibly. This effect was particularly heightened in the Screen Fail sample, with online options outranking individual psychotherapy in overall frequency. While it is evident that families of individuals with ASD experience more stress than families of typically developing children on average, these trends may be further exacerbated by an already at-

risk sample. As such, given the restriction on parent resources that were documented above, a system that is stressed due to co-occurring psychopathology in the family may be restricted even further.

In addition to constraint on resources, it is also possible that the prioritization of resource allocation does not fall in the favor of support services for family members. In comparison to parents' attitudes toward support services, when asking parents about the priority of service engagement for themselves and their typically developing child, these scores were found to be significantly lower. This suggests that while parents think supports would have a positive influence on their families, and have the means to access them, they are not a priority in their life at the moment. This may mean that, given the choice, parents are more interested in using their resources to access other activities (e.g., recreational, social) for themselves and their typically developing children than engaging with therapeutic supports. This may also reflect a prioritization of using support services for the child with ASD above and beyond themselves. This finding regarding prioritization did not differ by subgroup, suggesting that these differences in priority were a global trend impacting the majority of parents in the sample.

Finally, community based services geared toward families of individuals with ASD (e.g., Autism New Jersey, Autism Speaks), were by far the least endorsed support option (49.0%). This effect was observed to be even more salient in the Screen Fail sample (15.6%). While this service avenue was pursued by almost half of the whole sample, it suggests that families are the least inclined to pursue community support when other options are available.

Looking ahead to future service interest for parents of individuals with ASD, the



gravitation toward supports requiring less response effort was re-emphasized. While individual psychotherapy remained highly rated, with 78.5% of the sample reporting that they would be willing to access this service, online support services outranked this option. Further, parent skills training groups and in person parent support groups remained highly rated, though less preferred overall. Supporting the hypothesis regarding the additional resource burden on the Screen Fail sample, these families were again most likely to endorse online options. However, the Screen Pass families maintained a preference in in-person services, perhaps suggesting that more effortful services are not as much a deterrent for this subgroup.

Parents endorsed a very different service profile for their typically developing children. While individual psychotherapy remained the most endorsed service accessed, parents were much more likely to endorse in-person community-based service options for their children than for themselves. This included speaking with members of the religious community, teachers, and medical professionals. This again speaks to prioritization of resources in families of individuals with ASD. While parents reported the priority of accessing supports to be significantly lower than their positive attitude toward services, priority ratings for siblings were found to be significantly higher than for parents. This suggests that while priority is globally low, relative to other factors, parents still prioritize treatment access for their typically developing children over themselves. Finally, as seen in the parent sample, community-based support services were one of the least utilized options (49.0%) for the sample as a whole, as well as Screen Pass and Screen Fail groups.

Looking ahead to the future, the endorsement of individual services shifted significantly from those utilized in the past. Specifically, while individual psychotherapy

remained the most prevalent service interest, members of the religious community and pediatricians dropped in their relative popularity. Instead, the services occupying the most predominant spots were group therapy, sibling support groups, and sibling skills training groups. This was true of both the Screen Pass and Screen Fail samples, though the Screen Fail sample did not show a preference toward individual psychotherapy. This overall shift in service endorsement could reflect several different phenomena. The rise in interest for group psychotherapy and sibling groups in the future may be a product of novelty or lack of service availability in the past. If these services had not been previously available to families, these more tailored, specific options may be particularly appealing. However, the drop in treatment seeking behavior from community-based support systems may reflect a counter process. Perhaps this suggests that families who accessed these supports in the past did not have their needs met in the community-based area. As this possibility is arising in both parent and sibling service areas, looking at treatment satisfaction is an area to investigate further with more tailored research. Further, it may be particularly important to investigate the satisfaction of at-risk populations with community-based supports, as these families consistently rated these support networks as the least accessed and least appealing for future engagement. These ratings perhaps indicate an inherently different perspective on, or ability to access, these services for the parent and sibling populations.

#### Factors that Facilitate Service Access: Demographic Variables.

Looking at the whole of data collected for the sample, there were several factors that were associated with more service engagement (e.g., more services accessed in the past, or willing to access more services in the future) in parents and siblings of

individuals with ASD. Related factors included a host of demographic variables as well as psychosocial characteristics of the sample.

Looking first at demographics, mothers reported interest in significantly more future parent services than fathers. Women were also described as having a more positive attitude toward support services for families, and having more time to allocate toward these services than men. These differences in service engagement by gender are consistent with the general literature on outpatient psychotherapy services (Olfson & Marcus, 2010), with women consistently accessing support more often than men. Interestingly, this phenomenon was not reflected in past service access for this sample, with women and men accessing an equivalent amount of services.

Respondent race and ethnicity were also found to be associated with service engagement, both in the past and future. While ethnicity was only related to interest in future sibling services, respondent race showed more disparities. Specifically, participants who identified as White endorsed a more positive attitude toward support services, both parent and sibling, and also reported interest in more future services than Non-White participants. However, some of this effect was accounted for by subgroup, with Screen Fail status accounting for the differences in attitude toward sibling services and interest in future sibling services. This suggests that the higher proportion of Non-White participants in the Screen Fail sample accounted for these between group differences. However, Screen Fail status could not account for differences in attitude and interest in parent services in the future. These results indicate that, above and beyond group status, Non-White participants were interested in fewer parent services in the future, and carried a less positive attitude toward these services. Differences by

respondent race again reflect national statistics on service access (Olfson & Marcus, 2010), and mental health disparities influencing perception of services as helpful.

In addition to race and gender, parent education was found to be associated with service engagement. Specifically, those parents who endorsed having a Bachelor's level of education reported having accessed more overall services in the past, and having interest in more services in the future. This was true of parent and sibling services. Notably, parent education was not related to attitude toward services or the priority of these supports. While it is generally found that adults with more education access more outpatient services (Olfson & Marcus, 2010), it should be noted that the Bachelor's level was the large majority of education endorsement (65.66%). As such, this result may be inflated by the structure of the sample.

Notably, family level variables were also found to be associated with service engagement for parents and siblings. Specifically, it was found that parents with more children living in the home accessed fewer services for themselves in the past. This pattern may reflect difficulties with resource allocation necessary for accessing parent services. Interestingly, parents of older children with ASD endorsed interest in fewer support services for themselves in the future than parents of younger children. Whereas, parents of older typically developing children endorsed interest in more future sibling services than parents of younger typically developing children. These results may indicate different service engagement trajectories for parents and siblings. Specifically, it may suggest that parents feel most in need of their own support when their children are younger, while they view the service need to be heightened as their typically developing children grow older. Further, parents of female children with ASD reported having

accessed more past services for parents and sibling than those with male children with ASD. This trend runs contrary to research suggesting that parents of female children with ASD have better adjustment (Frey et al., 1989). While not corresponding to ASD severity on the GARS-3, this may instead reflect the social expectations of females in the United States more generally, and the unique stress this may place on the families of children not meeting these expectations.

Other family level variables included parents' report on family resources. Specifically, parents who reported more finances to devote to services endorsed interest in more access to past services and greater interest in future services. Further, reporting more time to devote to services was also related to interest in greater future service access for parents and siblings.

Interestingly, service engagement did not differ at all by respondent region. This runs contrary to the hypothesis that greater service density (e.g., the amount of services available in a given area) would correspond to greater past service access than areas of less service density. Service access and interest was also not related to general attitude toward services, or the priority of services within a given family. Therefore, while these differences in attitude and priority are evident across families, it is not in fact related to whether or not families pursue support.

#### Factors that Facilitate Service Access: Psychosocial Variables.

In addition to demographic variables, psychosocial measures were found to have moderate to strong relationships with service engagement for families. Looking first at child variables, higher overall ASD symptom severity on the GARS-3 was related to greater past and future service engagement for parents and siblings. This relationship

follows suit with the higher levels of stress observed in parents of more affected children with ASD (Baker et al., 2003; Frey et al., 1989; Gabriels et al., 2004). Relatedly, looking at parent variables, higher levels of overall parent stress, and higher levels of perceived social support, were also related to increased levels of service engagement, both for parents and siblings. Further, endorsement of fewer psychiatric symptoms lead to higher rates of services engagement for parents and siblings, running contrary to the original hypothesis.

Taken together, results suggest a complex mix of risk and protective factors were related to patterns of service engagement. First, factors that contribute to greater stress (e.g., ASD symptom severity, difficulties with parenting) in parents were strongly related to the amount of service engagement in families. This suggests that a certain level of stress was required to motivate parents to access services. This occurs above and beyond a parents' attitude toward services, or the priority of services. It should also be noted that all relationships between psychosocial variables and service engagement were stronger in the Screen Fail sample. This suggests that stressors may have a more significant impact on this at-risk sample, and may 'matter more' when it comes to seeking treatment help.

#### Best Predictors of Service Access: Past.

All of the above significant correlations were found to be independent predictors of service access and/or interest. Given the number of variables that contributed to the service engagement model, a series of hierarchical regression analyses were conducted to identify the factors that best predict whether or not parents will access services for themselves or their typically developing children. Predictors were grouped into three blocks: demographic variables, family-level variables, and psychosocial variables.

Looking first at predictors of past service access for parents, results suggest that all three blocks contributed significantly, and independently, to the prediction model. However, when the last block was entered into the model, only ASD symptom severity and parent ratings of their own financial resources remained significant. These findings suggest that more allocation of financial resources and higher scores on child-variables were the best predictors of past parent access. Notably, this was true for the Screen pass sample, but all variables were rendered nonsignificant for the Screen Fail sample. This likely speaks to the power of the multilevel model with a small sample size.

Looking at the factors that best predict past access for siblings, a more diverse model arises. Specifically, social support joined ASD severity and financial resources as significant predictors. This model again remained significant for the Screen Pass families only.

Taken together, these results suggest that ASD symptom severity, and financial allocation toward services, best predicted both past service engagement for parents and siblings. However, the addition of social support to the sibling model may imply that families who are able to access more for their children are those who have more perceived social connection overall. However, this may also suggest that social connection was in fact facilitated by those same services. Further, the absence of parent attitude toward services, and parent priority of services, from the predictive model suggests that circumstantial or logistical variables, such as finances or response effort, may weigh most heavily into parent decision-making.

Best Predictors of Service Access: Future.

The results for predictors of future service access are much more diverse for both

parents and siblings. Particularly, for parents, lower scores of parent anxiety, higher levels of social support, and ASD symptom severity were the best predictors. This was true of both groups, though psychiatric scores dropped out when looking at each group independently. Looking at predictors of future service access for siblings, high levels of parent stress, social support, and ASD severity were all related to more future service engagement. Importantly, financial resources dropped out of both models as a significant predictor.

From these results, a model of risk and protective factors emerge as predictors of service engagement for families. Results find that that a certain amount of child (i.e., ASD severity) and family stress (i.e., parent stress) is needed for families to be interested in pursuing services for themselves or their children. However, stress in the form of high levels of psychiatric symptoms may in fact impede access and interest in supports. Therefore, while stress is generally adaptive and functional, a certain level of psychiatric stress may debilitate families. Further, perceived social support, which is a predictor of reduced stress in families (Yau & Li-Tsang, 1999), is also related to greater service engagement. Social support is a common predictor of better psychosocial outcomes in adults and children, and may be a factor that facilitates connection to services in this stressed sample. Further, these relationships were strongest in the Screen Fail sample. This again suggests that factors related to stress have a greater impact on this at-risk sample, who already have fewer adaptive resources to combat the stress. Given the unique relationship of stressors to service engagement in the Screen Fail sample, it may be useful to investigate these factors more thoroughly in future studies.

Notably, the lack of attitude and priority ratings in this model again speaks to the



idea that these variables are not sufficient to lead a family to treatment. Instead, it is psychosocial variables that play a more active role in the decision-making process. The lack of parent finances as a predictor in the “future” models perhaps suggests a bit of an idealization of future service access for families. Specifically, parent finances played a crucial role in past access for parents and siblings. The lack of predictive value in future access perhaps reflects a parent’s desire for services without considering logistical restrictions.

#### Limitations and Future Directions.

While the present study revealed many important findings with regard to the service engagement of families, there are some inherent limitations. First, the sample as a whole is relatively homogenous with regard to marital status, race, ethnicity, and educational level of parent respondents. The Screen Fail sample is characterized by significantly more racial diversity than the sample overall; however this group only represents a small portion of the findings ( $n=32$ ). The homogeneity of the sample is generally characteristic of participants who complete online survey research, however this limits the ability to generalize the research findings to families from more diverse racial, ethnic, and socioeconomic backgrounds. It is important to gather information from a diverse sample for several reasons. Within this particular sample, racial and ethnic diversity impacted several important variables, such as overall service engagement and interest, resources to attribute to services, and psychosocial variables such as social support. Given these group differences, it is clear that diverse populations may exhibit significantly different patterns of decision making when it comes to service access. As such, it is important to gather information from a more inclusive sample in order to figure

out how to best serve different groups.

Similarly, the recruitment methods utilized to identify eligible families led to a relatively high stress, treatment-seeking sample. The families involved in the research were largely recruited from schools for individuals with ASD, as well as families already involved in support networks (e.g., support groups for parents and siblings). Given the predictive models proposed in this study, it is intuitive that the high levels of past and current service engagement endorsed by the sample was related to their globally high levels of stress. Including high stress, treatment-seeking families in this project is intuitive: when inquiring about what services parents and siblings have accessed in the past, and are interested in accessing in the future, it is important to hear from those who are motivated enough to have already pursued support options. However, it is also crucial to reach parents who are outside of treatment networks in order to discover what factors may be preventing their involvement in treatment. Future directions for this research would be to replicate the study in a more diverse sample of parents, including parents of diverse demographic backgrounds, as well as those who are not currently involved in treatment.

It is also important to consider the limitations of some of the survey techniques. First, this survey represents information about service access and interest in a cross sectional model. Research suggests that parents' subjective experience and level of stress can fluctuate over time (Scorgie et al., 1998), therefore it is logical to infer that service engagement would also change as they and their child age. As such, it is important to limit the interpretation of findings to reflect the interests of families at a single point in time. Future directions for this research would be to look at service engagement over time

in a longitudinal format.

An additional limitation of the survey method is the reliance on parent report only. Specifically, the online survey asked parents to respond on behalf of themselves, their typically developing children, and their child with ASD. As such, several variables should be interpreted with some caution. First, information used to characterize the sample was provided through the lens of parent perception. While it is crucial to consider the subjective experience of the parent, an objective measurement of ASD symptom severity, and other variables, may provide more valid information about predictors of service engagement. Further, this project relies on parents to describe interest in service engagement for themselves as well as their typically developing child. It is clear that parents are typically the access point for services in young children (e.g., providing transportation, finances, etc.). Further, it is suggested that parents play a mediating role in sibling stress (Giallo & Gavidia-Payne, 2006). Taken together, parents of these typically developing children play a crucial role in their ability to access support options, and are the primary stakeholders in this paradigm (Pellicano, Dinsmore, & Charman, 2014). However, as children age into adolescents and young adults, they become more independently able to pursue their own treatment. An important future direction is to consider siblings as important stakeholders in guiding the research on their own support, and asking them directly about their service interests and needs.

Another limitation to the survey questionnaire is difficulties with measurement. As a measurement of service engagement related to a diagnosis of ASD, parents were asked to indicate what services they had accessed following their child's diagnosis. While it is important to assess past service engagement, it is inherently difficult to differentiate

service access related to ASD from supports motivated by other factors. For example, parents and siblings may access services related to significant life events (e.g., a death in the family, a move), or a psychosocial condition unrelated to ASD explicitly (e.g., depression related to bullying). It may even more difficult to differentiate the motivation for treatment in the Screen Fail families, who may engage with treatment services related to their own psychopathology. While this limitation may be difficult to address in survey format, the use of interview data, or qualitative data, may help to clarify the motivations for treatment.

Further, the description of service engagement variables may also be limited by some aspects of the family services questionnaire. Specifically, the questionnaire asks parents to indicate whether or not they have accessed a particular service in the past. This provides parents with an absolute choice (e.g., yes or no), and does not account for degree of service engagement, such as the duration of service access, or the quality of the support. As such, parents who went to one session of individual psychotherapy received as much ‘credit’ as those who attended consistently for three months. The lack of control for service duration or quality may account for the high levels of past service endorsement seen in this sample. While this survey served as a preliminary investigation of service access and interest, it will be important to inquire about these qualitative variables in the future.

Further, analyses on the predictors of treatment access and interest rely on the degree of service engagement as a continuous variable. Specifically, engagement with services lies on a continuum of 0 to 13 possible options. While the current study viewed engagement with a higher number of services as a more positive outcome, this may not

be a true measure of success for all families. Specifically, it is possible that families could become involved with one or two particular services that fulfill their service needs. As such, it would not become necessary for families to access many options in order to feel sufficiently supported. However, high levels of stress reported in this sample suggest that there are many needs still left unfilled.

Thinking about treatment satisfaction within particular service options becomes even more relevant given the qualitative results discussed. Specifically, it was evident that parents and siblings accessed a significant amount of community-based services for their support needs. This included primary care physicians, teachers, members of the religious community, and community support networks specific to individuals with ASD (e.g., Autism Speaks). While siblings were much more likely to have accessed community supports than their parents in the past, these avenues dropped considerably out of favor when asked about preference for future support services. Further, community supports specific to ASD were the least favored for both parent and sibling groups in the past. It is clear from these patterns that families look to some members of the general community to seek support related to a diagnosis of ASD. The shift away from community providers may be indicative of families not having their needs met through these avenues. Given parents' initial preference toward trusted members of the community, it is important to understand where these services go wrong. For example, parents may encounter a lack of understanding of ASD, perceptions of stigma or judgment from a community provider, or inability to maintain long-term support. It is therefore crucial to actively engage parents and siblings in a discussion about past service access, and their satisfaction with those services. Further, given the high proportion of

services accessed outside of clinical settings, a future direction may be to educate community members about ASD, and the importance of supporting family members throughout the lifespan. Specifically, if community members are unable to provide family members with sufficient support, a knowledge appropriate referrals would be a helpful resource. As one parent wrote, their limitation of service access was being “not aware of what is offered for siblings.”

Lastly, looking at qualitative data specific to individual service endorsement for parents and siblings, there is a need for future research directions related to alternate service delivery models. The need for alternatives to both typical parent and sibling support options is warranted. Looking at future service interests for parents, the majority of families preferred options that required less response effort, or had more flexibility inherent in their access. Specifically, one parent wrote, “I am already so exhausted from going to meetings/therapies, doctor appointments related to my ASD child that I’m limited in time and energy re: seeking support for myself and my neurotypical child.” Further, when asking parents about future service interest for siblings, they were significantly more likely to endorse interest in more effortful options. Taken together, this suggests that parents are more likely to allocate resources to in-person services for their children than for themselves. Further, looking at factors that predict past service access for both parents and siblings, parent finances were found to significantly predict service engagement. In order to improve treatment access for families, it is crucial to take these factors into account, and rethink our current treatment approaches.

Other treatment communities have begun to investigate alternatives to traditional psychotherapy, even extending to individuals with ASD (Wainer & Ingersoll, 2014).

Specifically, researchers have begun conducting research outside of the clinic, such as in schools, and through online mediums, such as telehealth. However, a reconceptualization of service options for families of individuals with ASD have not yet been explored.

Given the restrictions on parent resources, and the preference for flexible support models, it may be beneficial to incorporate family services into more accessed in-person avenues.

One possible method for this is integration of family services into already-existing ASD therapeutic services. Specifically, as one parent wrote “If these services were integrated into other services (i.e., ABA, social skills, psychotherapy, etc.) that the child with ASD is getting, it would make it more convenient and more likely for us to access the sibling and parent services.” Creating appropriate, low effort services for parents and siblings may be an easy way to decrease the difficulties with service access.

#### Summary.

Overall, this study suggests that parents of individuals with ASD are interested in accessing support services for themselves and their typically developing children, and endorse a positive attitude toward these same supports. In looking at past service engagement, parents have accessed a diverse range of support services for themselves and their typically developing children in the past. Services include traditional modes of psychotherapy as well as more modern support options, such as message boards and support groups. Further, families are interested in accessing as many, if not more, services in the future. Future service interest reflects more low effort options for parents, and more in-person traditional options for siblings. Several demographic and psychosocial factors were related to service engagement for families. Parent attitude toward services, and service priority, did not independently predict service access and

interest. The most predictive factors included co-occurring family psychopathology, ASD symptom severity, financial support for services, and social support. This suggests that parent interest and perception of services was not adequate to predict their access of these same services. Instead, it was logistical and psychosocial factors that played the most important role. These findings provide important information about patterns of treatment access and interest for families of individuals with ASD, and helps to inform clinical treatment for these groups in the future.



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Appendix A  
Demographics and Family Profile Questionnaire

What is your family's state of residence?

- ☐ Alabama (1)
- ☐ Alaska (2)
- ☐ Arizona (3)
- ☐ Arkansas (4)
- ☐ California (5)
- ☐ Colorado (6)
- ☐ Connecticut (7)
- ☐ Delaware (8)
- ☐ Florida (9)
- ☐ Georgia (10)
- ☐ Hawaii (11)
- ☐ Idaho (12)
- ☐ Illinois (13)
- ☐ Indiana (14)
- ☐ Iowa (15)
- ☐ Kansas (16)
- ☐ Kentucky (17)
- ☐ Louisiana (18)
- ☐ Maine (19)
- ☐ Maryland (20)
- ☐ Massachusetts (21)
- ☐ Michigan (22)
- ☐ Minnesota (23)
- ☐ Mississippi (24)
- ☐ Missouri (25)
- ☐ Montana (26)
- ☐ Nebraska (27)
- ☐ Nevada (28)
- ☐ New Hampshire (29)
- ☐ New Jersey (30)
- ☐ New Mexico (31)
- ☐ New York (32)
- ☐ North Carolina (33)
- ☐ North Dakota (34)
- ☐ Ohio (35)
- ☐ Oklahoma (36)
- ☐ Oregon (37)
- ☐ Pennsylvania (38)
- ☐ Rhode Island (39)

- ☐ South Carolina (40)
- ☐ South Dakota (41)
- ☐ Tennessee (42)
- ☐ Texas (43)
- ☐ Utah (44)
- ☐ Vermont (45)
- ☐ Virginia (46)
- ☐ Washington (47)
- ☐ West Virginia (48)
- ☐ Wisconsin (49)
- ☐ Wyoming (50)

What is your gender?

- ☐ Male (1)
- ☐ Female (2)

How would you describe your role in your family?

- ☐ Mother (1)
- ☐ Father (2)
- ☐ Step mother (3)
- ☐ Step father (4)
- ☐ Legal Guardian (5)
- ☐ Other (6)

What is your current marital status?

- ☐ Never Married (1)
- ☐ Married (2)
- ☐ Partnered (3)
- ☐ Separated (4)
- ☐ Divorced (5)
- ☐ Widowed (6)

How would you describe your race?

- ☐ White (1)
- ☐ Black or African American (2)
- ☐ American Indian or Alaska Native (3)
- ☐ Asian (4)
- ☐ Native Hawaiian or Other Pacific Islander (5)
- ☐ Two or More Races (6)
- ☐ Other (7)

How would you describe your ethnicity?

- ☐ Hispanic (1)
- ☐ Non-Hispanic (2)

What is the highest level of education you have achieved?

- ☐ Some High School (1)
- ☐ High School Graduate (2)
- ☐ Some College (3)
- ☐ Associates Degree (4)
- ☐ Bachelor's Degree (5)
- ☐ Professional Degree (6)
- ☐ Some Graduate Education (7)
- ☐ Advanced Degree (Ph.D., M.D., J.D., etc) (8)

How many children do you currently have living in your home?

- ☐ 2 (1)
- ☐ 3 (2)
- ☐ 4 (3)
- ☐ 5+ (4)

Do you have at least one child with an Autism Spectrum Disorder (ASD)?

- ☐ Yes (1)
- ☐ No (2)

Do you have more than one child with ASD?

- ☐ Yes (1)
- ☐ No (2)

How old is your child with ASD?

- ☐ 0-1 year of age (1)
- ☐ 1-2 years of age (2)
- ☐ 2-3 years of age (3)
- ☐ 3-5 years of age (4)
- ☐ 6-8 years of age (5)
- ☐ 9-11 years of age (6)
- ☐ 12-14 years of age (7)
- ☐ 15-17 years of age (8)
- ☐ 18+ years of age (9)



Is your child with ASD male or female?

- ☐ Male (1)
- ☐ Female (2)

Answer If Do you have more than one child with ASD? Yes Is Selected

How old is your other child with ASD?

- ☐ 0-1 year of age (1)
- ☐ 1-2 years of age (2)
- ☐ 2-3 years of age (3)
- ☐ 3-5 years of age (4)
- ☐ 6-8 years of age (5)
- ☐ 9-11 years of age (6)
- ☐ 12-14 years of age (7)
- ☐ 15-17 years of age (8)
- ☐ 18+ years of age (9)

Answer If Do you have more than one child with ASD? Yes Is Selected

Is your other child with ASD male or female?

- ☐ Male (1)
- ☐ Female (2)

Do you have at least one typically developing child?

- ☐ Yes (1)
- ☐ No (2)

Do you have more than one typically developing child?

- ☐ Yes (1)
- ☐ No (2)

How old is your typically developing child?

- ☐ 0-1 year of age (1)
- ☐ 1-2 years of age (2)
- ☐ 2-3 years of age (3)
- ☐ 3-5 years of age (4)
- ☐ 6-8 years of age (5)
- ☐ 9-11 years of age (6)
- ☐ 12-14 years of age (7)
- ☐ 15-17 years of age (8)
- ☐ 18+ years of age (9)

Is your typically developing child male or female?

- ☐ Male (1)
- ☐ Female (2)

## Appendix B

### Family Support Questionnaire

Part I: The first set of questions will ask you about what services (if any) you have accessed for yourself in the past. Since your child's initial diagnosis of an autism spectrum disorder (ASD), have you ever sought support services for yourself through:

Individual Psychotherapy or Counseling (meeting one-on-one with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Group Psychotherapy or Counseling (a group of individuals meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Family Psychotherapy or Counseling (a set of family members meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Couples Therapy or Counseling (two partners meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Parent Support Group (In Person)

- ☐ Yes (1)
- ☐ No (2)

Parent Support Group (Online)

- ☐ Yes (1)
- ☐ No (2)

Informal Parent Group (E.g. meeting with other parents of children with ASD in an informal setting)

- ☐ Yes (1)
- ☐ No (2)

Parent Skills Training Group (E.g. learning parenting strategies and coping skills in a group setting)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Reading Posts)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Writing posts)

- ☐ Yes (1)
- ☐ No (2)

Primary Care Physician or Other Medical Professional

- ☐ Yes (1)
- ☐ No (2)

Members of your religious community (E.g. priest, rabbi, imam, etc)

- ☐ Yes (1)
- ☐ No (2)

Other community support related to ASD or other disabilities (E.g. Autism NJ, Autism Speaks)

- ☐ Yes (1)
- ☐ No (2)

Part I (cont.) This next set of questions will ask you about what services (if any) have been accessed for your typically developing child/children in the past. Since your child's initial diagnosis of ASD, has/have your typically developing child/children ever received support services for himself/herself/themselves through:

Individual Psychotherapy or Counseling (meeting one-on-one with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Group Psychotherapy or Counseling (a group of individuals meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Family Psychotherapy (a set of family members meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Sibling Support Group (In Person)

- ☐ Yes (1)
- ☐ No (2)

Sibling Support Group (Online)

- ☐ Yes (1)
- ☐ No (2)

Informal Sibling Group (E.g. meeting with other siblings who have a brother or sister with ASD in an informal setting)

- ☐ Yes (1)
- ☐ No (2)

Sibling Skills Training Group (E.g. learning strategies to help interact with their sibling, or to help with treatment, in a group setting)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Reading Posts)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Writing posts)

- ☐ Yes (1)
- ☐ No (2)

Teachers at School

- ☐ Yes (1)
- ☐ No (2)

Pediatrician or Other Medical Professional

- ☐ Yes (1)
- ☐ No (2)

Members of your religious community (E.g. priest, rabbi, imam, etc)

- ☐ Yes (1)
- ☐ No (2)

Other community support related to ASD or other disabilities (E.g. Autism NJ, Autism Speaks)

- ☐ Yes (1)
- ☐ No (2)

Part II: This next set of questions will ask you about what services (if any) you may be interested in accessing for yourself in the future. Please assume that these services would be available to you when considering your responses. Would you ever consider seeking support services for yourself through:

Individual Psychotherapy or Counseling (meeting one-on-one with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Group Psychotherapy or Counseling (a group of individuals meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Family Psychotherapy or Counseling (a set of family members meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Couples Therapy or Counseling (two partners meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Parent Support Group (In Person)

- ☐ Yes (1)
- ☐ No (2)

Parent Support Group (Online)

- ☐ Yes (1)
- ☐ No (2)

Informal Parent Group (E.g. meeting with other parents of children with ASD in an informal setting)

- ☐ Yes (1)
- ☐ No (2)

Parent Skills Training Group (E.g. learning parenting strategies and coping skills in a group setting)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Reading Posts)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Writing Posts)

- ☐ Yes (1)
- ☐ No (2)

Primary Care Physician or Other Medical Professional

- ☐ Yes (1)
- ☐ No (2)

Members of your religious community (E.g. priest, rabbi, imam, etc)

- ☐ Yes (1)
- ☐ No (2)

Other community support related to ASD or other disabilities (E.g. Autism NJ, Autism Speaks)

- ☐ Yes (1)
- ☐ No (2)

Part II (cont): This next set of questions will ask you about what services (if any) you may be interested in accessing for your typically developing child/children in the future. Please assume that these services would be available to your child/children when considering your responses. Would you ever consider seeking support services for your typically developing child/children through:

Individual Psychotherapy or Counseling (meeting one-on-one with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Group Psychotherapy or Counseling (a group of individuals meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Family Psychotherapy (a set of family members meeting together with a therapist or counselor)

- ☐ Yes (1)
- ☐ No (2)

Sibling Support Group (In Person)

- ☐ Yes (1)
- ☐ No (2)

Sibling Support Group (Online)

- ☐ Yes (1)
- ☐ No (2)

Informal Sibling Group (E.g. meeting with other siblings who have a brother or sister with ASD in an informal setting)

- ☐ Yes (1)
- ☐ No (2)

Sibling Skills Training Group (E.g. learning strategies to help interact with their sibling, or to help with treatment, in a group setting)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Reading Posts)

- ☐ Yes (1)
- ☐ No (2)

Online Message Boards (Writing posts)

- ☐ Yes (1)
- ☐ No (2)

Teachers at School

- ☐ Yes (1)
- ☐ No (2)

Pediatrician or Other Medical Professional

- ☐ Yes (1)
- ☐ No (2)

Members of your religious community (E.g. priest, rabbi, imam, etc)

- ☐ Yes (1)
- ☐ No (2)

Other community support related to ASD or other disabilities (E.g. Autism NJ, Autism Speaks)

- ☐ Yes (1)
- ☐ No (2)

Part III: In the questions in Part II, you indicated whether you would ever access different support services for yourself. For the following questions, we would like to know what might factor into these decisions. In other words, what makes you choose to pursue a service, or not pursue a service. Rate each of the following statements on a scale of 1 to 5 as they relate to support services for yourself:

|  | Strongly<br>Disagree (1) | Disagree (2)          | Neither<br>Agree nor<br>Disagree (3) | Agree (4)             | Strongly<br>Agree (5) |
|--|--------------------------|-----------------------|--------------------------------------|-----------------------|-----------------------|
| I think support services would be helpful to me (1)  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I've had good experiences with support services in the past (2)  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| Obtaining support services for myself is a priority for me (3)   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I prioritize leisure activities (e.g. recreation, time with friends, etc) more highly than support services (4)      | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I prioritize my responsibilities (e.g. childcare, work, etc) more highly than support services (5)                   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I worry that accessing support services may be stigmatizing for me (e.g., people will think it is weird/strange) (6) | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are skills-based (e.g. teaching coping/parenting skills) (7)                                | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |



| I prefer activities that are support-based (e.g. sharing experiences with others) (8)             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I am interested in accessing support services with other adults/parents (9)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am interested in accessing support services that are more individual (10)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can find time to participate in support services for myself (11)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services during the weekdays (12)                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services during the weekend (13)                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are close to home (less than 20 miles) (14)     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are farther from home (more than 20 miles) (15) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I am able to participate in support services that meet in person (16)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that meet online (17)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have the finances to participate in support services (18)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can arrange childcare in order to participate in support services (19)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think support services would be helpful to me (1)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've had good experiences with support services in the past (2)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Obtaining support services for myself is a priority for me (3)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prioritize leisure activities (e.g. recreation, time with friends, etc) more highly than support services (4) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I prioritize my responsibilities (e.g. childcare, work, etc) more highly than support services (5)                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I worry that accessing support services may be stigmatizing for me (e.g., people will think it is weird/strange) (6) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are skills-based (e.g. teaching coping/parenting skills) (7)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are support-based (e.g. sharing experiences with others) (8)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am interested in accessing support services with other adults/parents (9)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am interested in accessing support services that are more individual (10)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can find time to participate in support services for myself (11)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I am able to participate in support services during the weekdays (12)                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services during the weekend (13)                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are close to home (less than 20 miles) (14)     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are farther from home (more than 20 miles) (15) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that meet in person (16)                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that meet online (17)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have the finances to participate in support services (18)                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can arrange childcare in order to participate (19)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I think support services would be helpful to me (1)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've had good experiences with support services in the past (2)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Obtaining support services for myself is a priority for me (3)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prioritize leisure activities (e.g. recreation, time with friends, etc) more highly than support services (4)      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prioritize my responsibilities (e.g. childcare, work, etc) more highly than support services (5)                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I worry that accessing support services may be stigmatizing for me (e.g., people will think it is weird/strange) (6) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are skills-based (e.g. teaching coping/parenting skills) (7)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

| I prefer activities that are support-based (e.g. sharing experiences with others) (8)             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I am interested in accessing support services with other adults/parents (9)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am interested in accessing support services that are more individual (10)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can find time to participate in support services for myself (11)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services during the weekdays (12)                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services during the weekend (13)                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are close to home (less than 20 miles) (14)     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are farther from home (more than 20 miles) (15) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I am able to participate in support services that meet in person (16)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that meet online (17)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have the finances to participate in support services (18)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can arrange childcare in order to participate in support services (19)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think support services would be helpful to me (1)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I've had good experiences with support services in the past (2)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Obtaining support services for myself is a priority for me (3)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prioritize leisure activities (e.g. recreation, time with friends, etc) more highly than support services (4) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I prioritize my responsibilities (e.g. childcare, work, etc) more highly than support services (5)                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I worry that accessing support services may be stigmatizing for me (e.g., people will think it is weird/strange) (6) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are skills-based (e.g. teaching coping/parenting skills) (7)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are support-based (e.g. sharing experiences with others) (8)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am interested in accessing support services with other adults/parents (9)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am interested in accessing support services that are more individual (10)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can find time to participate in support services for myself (11)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |



|   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I am able to participate in support services during the weekdays (12)                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services during the weekend (13)                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are close to home (less than 20 miles) (14)     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that are farther from home (more than 20 miles) (15) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that meet in person (16)                             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I am able to participate in support services that meet online (17)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have the finances to participate in support services (18)                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can arrange childcare in order to participate in support services (19)                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Part III (cont): In the questions in Part II, you also indicated whether you would ever access different support services for your typically developing child/children. For the following questions, we would like to know what might factor into these decisions. In other words, what makes you choose to pursue a service for your child/children, or not pursue a service for your child/children.

Rate each of the following statements on a scale of 1 to 5 as they relate to support services for your typically developing child:

|  | Strongly<br>Disagree (1) | Disagree (2)          | Neither<br>Agree nor<br>Disagree (3) | Agree (4)             | Strongly<br>Agree (5) |
|--|--------------------------|-----------------------|--------------------------------------|-----------------------|-----------------------|
| I think my child is in need of support services (1)  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| My child has had good experiences with support services in the past (2)  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I think support services would be helpful to my child (3)  | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| Obtaining support services for my child is a priority for me (4)   | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I prioritize leisure activities (e.g. recreation, time with friends, etc) more highly than support services for my child (5) | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |
| I prioritize responsibilities (e.g. schoolwork, chores, etc) more highly than support services for my child (6)              | <input type="radio"/>    | <input type="radio"/> | <input type="radio"/>                | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I worry that accessing support services may be stigmatizing for my child (e.g., people will think it is weird/strange) (7) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are skills based (e.g. teaching coping/teaching skills) for my child (8)                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I prefer activities that are support-based (e.g. sharing experiences with others) for my child (9)                         | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think my child would be interested in accessing support services (10)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think my child would be interested in accessing support services with other children (11)                                | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I think my child would be interested in accessing support services that are more individual (12)                           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|   |                       |                       |                       |                       |                       |
|---|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| I can find time to transport my child to support services (13)                        | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My child is able to participate in support services during the weekdays (14)          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My child is able to participate in support services during the weekend (15)           | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My child is able to participate in support services that meet in person (16)          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| My child is able to participate in support services that meet online (17)             | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I have the finances for my child to participate in support services (18)              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| I can arrange childcare in order for my child to participate in support services (19) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

Part IV: We have tried to anticipate many of the reasons why families would/would not seek support services for themselves. Please tell us if there are any other reasons that you or your typically developing child/children may/may not participate:

## Appendix C

### Inventory of Socially Supportive Behaviors (ISSB)

We are interested in learning about some of the ways that you feel people have helped you or tried to make life more pleasant for you over the past four weeks. Below you will find a list of activities that other people might have done for you, to you, or with you in recent weeks. Please read each item carefully and indicate how often these activities happened to you during the past four weeks.

During the past four weeks, how often did other people do these activities for you, to you, or with you:

|   | Not at all (1)        | Once or twice (2)     | About once a week (3) | Several times a week (4) | About every day (5)   |
|---|-----------------------|-----------------------|-----------------------|--------------------------|-----------------------|
| Looked after a family member when you were away (1)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Was right there with you (physically) in a stressful situation (2)                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Provided you with a place where you could get away for a while (3)                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Watched after your possessions, when you were away (pets, plants, home, apartment, etc) (4) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Told you what she/he did in a situation that was similar to yours (5)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Did some activity with you to help you get your mind off of things (6)                      | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Talked with you about some interests of yours (7)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |
| Let you know that you did something well (8)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/>    | <input type="radio"/> |



| Went with you to someone who could take action (9)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Told you that you are OK just the way you are (10)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Told you that she/he would keep things that you talk about private- just between the two of you (11) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Assisted you in setting a goal for yourself (12)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Made it clear what was expected of you (13)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Expressed esteem or respect for a competency or personal quality of yours (14)                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Gave you some information on how to do something (15)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Suggested some action that you should take (16)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Gave you over \$25 (17)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Comforted you by showing you some physical affection (18)                              | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Gave you some information to help you understand a situation you were in (19)          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provided you with some transportation (20)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Checked back with you to see if you followed the advice you were given (21)            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Gave you under \$25 (22)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Helped you understand why you didn't do something well (23)                            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Listened to you talk about your private feelings (24)                                  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Loaned or gave you something (a physical object other than money) that you needed (25) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Agreed that what you wanted to do was right (26)                                       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Said things that made your situation clearer and easier to understand (27) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Told you how he/she felt in a situation that was similar to yours (28)     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Let you know that he/she will always be around if you need assistance (29) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Expressed interest and concern in your well-being (30)                     | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Told you that she/he feels very close to you (31)                          | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Told you who you should see for assistance (32)                            | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Told you what to expect in a situation that was about to happen (33)       | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Loaned you over \$25 (34)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Taught you how to do something (35)  | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

|  |                       |                       |                       |                       |                       |
|--|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Gave you feedback on how you were doing without saying it was good or bad (36) | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Joked and kidded to try to cheer you up (37)                                   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Provided you with a place to stay (38)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Pitched in to help you do something that needed to get done (39)               | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Loaned you under \$25 (40)   | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |