
THESIS

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Abstract

The purpose of the study is to explore parents’ future plans for their children with Autism Spectrum Disorders (ASD) in the areas of self-assessed parental emotional status, children’s independent living, and the families’ (including the parents and the children) social service needs. In this study, comparisons will be made between Asian Immigrant parents and American-Born parents in the dimensions of: 1) parents’ current future plans for their children with ASD; 2) parent’s expectations on available social services; and 3) parent’s self-assessment of their issue-handling capabilities to plan for their children’s future.

This is an exploratory study, which utilizes a self-designed questionnaire for data collection. The questionnaire consists of both close-ended and open-ended questions. The primary questions addressed are the statuses of the parents’ current plans for their children’s future, self-assessed parental emotional status, and issue-handling capabilities in terms of the planning process, parents’ expectations on their children with ASD, and parents’ expectations on services and supports. This study employs a non-probability sampling method, or in other words a convenient sampling design.

Quantitative analyses done on the results reveal that: 1) parents have high expectations on their children with ASD; 2) parents show high levels of worrying and stress regarding the future plans of their children with ASD; 3) parents expect the availability of services
that help them with future planning for their children with ASD, however there is a lack of such services as well as relevant peer support - in addition, parents are dissatisfied with the current services that they receive; 4) while gender and race do not influence the self-assessed parental emotional status, the parents’ ages are significantly related to their satisfactions of their relationships with their children with ASD; 5) the parents’ education levels influences their stress levels as well as their expectations on their children’s potential friendships in the future; 6) the parent’s levels of satisfaction with the services that they currently receive influence their confidence regarding of their abilities to plan for a successful future for their children; and lastly, 7) Asian immigrant parents show themselves as having lower issue-handling capabilities than American-born parents.

The following recommendations in response to the findings of this study:

1. It is important to build networks and social support systems for parents of children with ASD, which can help the parents with coping with issues related to their children’s disabilities.

2. Asian immigrant parents of children with ASD need more attention and assistance regarding difficulties related to cultural adaptation.

3. Effective programs and social policies are tremendously helpful for parents with planning for their children’s future.

4. Studies to fully address Asian immigrant parents of children with ASD regarding emotional status, social and service needs, services receiving status, and difficulties when planning for the children’s future are extremely needed.
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Fields of Study

Major Field: Social Work
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Chapter 1: Introduction

Background

Childbirth signifies a new life stage and brings about enormous changes for a family. Parents participate in their children’s lives in a plethora of areas such as family relationship, education, social interaction, life transitions, employment, and so on. Raising a typically functioning child is already a challenge for ordinary families; let alone families with children with autism spectrum disorders (ASD). From the onset of their children’s ASD diagnosis, parents experience great shock, grief, and will most likely sacrifice their time in assuming other social and family roles, such as parents of another child, spouses, and employees (Orsmond, Lin, & Seltzer, 2007).

Parents of children with ASD need to be strong enough to manage the complicated issues in both theirs and their children’s lives, as well as to cope with the negative emotions occurring from the onset of the children’s diagnoses (Seltzer & Krauss, 1989). Surveys indicate that families with a child with ASD encounter more stresses and have a higher risk of mental health problems among family members compared with families without a child with ASD (Abbeduto, Seltzer, Shattuk, Krauss, Ormond, & Murphy, 2004). The resilience of a family of a child with ASD is believed to be lower than that of a general family by many studies (Greeff & Walt, 2010). Furthermore, a study shows that family strengths and
adaptabilities are unrelated to exterior factors such as family income, education level, and the degree of children’s disability; instead, those factors appear to be impacted by internal factors such as family structure, family functioning, family skills and family support (Trute & Hauch, 1988).

Parents with children with ASD usually exhibit higher levels of depressive symptoms and anxiety, and such families are characterized by lower adaptability and cohesion when compared with families without children with ASD. Disabled children are life-long burdens for families, which emphasizes the need for early life planning and socialization. Coping skills and problem-solving strategies have been found to be important factors for successful family adaptation (Orsmond, Lin, & Seltzer, 2007).

The increasing prevalence of ASD diagnoses has been attracting great attention from researchers. According to the 2012 Community Report from the Autism and Developmental Disabilities Monitoring (ADDM) Network, the overall number of ASD diagnoses among children in the United States have been steadily increasing: from 1 in 150 in 2007, 1 in 110 in 2008, to 1 in 88 in 2009 (according to the Centers for Disease Control and Prevention); in terms of gender differences, it was found that there is 1 ASD diagnosis per every 54 boys, and 1 in every 252 girls; in terms of different race/ethnicity, there are 12 ASD diagnoses per 1,000 individuals in White, non-Hispanic population, 10.2 per 1,000 individuals in Black and non-Hispanic population, 7.9 individuals per 1,000 in Hispanic population, and 9.7 individuals per 1,000 in Asian / Pacific Islander population - reports show that ASD occur among all racial, ethnic, and socioeconomic groups (National Center on Birth Defects and
Developmental Disabilities & Division of Birth Defects and Developmental Disabilities, 2012). The 2012 ADDM fact sheet reports that care for children with ASD can be costly: “medical costs for children with ASD are estimated to be six times higher than for children without ASD … In addition to medical costs, intensive behavioral interventions for children with ASD can cost $40,000 to $60,000 per child per year”.

Parents cannot realistically take care of their children with ASD for their whole lives; however, a study conducted in the 90’s found that those parents would still prefer to keep their children at home instead of having them be institutionalized (Griffiths & Unger, 1994). Compared with counterparts, parents of children with ASD have greater needs to plan for their children’s future and to help them become as independent as possible. Research also shows that parents with disabled children feel more stressful than parents with typically functioning children (Gupta & Singhal, 2005). A 1997 study shows that less than 50% parents of had a residential plan for their disabled children with mental retardation; in the 3-year follow-up survey, it was found that families who had a future plan in place 3 year ago for their disabled children were 1.6 times more likely than families without a future plan to have obtained their shot-term goals (Freedman, Krauss, & Seltzer, 1997).

A 2000 study reveals that many parents lack knowledge of available services for their children with ASD and underutilize them (Smith, Hatfield, & Miller, 2000). Parents expect a long-term support system, rather than relying only on day-to-day care (Lefley, 1987), that can help their children in the future when they grow older. However, there are few studies that explore the comprehensive aspect and general status of parents’ plan for their children
with ASD. Furthermore, most of the studies mentioned above focused on Caucasian population in western countries rather than populations of other ethnicities. In other words, researchers have not examined the differences in how parents of different ethnicities in the United States plan for their children with ASD.

According to data from United States Census Bureau issued in 2012, the Asian alone population in the United State constitutes 4.8% of the U.S. population (Hoeffel, Rastogi, Kim, & Shahid, 2012). This writer argues that issues specific to the Asian population in the United States deserve attention from researcher – for example, immigrant Asian parents of children with ASD may face more challenges than local American parents because of the cultural differences and barriers to access available services that they experience (Guendelman, Schauffler, & Samuels, 2002). In addition, Asian individuals is family oriented and consider family as their support system, so they prefer not to talk with other people about their situations (Sands, 2001), which may increase their risk of developing mental health problems.

In summary, although increasing interests are shown in parents across cultures to develop future plans for their children with ASD, policy makers and caregivers still lack data and therefore struggle to formulate and deliver effective options to help parents with children with life-long disabilities, which have been major issues for some time (Smith, Hatfield, & Miller, 2000).
**Purpose of the Study**

The purpose of the study was to explore the future plans of parents for their children with ASD in areas such as their children’s independent living and social service needs, and as well as to investigate the parents’ self-assessed emotional status related to the plans. In this study, comparisons were made between Asian Immigrant parents and American-Born parents with children with ASD in the dimensions of: (1) parents’ expectations of their children’s futures; (2) parents’ current plans for their children; (3) parents’ expectations of social services available to their children and themselves; and (4) parent’s self-assessed of their emotional status and issue-handling capability to plan for their children’s future.

**Conceptual Framework**

The conceptual framework for this study is based on the resilience theory from the strength-based perspective. The framework informs the study in the flowing measures: family resilience, parents’ emotional status, parents’ issue-handling capability, and parents’ future plans for their children with ASD, as well as development of children with ASD. According to previous findings, family resilience is significant influenced by the availability of social services, family interactions, family support, and social interaction support. In this framework, parents’ emotional status and parents’ issue-handling capability are core factors for their children’s development and the parents’ future plans. Furthermore, family resilience serves as an important factor that influences parents’ emotional status and issue-handling capability, and therefore is a fundamental factor of healthy family dynamics. Figure 1.1 briefly illustrates the framework of the study.
Figure 1.1: Conceptual framework
General Research Questions

The general questions addressed in this study were:

1. For parents of children with ASD, what are their expectations for their children?

2. What are the parents’ current plans for their children, and what are some of the difficulties during the planning process?

3. What are the parents' expectations of available social services, and what are their current statuses of receiving services?

4. Are there any differences between Asian Immigrant and American-Born parents with children with ASD in the above areas?

Thesis Format

This thesis is organized as follows: chapter I provides a brief introduction which covers background information for the study from literary, the importance of this study, the framework used in this study, and general research questions; chapter II contains a review of relevant literature and prevalent model in the study area; chapter III discusses the methods employed in this study, including research design, sample methods, variables, and data analysis; chapter IV presents the results and descriptions for them; lastly, chapter V provides conclusions drawn from the results and their implications.
Chapter 2: Review of Relevant Literature

Introduction

This chapter contains a critical examination of previous literature associated with Autism Spectrum Disorder (ASD). The topics receiving the most attention in this area include theories and models, children’s development and treatment, parenting strategies, sibling support, family resilience, ASD-related needs and services, future plan for children with ASD, and so on. Firstly, the current perspectives on ASD, with the strength-based view based on the family resilience model being the most popular, will be briefly discussed. Secondly, the family resilience model will be described, and methods to improve family resilience will be explored. Thirdly, family needs and existing social services related to ASD are examined in both parents’ perspective and the caregivers’ perspective. Fourthly, Asian parents’ parental style and characteristics will be presented for a general review. Lastly, because of the limited amount of existing study on the long-term outlook of children with ASD, parents’ future plan for their children with mental illness and developmental disabilities will be discussed. Lastly, a brief summary of the above discussions will be given.

Perspective on the ASD

It is believed that parents’ parenting styles influence their children’s development and future personality; the belief stands true for children with ASD as well. Being healthy and resilient appears to be more important for families with children of ASD in promoting the healthy development of their children. Researchers have found that “parental distress and family functioning impact children in numerous ways, affecting their cognitive, behavioral and social development” in both families with typically functioning children and families
with disabled children (Gupta & Singhal, 2005). Gupta & Singhal (2005) addresses the importance of psychosocial support services for parents and siblings of children with autism. Gupta & Singhal (2005) points out that the lack of effective coping resources and related services for families with children with ASD needs to be solved – having the families collaborate with the professionals during the development of children with autism is a powerful way to provide effective intervention.

Studies so far have found that while there is no cure for ASD, people with ASD can nevertheless live a successful life with necessary and appropriate support (Carr & Pratt, Positive Behavioral Supports: Creating Meaningful Life Options for People With ASD, 2007). One approach that has been found to be effective in enhancing the quality of life of people with ASD is positive behavioral support (PBS). PBS emphasizes the importance of individuals living with ASD pursuing a quality, creative and meaningful life based on their own life purposes in a supportive social environment (Carr & Pratt, 2007; Carr, 2007).

Children with ASD face various barriers to success, such as “problem behavior, skill deficits, and dysfunctional systems” (Carr, 2007). Parents with ASD may be inclined to think that their children’s ASD diagnoses signify perpetual caregiving due to a lack of hopeful future for them. However, several studies indicate that professional efforts to create PSB systems / services and to solve barriers to success may restore a sense hope in parents and siblings of children with ASD: for example, Carr & Pratt (2007) concludes that children with ASD can, with help from parents and professionals, choose a job to work, choose a place to live, and choose a life goal to fulfill. Carr (2007) suggests that such outcomes can be obtained by: “(a) developing and implementing family-centered, home-based positive behavioral support services; (b) expanding the analysis and intervention to focus on family routines, and (c) teaching professionals to build collaborative partnerships”.

Theories on working with children with ASD and their families have changed from the
deficit-based model to the strengths-based model throughout the years. For example, McCubbin et al. (1996) developed the “Resiliency Model of Family Stress, Adjustment and Adaptation”, which has been used by many studies as a conceptual framework and facilitated the switch to the strengths-based model in the study of ASD (Luther, Canham, & Cureton, 2005; Greeff & Walt, 2010).

Luther et al. (2005) builds on Maccubbin et al.’s family resilience theory (1996) and proposes a two-phase model of coping, which includes the adjustment phase and adaptation phase. The study suggested that the protective factors for at-risk families include: 1) self-efficacy and self-esteem at the personal level; 2) communication among family members, problem solving, and support from extended family at the family level; and 3) the family’s social network for informal support, religious and cultural associations, as well as formal support such as health professionals at the community level. The researchers administered two instruments, the Social Support Index and the Family Crisis Oriented personal Evaluation Scales, to 18 participants in order to examine the factors, as perceived by parents’ with children living with ASD, to have assisted the families with their coping process - results shows that acquiring social support and reframing are the most used coping strategies. Reframing helps the family to view their experiences in perspectives that are more positive. Viewing their children’s diagnoses and capabilities as well as life stresses positively helps families cope effectively and with more success. Furthermore, the results of this study also indicate that participating in parental support groups and informal / formal social networks, which provide not only information but also support, is also a powerful coping strategy. Unfortunately, like most other studies on ASD, this study suffers from the significant statistical limitation of its small sample size.

In summary, studies about ASD have been gradually adopting a strength-based perspective, and researchers have started to think about service design and delivery in terms
of factors such as family routine, individual developmental status, and community systems.

**Family Resilience**

“Family resiliency is the family’s ability to cultivate strengths to positively meet the challenges of life” (McGee, 2012). Family resilience has been defined differently by different groups of people which cause some confusion among researchers. Family resilience can be seen as the resilience when family dealing with difficulties and challenges which also means how well the family can cope with difficulties in their life and remain healthy (PattersonReviewed, 2002). When talking about family resilience, researchers show emphasizes on family strength and mental health among family members (PattersonReviewed, 2002). When facing stress, challenge, and crisis, families who have high family resilience will maintain their family structure as healthy as possible and recover from the changes quickly. Building family resilience is important for every family especially for families with children with special needs. Helping family with children with ASD build family resilience will decrease the negative influence on family members because of the ASD diagnosis. There are many researchers using family resilience theory into their studies about family with children with ASD.

Trute & Hauch’s 1988 study is based on the theory that family resilience can be observed in families who have successfully coped with and adjusted to difficulty issues related to their children with developmental disabilities. Potential sample families were obtained from a child development center and screened by both social workers and pediatricians with 3 criteria: 1) good family adjustment; 2) well-functioning children, and 3) successful child development. The final sample size was 36 families, both parents / caretakers of which participated in a 2-hour home interview: five measurement instruments were used to examine the family system, family functioning, self-esteem, depression, children’s developmental...
capabilities, and satisfaction of family support. Results indicate that mothers with disabled children from families that have higher levels of resilience are more likely to have normal depression and self-esteem levels. Family strengths was found to be related to ideal family structure and functioning, such as a core family with both parents and a fewer number of kids, as well as healthy parent subsystem, possession of adequate friendship system, as well as effective parenting. However, family resilience was not found to be directly related to children’s disability level, family income, parents’ employment status, easiness to be soothed, and the number of children the family has. Trute & Hauch also speculated that parents’ possession of positive perspective on their children’s capabilities is also an indicator of the children’s future well adjustment and development.

Studies seem to disagree on the effect of having children with ASD on the longevity of marriages / partnerships: some studies conclude that families with children with ASD have higher divorce rates than general families (Hartley, Barker, Seltzer, Floyd, Greenberg, & Orsmond, 2010), while others argue that there exists no significant difference (Urbano & Hodapp, 2007). Nevertheless, marital patterns are impacted by the children’s ASD diagnoses, and adjustment efforts need to be made accordingly. A study conducted by Bristol and Gallagher (1988) explores the importance of spousal support, especially the fathers’ involvement. Thirty-one families each with a disabled male child and twenty-five families without disabled male children participated in this study. Sample measures were obtained with self-assessments as well as interviews about marital, parental, and child functioning. Results show that the mothers are more depressed and more involved in family responsibilities for their disabled children than the fathers. Furthermore, results show that fathers’ involvement and relationship with their children with ASD have a significant impact on the atypical behaviors of disabled children; however, it was also discovered that fathers are more likely to be absent and less likely to exert full responsibility for their children with...
developmental disabilities than their typically-functioning siblings. Therefore, the results of the study imply that paternal support is not only helpful in maintaining marital status, but also beneficial for the development of their disabled children.

A 2010 international study by Greeff & Walt was conducted within the framework of the Resilience Model of Stress, Adjustment and Adaptation. The investigators recruited 34 families whose children attended a school for autistic learners in South Africa. A self-report questionnaires as well as an open-ended question were used to collect data. Results reveal that family resilience is statistically positively correlated with higher socioeconomic status, decent occupation classification, well-functioning social support, open and predictable family communication pattern, supportive family environment, commitment and flexibility, family hardiness, internal and external coping strategies, positive attitude toward life, as well as family belief system. The findings are similar to those of previous studies, which imply that in order to help families with a child of ASD, professionals and practitioners need to focus on enhancing family resilience and building a supportive social environment for both children with ASD as well as their parents.

**Study on the Needs of the Caregiver and Current Services**

After researchers became certain of the protective factors for families of children with ASD, subsequent studies began to focus on assessing such individuals’ needs as well as the system that delivers the necessary services for them – a focus that has been further enhanced by the increasing prevalence of ASD diagnoses. In families of children with ASD, not only the children themselves but also their parents may require outside assistance. Assessing the needs of the entire family is therefore an important process when developing and targeting services and policies.

While most of the studies took a professional perspective when assessing the needs of
families of children with ASD, Siklos & Kerns (2006) instead assessed family needs from a family perspective. The study modified the Family Needs Questionnaire (FNQ; Waaland et al., 1993) and used it to interview fifty-six parents of children with autism. The results show that the needs presented by parents of children with autism are child-centered, including the needs for therapies and children support groups; over 93% of parents interviewed were unsatisfied with the services that they received, and reported that their important needs were unmet. The authors suggest that further studies are needed to explore the availability of resources for parents of children with ASD, as well as such parents’ knowledge of available services around them.

The advent of the strengths-based model as well as increased emphasis on self-care and self-determination for people with developmental disabilities has resulted in conflict between medical care and social support. Specifically, the widespread recognition of and advocacy for the empowerment of individuals with disabilities caused confusion among case managers and service providers in terms of how services are to be provided / delivered. A study on the perspectives of case managers and independent living counselors (CM/ILCs) was conducted by James & Shireman (2010) to explore the reasons and possible solutions for this issue. The CM/ILCs reported that while health promotion activities are essential, unlike social services they rarely have sufficient time to coordinate, design, and to follow-up. The authors concluded from the results that health maintenance and promotion of socially independent functioning are both needed. The study also suggests CM/ILCs to design their interventions so they are well received, effective, and impactful on the population as well as the society. To ensure the quality services, CM/ILCs may need extra training and/or education to maximize the effects of their programs, services, and activities.
Asian Immigrant Parental Status

As Asian population possesses a large proportion among American immigrant population, a great number of researchers studied about Asian population and their parental characteristics. Research shows that Asian immigrant children are less likely to absence at school and less likely to access to long term American health system (Yu, Huang, & Singh, 2004). “These attributes are negatively associated with health care access and utilization, suggesting the need for outreach to Asian immigrant populations to educate them on accessing the US health care system (Yu, Huang, & Singh, 2004).” This result shows the medical care situation of Asian immigrant population need to be improved. Children with ASD and their parents need additional help to access to American health system and improve the services utilization.

Asian American population as a minority population in U.S., are difficult to involve in a new culture, they need to work harder and more successful to increase their social class level and gain more resources than white people. Asian American parents have higher expectations on their children’s education attainment than whites as a study mentioned (Goyette & Xie, 1999). Culture differences and adaptation situation also influence Asian immigrants’ life quality and emotional status. In a study, the authors pointed out that “cultural marginalization is significantly related to depressive symptoms in Korean American, Chinese American, and Japanese American parents and adolescents living in the United States” (Kim, Gonzales, Stroh, & Wang, 2006). It is difficult to maintain a healthy life style and mental situation for general Asian immigrant family, let alone Asian immigrant families of children with disability. Few studies explored this area and the situation of Asian immigrant families of children with ASD extremely needed to be addressed. A study investigated 172 Asian American college students and their parents and indicates that acculturation level and perceived acculturation parent-children gap are significant influence factors for parent-children relationship (Dinh &
Nguyen, 2006). In this study, the mother-child and father-child relationships consist of four dimensions: depth, support, conflict, and satisfaction. Acculturation is a process for all Asian immigrant family to involve in the new culture. So to improve parent-child relationship, practitioners should pay attention to the acculturation process and build family resilience during this process.

**Parents’ Future Plan for Their Children with ASD**

Though there are numerous studies concerning the future of individuals with developmental disabilities, they rarely focus on future plans of the parents of such individuals, and they usually do not focus specifically on the ASD population. Also, few researchers have taken into consideration the possibility that the cultural heritages of parents, as an influence factor of caregiving style, might influence the specifics of their plans for their children with ASD.

A study done in 1994 by Griffiths & Unger focused primarily on future planning by parents and siblings of adults with mental retardation (MR); the authors noted “little was known about how families plan for the future and make decisions concerning the future care of adult-children with mental retardation”. By researching this issue, the authors hoped to help caregivers to arrange and to improve future planning. The study recruited forty-one pairs of parents and siblings to complete a questionnaire, which consists of five sections: a) demographics, b) family functioning, c) stress/distress, d) future caregiving responsibility / future planning, and e) satisfaction with future plans. Results show that only 22% parents would like the siblings to be their children’s caregivers in the future, 51% of them preferred to place their children with MR in group homes or state-operated facilities, and 15% of the parents had no plans for the future. The results seem to indicate that parents of children with MR do not want to pass on the responsibilities to their other children without MR, and that
they prefer their children with MR to have independent lives in community living centers. On the other hand, the results also indicate that most of the siblings would like to take on the responsibilities of taking care of their siblings with MR from their parents, and female siblings are more likely to be considered as a future caregiver of their siblings with MR by their parents. Furthermore, the results show that factors such as the cognitive demands of individuals with MR and family communication problems decrease the willingness of their siblings to help and to assume responsibilities for their siblings with MR. The study makes the recommendation that communication among family members about futures plans for their children/siblings with MR will help reduce the stress of caregiving and will promote the future plan themselves, and therefore validates the importance of designing services that are focused on siblings of individuals with MR to help them with handling the issues related to caregiving and future-planning for their siblings.

A longitudinal study was conducted by Freedman, Krauss, & Seltzer (1997) to investigate aging parents’ residential plans for their adult children with mental retardation; the authors mentioned that the parents experienced much emotional pain thinking about how their children will no longer be able to live in their life-long homes. The sample consisted of 461 families, and data was collected every 18 months using structured interviews and self-administered standardized assessments for a total duration of three years. The study was able to collect a total of 340 valid data sets. Results reveal that less than 50% of the parents had plans for their children with mental retardation. After analyzing the data, the authors divided the sample families into four categories: a) Short-term Planners - 21.18% of families with residential plans who preferred out-of-home placement within the next 2 years; b) Long-term Planners - 24.12% of families with plans but preferred continued home placement for the next 2 years; c) Wishful Thinkers - 16.76% of families who did not have plans but preferred out-of-home placement within the next 2 years; and d) The Status Quo - 37.94% of
families who did not have plans and preferred continued home placement for the next 2 years. In addition, those mothers who did have future plans for their adult children with MR had higher psychological wellbeing because of they were ready for future and had a sense of purpose in their lives. In conclusion, the study shows that having short-term future residential plans significantly promote placement success in the near future. The authors suggest that services targeting such population need to address the difficulties that parents encounter, and they also need to consider the various factors associated with the diverse situations in each family – in other words, such agencies and services should provide assistance with personal planning.

Another study examined specifically older mothers’ future planning for their children with serious mental illness (Smith, Hatfield, & Miller, 2000). Though it is not a study on the ASD population, the parents of either population arguably share similar needs to plan for their children’s future independent living. The study results suggest the importance of spousal (i.e. the fathers’) support for mothers of children with disabilities. Though most of the mothers who participated in the study expressed their eagerness to receive quality services that assist with future planning, only one third of them reported that they received relevant services. The study suggests the families to involve elements such as sibling involvement and family discussions are necessary; on the other hand, the study suggests services providers to work together with families and to help them with planning a separation strategy pre- and post- parental death.

A recent study focuses on siblings of adults with developmental disabilities in areas of psychosocial outcomes, relationships, and future planning (Heller & Arnold, 2010). The study results imply the importance of sibling support to the futures of individuals’ with developmental disabilities. The study also yielded results similar to those of previous studies that female siblings are more eager to take on the responsibilities of caring for their siblings.
with DD’s, and that same-gender siblings are most likely to be considered as caregivers. Furthermore, the conclusion can be made that good family relationships have positive impacts on the siblings’ eagerness to take care of their siblings with developmental disabilities.

Summary

Parents’ future plans for their children with ASD seem to be related to the parents’ own issue-handling capabilities and mental health statuses, which are influenced by factors such as family resilience and social support. Based on the strengths-based perspective, parents and caregivers of children with ASD should be encouraged to have faith in their capabilities to lead independent lives and to have meaningful futures, given that the society provides them with a supportive social environment. In addition, existing studies emphasize the importance of spousal support, sibling support, healthy family interaction patterns, and positive cognitive frames regarding this issue. Unfortunately, existing studies on the needs of parents of children with developmental disabilities show that the availability of effective services and support are still limited, and thus the important needs of such parents are unmet.
Chapter 3: Study Methodologies

Overview

A description of the design and sampling procedures of this study will be provided in this chapter, followed by the research questions and hypotheses. A summary of the data collection procedures will be detailed, and the variables as well as their operational definitions will be listed. The data analysis process will be briefly described at the end of this chapter.

Research Design

This is an exploratory study that employs a survey research design. The purpose of the study is to explore parents’ future plans for their children with ASD in the areas of self-assessed parental emotional status as well as the children’s future plans and social service needs. A questionnaire designed by the investigator, which consists of both close-ended and open-ended questions, was used to survey the participants. The primary questions addressed are the statuses of the parents’ current plans for their children’s futures, the parents’ self-assessment of their emotional status and issue-handling capabilities in the planning process, the parents’ expectations for their children with ASD, and the parents’ expectations for services and supports. Comparisons are made to examine the differences between Asian immigrant parents and American born parents in terms of the measures listed above.

The self-constructed questionnaire methodology was chosen for data collection, primarily because this is an exploratory study, and the survey addresses various areas relative to the parents’ plans for their children’s futures; the other reason was that there is no existing questionnaire that addresses for all of the research areas covered in this study. It was also decided that the questionnaire needs to be short in order to better accommodate the
participants, who are busy with both their children’s and their issues.

A quantitative approach was chosen for hypothesis testing. The investigation focuses on the following areas: 1) parents’ expectations for their children with ASD; 2) self-assessed parental emotional status, issue-handling capabilities, and satisfaction levels of their relationships; 3) services and support; 4) parents’ current plans for the futures of their children with ASD; and 5) a comparison between Asian immigrant parents and American-born parents in terms of the areas mentioned.

A qualitative approach was chosen for analyzing the responses to the open-ended questions in the questionnaire, which address the narratives of the participants on their additional opinions, difficulties that they face, their suggestions, as well as their plans. The availability of qualitative analysis in the study enables the parents to express their opinions and needs directly.

**Sampling Procedures**

The sample consists of 23 participants of both genders which include 17 (73.9%) female respondents and 6 (26.1%) male respondents who are parents of children with ASD, who receive services from both the OSU Nisonger Center and Asian American Community Services (AACS). Potential participants were not excluded by age, gender, pregnancy status, language, education, or financial status; because of the purpose of the study, the sample only consists of Asian Immigrant parents and American-born parents (of any race / ethnicity).

To be eligible for inclusion in the study, a potential participant needs to be 1) a parent with a child who has a Autism Spectrum Disorder (ASD) diagnosis, and he or she needs to be either 2) an Asian immigrant or American-born. The survey was given out via two routes of delivery – either directly or through email. Around 60 physical copies of the questionnaire were given directly by the investigator to parents who participate in parent support groups at
both the OSU Nisonger Center as well as Asian American Community Service (AACS). Participants had a choice to either finish the survey during the meetings, or they could finish the surveys at home and bring it back to the next scheduled group session – a total of 18 questionnaires that were handed out directly were completed and returned to the investigator. On the other hand, personnel from the Nisonger Center and AACS forwarded a scripted email to eligible individuals on a contact list, both provided by the investigator: 7 potential participants showed interest to participate in the study, and an electronic copy of the questionnaire was sent to them - a follow-up email was also sent to remind them to complete and email back the questionnaire. An additional five completed questionnaires were obtained through this route.

**Research Questions and Hypotheses**

The specific questions and hypotheses examined by this study are as follows:

1. **Questions:** What are the significant influencing factors for the parents’ self-assessed emotional statuses in terms of their age range, gender, education levels, marriage / partnership status?

   **Hypothesis:** Older parents, female parents, parents with lower education levels, and parents who are single are more likely to experience dissatisfaction, stress, but optimism when thinking about the futures of their children with ASD.

2. **Questions:** What are the significant influencing factors for the parents’ perceived futures of their children with ASD in terms of their age range, gender, education levels, and marriage / partnership status?
Hypothesis: Younger parents, female parents, parents with lower education levels, and parents who are single are more likely to lack confidence when thinking about the futures of their children with ASD.

3. Questions: What are the significant influencing factors for the parents’ level of expectations of their children’s future in terms of their age range, gender, education levels, and marriage / partnership status?

Hypothesis: Younger parents, female parents, and parents with higher education levels are more likely to hold higher expectations for their children with ASD.

4. Questions: What are the significant influencing factors for the number of services that the parents receive as well as their satisfaction of such services in terms of the parents’ age range, gender, education levels, and marriage / partnership status?

Hypothesis: Younger parents with lower education levels are more likely to receive fewer services. Older parents with higher education levels are more likely to have lower satisfaction levels of existing services.

5. Questions: What are the significant influencing factors for the statuses of the parents’ future plans for their children in terms of their gender, education levels, and marriage / partnership status?

Hypothesis: Female parents start thinking about their children’s future earlier and
more often than their male counterparts. Parents who are married and have higher education levels are more likely to feel confident to make successful plans for their children’s future.

6. Questions: Do the parents’ levels of expectations for their children with ASD influence the levels of their self-report stress, optimism, and issue-handling capability?

Hypothesis: Parents who have higher expectations for their children with ASD are more likely to have higher levels of self-report stress and optimism, but lower levels of self-report issue-handling capability when in terms of handling their future plans for their children.

7. Questions: Are the parents’ levels of confidence in terms of planning for their children’s future influenced by 1) their levels of expectations for their children with ASD, 2) their statuses of receiving services, and 3) their satisfactions for the services that they receive?

Hypothesis: Parents who have higher expectations for their children with ASD, who have higher levels of services receiving statuses, and who have higher satisfactions for the services that they receive are more likely to have higher levels of confidence in terms of planning for their children’s future.

8. Questions: Are there differences in the levels of expectations for their children with ASD between Asian immigrant parents and American-born parents?
Hypothesis: Asian parents are more likely to have higher expectations for their children with ASD in all the four areas of expectation: education attainment, employment, friendship and intimate relationship.

9. Questions: Are there differences in the levels of stress, optimistic emotions, and issue-handling capabilities between Asian immigrant parents and American-born parents in terms of thinking about planning for the future of their children with ASD?

Hypothesis: Immigrant experiences of Asian parents are likely to influence their self-assessed emotional statuses and issue-handling capabilities in terms of planning for their children’s future.

10. Questions: Are there differences in the statuses of the parents’ current future plans for their children with ASD between Asian immigrant parents and American-born parents?

Hypothesis: Asian immigrant parents are more likely to start planning for their children’s future earlier than American-born parents.

11. Questions: Are there differences in the parents’ levels of service receiving and satisfaction of services in terms of future planning for their children with ASD between Asian immigrant parents and American-born parents?

Hypothesis: Asian immigrant parents are more likely to self-report receiving fewer
services and having higher dissatisfactions with such services.

**Methods of Data Collection**

This study employs a non-probability sampling method – in other words, a convenience sampling design. Because of the limited availability of Asian Immigrant families with children with ASD to the investigator, it was challenging to form groups of equal sizes with each of the targeted populations. The instrument used in this study is a demographic survey designed by the investigator, which was distributed to participants, who completed them independently. The investigator consulted an existing survey designed by Benjamin M. Ogles & Southern Consortium for Children, “Ohio Mental Health Consumer Outcomes System - Ohio Youth Problem, Function, and Satisfaction Scale”, and some questions were adapted to be used in this study with the original authors’ express agreement. A written script which briefly introduces the research and survey process was written by the investigator, which was either given to parents during a parent support group session by the investigator or via email by personnel at both the OSU Nisonger Center and AACS. Parents who showed interests in participating in the study were each given a consent form, along with the survey questionnaire. The parents completed the survey independently, either during a support group session and handed back to the investigator at the end of the session, or at home and returned via email within four weeks after it was originally sent.

**Variables**

A. **Independent Variable**

B. **Dependent Variables**
   1. Parent’s expectations for his/her child’s future regarding:
a) Educational attainment

b) Employment

c) Intimate relationships

d) Friendships

2. Parent’s levels of satisfaction of
   a) Relationship between the parent and their child with ASD
   b) Relationship between the child with ASD and their siblings

3. Parent’s self-assessed emotional status and issue-handling capabilities in terms of:
   a) Coping with his/her child’s issues related to his/her ASD diagnosis
   b) Parent’s stress level when thinking about the future independent living plans
      of his/her child with ASD
   c) Level of optimism regarding the future of his/her child with ASD

4. Parent’s self-report about the services and supports that his/her child with ASD receives
   a) Parent’s self-report about the extent of services and supports that he/she has
      received in the past to help plan for the future of his/her child with ASD
   b) Parent’s self-report about the extent of services and supports that he/she
      currently receives to help plan for the future for his/her child with ASD
   c) Parent’s satisfaction of the services and supports that he/she receives to help
      plan for the future of his/her children with ASD
   d) Parent’s level of peer support in terms of the future plans for his/her child
      with ASD
   e) Parent’s self-report of availability of alternative sources of care for his/her
      child with ASD
5. Parent’s self-report of his/her current future plans for his/her child with ASD in terms of:
   a) How much does he/she think about his/her child’s independent living in the future
   b) The age level that his/her child with ASD was at when he/she started thinking about issues related to his/her child’s future independent living
   c) Confidence in the plan being sufficient enough to prepare for a successful future for his/her child with ASD
   d) Planned future care-taker for his/her child with ASD

**Operational Definition**

1. Parent’s expectations for the child’s future - definition based on four questions in a section in the questionnaire regarding expectations of the child’s education attainment, employment, intimate relationships, and friendships.

2. Satisfaction of relationships: parent-child relationship and child-sibling relationship - examined with two questions in the questionnaire about how satisfied the parent is with their relationship with their child with ASD, as well as how satisfied the parent is with the relationship(s) between his/her child with ASD and the child’s sibling(s).

3. Self-assessed parental emotional status - addressed by three questions: 1) about the parent’s issue-handling capability of planning for the children’s future, 2) the parent’s stress level when thinking about the child’s future, and 3) parent’s level of optimism about the child’s future.

4. Statuses of receiving services and support, and satisfaction of such services and support - addressed by the following questions: 1) the sufficiency of the levels of
services that they have received in the past and are receiving now 2) satisfaction level of the services that they currently receive that help to plan for the future of the child with ASD, and 3) accessibility of peer support.

5. Current status of plan for the future of the child with ASD - measured with four questions regarding 1) how often the parent thinks about his/her child’s independent living issues in the future, 2) the age range of parent when he/she started thinking about his/her child’s future, 3) how well the parent feels that he/she could make a successful future plan for his/her child with ASD, and 4) the parent’s current plan for his/her child’s future caretaking.

**Data Analysis**

1. Descriptive statistics of the respondents’ demographical data

2. Cross-tabulation (Chi-square) is used to analyze the effects of the parents’ demographic features (i.e. age range, gender, education level, marriage/partnership status, and children’s diagnoses) on their self-assessed emotional status, self-assessed issue-handling capability to formulate future plans for their children with ASD, their expectations of their children’s future, their statuses of receiving services status satisfaction with such services, as well as the statuses of their future plans for their children.

3. Cross-tabulation (Chi-square) was also used to examine whether or not there are differences in the following measures between Asian immigrant parents and American-born parents: 1) levels of expectations for their children with ASD, 2) levels of stress, optimistic emotions, as well as issue-handling capabilities when thinking about planning for the future for their children with ASD, 3) current future plans for their children with ASD, and 4) levels of service receiving and
satisfaction with services associated with future planning for their children with ASD. If the Chi-square test shows significant difference among variables, scores were assigned to the categories according the levels of the variable that they represent. The scores for each category are summed and divided by the total number of respondents within the category in order to obtain the averages; the averages of the categories are then compared to see the detail results.
Chapter 4: Results

Introduction

This section contains results of data analysis, which includes 1) profiles of the respondents and their children with ASD, 2) descriptive analysis of the variables, and 3) qualitative analysis of the variables.

Profiles of the Respondents

The final sample of the study consists of 23 respondents, including 7 (30.4%) Asian immigrant parents and 16 (69.6%) American born parents. 17 (73.9%) of the respondents are female, and 6 (26.1%) are male. The respondents’ average age is 51.65 years old ranging from 32 to 69 years old: 3 are in the 31-40 year-old age range, 7 of them are in the 41-50 year-old age range, 9 of them are in the 51-60 year-old age range, and 4 of them are in the 61-70 year-old age range. The average number of children in each family was 2.43 children. 16 of the respondents have a spouse / partner (See table 4.1). The respondents highest education levels are shown in Figure 4.1: 4 respondents are high school graduates, 7 have some undergraduate education, 10 have graduate degrees, and 2 did not specify (“others”); notably, all Asian immigrant respondents reported having either undergraduate education (4) or graduate degrees (3) (See Figure 4.2). Lastly, the Asian immigrant respondents reported immigration lengths from 4 to 30 years.
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<td>N=23</td>
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| Average age       | 51.65 |
|                  |       |
| **Age category**  |       |
| 31-40             | 3 (13.1%) |
| 41-50             | 7 (30.4%) |
| 51-60             | 9 (39.1%) |
| 61-70             | 4 (17.4%) |
| **Age range**     | 32-69 |
| **Gender**        |       |
| Female            | 17 (73.9%) |
| Male              | 6 (26.1%) |
| **Origin**        |       |
| Asian Immigrant   | 7 (30.4%) |
| American Born     | 16 (69.6%) |
| **Family Status** |       |
| Average Number of Children | 2.43 |
| Have Spouse/partner | 16 (69.56%) |

Table 4.1: Parents’ profiles
Figure 4.1: Parents’ highest education levels
Figure 4.2: A comparison of parents' highest education levels between two populations
The sample includes 23 children with ASD, one from each family/respondent. The average age of the children is 20.39 years old, ranging from 3 to 38 years old. 2 (8.7%) of the children are female, and 21 (91.3%) are male children. According to the parents’ reports, 12 (52.2%) of the children are diagnosed with Asperger Syndrome, 7 (30.4%) are diagnosed with Autism, and 4 (17.4%) are either diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS), or their parents did not specify on their survey responses (See table 4.2).

<table>
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<th>N=23</th>
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<tbody>
<tr>
<td>Average age</td>
<td>20.39</td>
</tr>
<tr>
<td>Age range</td>
<td>3-38</td>
</tr>
<tr>
<td>Gender</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>2 (8.7%)</td>
</tr>
<tr>
<td>Male</td>
<td>21 (91.3%)</td>
</tr>
<tr>
<td>Diagnosis</td>
<td></td>
</tr>
<tr>
<td>Asperger syndrome</td>
<td>12 (52.2%)</td>
</tr>
<tr>
<td>Autism</td>
<td>7 (30.4%)</td>
</tr>
<tr>
<td>Others</td>
<td>4 (17.4%)</td>
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</table>

Table 4.2: Profiles of children with ASD
Descriptive Analysis of the Variables

Parents’ expectation of their children’s future:

8 (34.78%) of the respondents expect their children with ASD to, in the future, attend a 4-year full time undergraduate college; 1 (4.35%) of them expect his/her child to obtain graduate degree(s); 5 (21.74%) of them expect their children to attend a community college; 3 (13.04%) of them expect their children to attend vocational school; 1 (4.35%) of them expect his/her child to receive only job training; and 5 (21.74%) of them expect their children to receive both series of job training and related studies; in other words, 60.87% of the respondents expect their children to go to a college in the future, while the rest (39.13%) of them expect their children to only receive job-related training or schooling (See Figure 4.3).

13 (56.52%) of the respondents expect their children with ASD to, in the future, have a full-time job; 6 (26.09%) of them expect their children to have a part-time job; and 4 (17.39%) of them expect their children to hold a supported job, where they receive specialized assistance with duties and responsibilities; no respondent expect their children to attend a sheltered workshop, nor do they expect their children not to work (See Figure 4.4).
Figure 4.3: Parents’ expectations of their children’s education attainment
Figure 4.4: Parents’ expectations of their children’s employment in the future
As shown in Figure 4.5, all the respondents reported having positive expectations of their children’s friendships in the future: 15 (65.2%) of them expect their children to have a group of friends in the future, 7 (30.43%) of them expect their children to have at least one friend, and 1 (4.35%) of them expect his/her child to be popular among the child’s peers, which implies that the parent expect his/her child to have excellent social interaction skills.

![Figure 4.5: Parents’ expectations of their children’s friendships in the future](image-url)
The parents appear to possess positive expectations for the intimate relationships of their children with ASD. Among all the respondents, 9 (39.13%) of them expect their children with ASD to get married in the future, 2 (8.7%) of them expect their children to engage in romantic relationships but not marriage, and while 12 (52.17%) of them reported that they will respect their children’s decisions for their own intimate relationships in the future and do not have much expectations for such (See Figure 4.6).

Figure 4.6: Parents’ expectation for their children's intimate relationships in the future
Parents’ self-assessed emotional status:

4.35% of the respondents reported having “unbearable” amounts of stress, 52.17% of them reported being “very” stressed, 17.39% of them reported having “quite a bit” of stress, 21.74% of them reported having “some” stress, and 4.35% of them reported having “a moderate amount” of stress (See Figure 4.7). A total of 57.52% of the respondents reported having either “very” much or “unbearable” amounts of stress.

Figure 4.7: Parents’ self-assessment of their levels of stress
Respondents were asked to assess how optimistic they feel when they think about their children’s futures. 13.04% of the respondents felt that their children’s futures “look very bright”, 26.09% of them thought their futures look “somewhat bright”, 39.1% of them felt their futures look “both good and bad”, 17.39% of them feel their futures “look bad”, and 4.35% of them feel their futures look “very bad” (See Figure 4.8). In total, most of the respondents reported that they feel optimistic about their children’s future, though some of them anticipate difficulties.

Figure 4.8: Level of optimism about the children’s future
In terms of their issue-handling capabilities, 30.43% of the respondents reported that they are “extremely capable” with handling issues related to ASD, 34.78% of them reported being “moderately capable” with handling such issues, 26.09% of them reported being “somewhat capable”, and only 8.7% of them reported being “moderately incapable” with handling such issues (See Figure 4.9).

Figure 4.9: Levels of issue-handling capability
Parents’ self-report of receipt of services and support:

The respondents self-reported that the amount of services related to future planning that they have previously received is, on average, insufficient: 26.09% of the respondents reported that they received no service to help planning for their children’s future, 34.78% reported they received “a little”, 17.39% reported that they received such services “somewhat”, 8.7% reported to have received “quite a bit”, 4.35% reported “moderately”, and 8.7% reported “a great deal” (See Figure 4.10). The answer “not at all”, “a little” and “somewhat” are considered as insufficient levels of service receipt, therefore a total of 78.26% of the respondents reported having received insufficient levels of services related to future planning for their children with ASD.

Figure 4.10: Amount of services Received
Self-reported levels of satisfaction with services that the respondents have received that helped with planning for their children’s future are shown in Figure 4.11. Among all the respondents, 13.04% of them reported being “extremely dissatisfied” with such services, 17.39% reported being “moderately dissatisfied”, 17.39% reported being “somewhat dissatisfied”, 34.78% reported being “somewhat satisfied”, 17.39% reported being “moderately satisfied”, and none reported being “extremely satisfied”. In total, 47.82% of the respondents reported being dissatisfied with the services related to future planning for their children that they have received.

Figure 4.11: Levels of Service Satisfaction
Figure 4.12 shows the parents’ self-reported statuses of current receipt of services related to future planning for their children with ASD. 27.27% of the participants reported that they are receiving no such service currently, 36.36% reported receiving “a little”, none reported receiving services “somewhat”, 9.09% reported receiving “quite a bit”, 22.73% reported receiving services “moderately”, and 4.55% reported receiving “a great deal” of services. In total, 63.63% of respondents reported that they are currently receiving insufficient amounts of services related to future planning for their children with ASD.

Figure 4.12: Amount of services currently receiving for future planning
In terms of the respondents’ alternative options of caregivers for their children with ASD, only 34.78% of them reported that they have people besides their spouses/partners who can help them with taking care of the children with ASD, while 65.22% of them reported that that they 1) cannot find temporary alternative caregivers, and 2) their parents and spouses/partner cannot take care of the children (See Figure 4.13).

Figure 4.13: Parent’s self-report of availability of alternative sources of care for their children with ASD
In terms of how often the respondents talk about issues related to future planning for their children with ASD with other people who also have children with special needs, 8.7% of them reported “not at all”, 26.07% of them reported “a little”, 26.09% of them reported “somewhat”, 13.04% of them reported “quite a bit”, 13.04% reported “moderately”, and 13.04% of them answered “a great deal” (See Figure 4.14). In total, the respondents reported that they are receiving insufficient amounts of peer support.

Figure 4.14: Self-report amounts of peer support
Current future caregiver plan by parents:

As Figure 4.15 shows, 15.63% of the respondent plan to let the siblings of their children with ASD to take care of them in the future, 6.25% of them prefer their relatives, 15.63% of them prefer their spouses/partners, 15.63 of them prefer help from the government as well as some agencies, 3.125% of them prefer private caregivers, 9.375% of them prefer community living centers, 15.63% of them reported having no plan, and 18.75% reported “others”, which included answer such as they don’t know what to do for now, or that they are currently considering which option is the best.
Figure 4.15: Parents’ current future caregiver plan for their children with ASD
**Hypothesis 1**: Older parents, female parents, parents with lower education levels, and parents who are single are more likely to experience dissatisfaction, stress, but optimism when thinking about the futures of their children with ASD.

**Age range as a factor:**

Table 4.3 presents the results of the respondents’ self-report levels of satisfaction with their relationships with their children with ASD. Scores were assigned to the categories according the levels of satisfaction that they represent: “Extremely Dissatisfied” is assigned a score of 0, “Moderately Dissatisfied” is assigned a score of 1, “Somewhat Dissatisfied” is assigned a score of 2, “Somewhat Satisfied” is assigned a score of 3, “Moderately Satisfied” is assigned a score of 4, and “Extremely Satisfied” is assigned a score of 5. The scores for each category are summed and divided by the total number of respondents within the category in order to obtain the averages; the averages of the categories are then compared. Results show that respondents who are in age range of 51 to 60 years old have the highest self-report satisfaction scores on average (m = 3.56) compared with respondents who are in the other age ranges (m = 2.67 for 31-40; m = 3.14 for 41-50; m = 3 for 61-70); in addition, respondents who are in the age range of 31 to 40 years old reported the lowest satisfaction scores on average (m = 2.67) (See Figure 4.16 and Table 4.4).

Chi-square analyses show that: 1) respondents’ age categories significantly influence their satisfaction levels with their relationships with their children with ASD (p = 0.045 < α = 0.05); 2) respondents’ age categories do not significantly influence their satisfaction levels of the relationships of their children with ASD with their siblings (p = 0.383 > α = 0.05); and 3) respondents’ age categories do not significantly influence the respondents’ self-reported stress levels (p = 0.145 > α = 0.05) and level of optimism about their children’s futures (p = 0.169 > α = 0.05).
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<th>61-70</th>
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<tr>
<td>Average satisfaction score</td>
<td>2.67</td>
<td>3.14</td>
<td>3.56</td>
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</tr>
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Table 4.3: Average satisfaction score on parent-child relationship for each age group

<table>
<thead>
<tr>
<th>Age Range</th>
<th>Overall (%)(N=23)</th>
<th>31-50 (%)(n=3)</th>
<th>41-50 (%)(n=7)</th>
<th>51-60 (%)(n=9)</th>
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<tbody>
<tr>
<td>Extremely satisfied</td>
<td>13.04</td>
<td></td>
<td></td>
<td></td>
<td>13.04</td>
</tr>
<tr>
<td>Moderately satisfied</td>
<td>43.48</td>
<td>4.35</td>
<td>13.04</td>
<td>17.39</td>
<td>8.70</td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td>17.39</td>
<td>13.04</td>
<td></td>
<td>4.35</td>
<td></td>
</tr>
<tr>
<td>Somewhat dissatisfied</td>
<td>8.70</td>
<td>8.70</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderately dissatisfied</td>
<td>13.04</td>
<td>4.35</td>
<td>4.35</td>
<td>4.35</td>
<td></td>
</tr>
<tr>
<td>Extremely dissatisfied</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td>4.35</td>
</tr>
</tbody>
</table>

χ²=25.362 df=15, p=0.045<0.05

Table 4.4: Chi-Square results of respondent’s age category * satisfaction with relationship with child with ASD (N=23)
Gender as a factor:

Data analysis shows the respondents’ genders have no significant influence on their self-report satisfaction levels for the relationships with their children with ($p = 0.446 < \alpha = 0.05$), satisfactions levels for the relationships between their children with ASD and their siblings ($p = 0.654 > \alpha = 0.05$), the respondents’ self-report stress levels ($p = 0.087 > \alpha = 0.05$), as well as the respondents’ self-report levels of optimism ($p = 0.955 > \alpha = 0.05$).

Respondents’ education levels as a factor:

Scores are assigned to the answer categories according the different stress levels that they represent: “A moderate amount” is assigned a score of 0, “Some” is assigned a score of
“Quite a bit” is assigned a score of 2, “Very” is assigned a score of 3, “A great deal” is assigned a score of 4, and “Unbearable amounts” is assigned a score of 5. The scores for each category are summed and divided by the total number of respondents within the category in order to obtain the averages; the averages of the categories are then compared. Results show that respondents who hold undergraduate and/or graduate school degrees have higher self-report stress scores on average than respondents who have received only high school education (See Table 4.5 and Figure 4.17).

Chi-square analyses show that: 1) the respondents’ education levels have statistically significant influence on their self-report stress levels ($p = 0.015 < \alpha = 0.05$), 2) the respondents’ education levels have no significant influence on their self-report satisfaction levels for their relationships with their children with ASD ($p = 0.777 > \alpha = 0.05$), 3) the respondents’ education levels have no significant influence on their self-report satisfaction levels for the relationships between their children with ASD and their siblings ($p = 0.333 > \alpha = 0.05$), and 4) the respondents’ education levels have no significant influence on the respondents’ self-report levels of optimism ($p = 0.88 > \alpha = 0.05$) (See Table 4.6).

<table>
<thead>
<tr>
<th>Education level</th>
<th>High school</th>
<th>Undergraduate</th>
<th>Graduate</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average stressful score</td>
<td>1.5</td>
<td>3</td>
<td>2.5</td>
<td>1</td>
</tr>
</tbody>
</table>

Table 4.5: Respondents’ average self-report stressful scores for each education level
<table>
<thead>
<tr>
<th>Stressful Level</th>
<th>Overall (%)</th>
<th>High school (%)</th>
<th>Undergraduate (%)</th>
<th>Graduate (%)</th>
<th>Others (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A moderate amount</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td>17.39</td>
<td>13.04</td>
<td></td>
<td>8.70</td>
<td></td>
</tr>
<tr>
<td>Quite a bit</td>
<td>17.39</td>
<td></td>
<td></td>
<td>8.70</td>
<td>4.35</td>
</tr>
<tr>
<td>Very</td>
<td>52.17</td>
<td>4.35</td>
<td></td>
<td>17.39</td>
<td>30.43</td>
</tr>
<tr>
<td>Unbearable amounts</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td>4.35</td>
</tr>
</tbody>
</table>

\[ \chi^2 = 24.963, df = 12, p = 0.015 < 0.05 \]

Table 4.6: Chi-Square results of respondents’ highest education levels * Stress level (N=23)

Figure 4.17: Respondents’ Stress Levels by Education Level
Marriage / Partnership status as a factor:

Chi-square analyses show that the respondents’ marriage / partnership statuses have no statistically significant influence on their: 1) self-report satisfaction levels of their relationships with their children with ASD (p = 0.668 > α = 0.05), 2) self-report satisfaction levels of the relationships between their children with ASD and their siblings (p = 0.674 > α = 0.05), 3) self-report stress levels (p = 0.889 > α = 0.05), and 4) levels of optimism (p = 0.108 > α = 0.05).

**Hypothesis 2**: Younger parents, female parents, parents with lower education levels, and parents who are single are more likely to lack confidence when thinking about the futures of their children with ASD.

Chi-square analyses show that the respondents’ age ranges, genders, education levels, and marriage / partnership statuses have no statistically significant influences on confident the respondents feel about their ability to plan successful futures for their children with ASD: age – p = 0.667 > α = 0.05; gender – p = 0.748 > α = 0.05; education level – p = 0.309 > α = 0.05; marriage / partnership status – p = 0.118 > α = 0.05 (See Table 4.7).

<table>
<thead>
<tr>
<th></th>
<th>df</th>
<th>p value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age range</td>
<td>12</td>
<td>0.667</td>
</tr>
<tr>
<td>Gender</td>
<td>4</td>
<td>0.748</td>
</tr>
<tr>
<td>Education level</td>
<td>12</td>
<td>0.309</td>
</tr>
<tr>
<td>Marriage / Partnership status</td>
<td>4</td>
<td>0.118</td>
</tr>
</tbody>
</table>

Table 4.7: factors influence parents’ confidence of planning future
**Hypothesis 3**: Younger parents, female parents, and parents with higher education levels are more likely to hold higher expectations for their children with ASD.

Scores were assigned to the answer categories according their level of expectation: “Would prefer the child have little contact with their peers” is assigned a score of 0, “Have at least one friend” is assigned a score of 1, “Have a group of friends” is assigned a score of 2, and “Are popular with their peers” is assigned a score of 3. The scores for each category are summed and divided by the total number of respondents within the category in order to obtain the averages; the averages of the categories are then compared (See Table 4.9 and Figure 4.18). Analysis shows that respondents who have received higher education (i.e. undergraduate and graduate) are more likely to have lower expectations for the future friendships of their children with ASD, whereas respondents who hold only high school degrees are more likely to have high expectations; high school: m = 2, undergraduate: m = 1.57, graduate: m = 1.6, others: m = 2.5. Factors such age range, gender, education level, spouse/partner status do not show significant influence on parents’ expectations on children’s education attainment, friendship, intimate relationship and employment in the future.

Chi-square analyses show that the respondents’ education levels have statistically significant influence on their expectations on the friendships for their children with ASD (See Table 4.8)
### Education Level Expectation Overall (N=23) High school (%) (n=4) Undergraduate (%) (n=7) Graduate (%) (n=10) Others (%) (n=2)

<table>
<thead>
<tr>
<th>Expectation</th>
<th>Overall (%)</th>
<th>High school (%)</th>
<th>Undergraduate (%)</th>
<th>Graduate (%)</th>
<th>Others (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Little contact peers</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>At least one friend</td>
<td>30.43</td>
<td>13.04</td>
<td></td>
<td>17.39</td>
<td></td>
</tr>
<tr>
<td>A group of friends</td>
<td>65.22</td>
<td>17.39</td>
<td>17.39</td>
<td>26.09</td>
<td>4.35</td>
</tr>
<tr>
<td>Popular with peers</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td>4.35</td>
</tr>
</tbody>
</table>

$\chi^2 = 13.906$  df=6,  $p=0.031<0.05$

Table 4.8: Chi-Square results of respondents’ education levels * expectations on their children’s future friendships (N=23)

<table>
<thead>
<tr>
<th>Education level</th>
<th>High school</th>
<th>Undergraduate</th>
<th>Graduate</th>
<th>Others</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average expectation score</td>
<td>2</td>
<td>1.57</td>
<td>1.6</td>
<td>2.5</td>
</tr>
</tbody>
</table>

Table 4.9: Parents average expectation score in each education level.
Hypothesis 4: Younger parents with lower education levels are more likely to receive fewer services. Older parents with higher education levels are more likely to have lower satisfaction levels of existing services.

Age range and education level appear to non-significant influence the respondents’ receipt of services related to future planning for their children with ASD, both in the past and currently, as well as their satisfaction with such services.

Hypothesis 5: Female parents start thinking about their children’s future earlier and more
often than their male counterparts. Parents who are married and have higher education levels are more likely to feel confident to make successful plans for their children’s future.

Age range, education level, and marriage / partnership status do not have statistically significant influence on the age level of the respondents’ children with ASD at which the respondents started thinking about their children’s independent living issues.

**Hypothesis 6:** Parents who have higher expectations for their children with ASD are more likely to have higher levels of self-report stress and optimism, but lower levels of self-report issue-handling capability when in terms of handling their future plans for their children.

Scores are assigned to the answer categories according levels of stress: “A moderate amount” is assigned a score of 0, “Some” is assigned a score of 1, “Quite a bit” is assigned a score of 2, “very” is assigned a score of 3, “A great deal” is assigned a score of 4, and “Unbearable amounts” is assigned a score of 5. The scores for each category are summed and divided by the total number of respondents within the category in order to obtain the averages; the averages of the categories are then compared (See Figure 4.19 and Table 4.11). It was found that respondents who reported lower expectations on the future friendships of their children with ASD are more likely to have higher levels of stress - “at least one friend”: $m = 3.28$, “a group of friends”: $m = 2.6$.

Chi-square analyses reveal that the respondents’ expectations on their children’s future friendship have statistically significant influence on their self-report stress levels ($p = 0.001 < \alpha = 0.05$), and that the respondents’ expectations on other aspects of their children like education attainment, employment, intimate friendship do not have statistically significant influence on their self-report levels of stress, optimism and issue-handling capabilities in
terms of future planning.

<table>
<thead>
<tr>
<th>Expectation on friendship</th>
<th>At least one friend</th>
<th>A group of friends</th>
<th>Popular with peers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average stressful score</td>
<td>3.28</td>
<td>2.6</td>
<td>0</td>
</tr>
</tbody>
</table>

Table 4.10: Chi-Square result of respondents’ expectations on children’s friendship in the future * respondents’ self-report stress level (N=23)

<table>
<thead>
<tr>
<th>Stressful Level</th>
<th>Expectation</th>
<th>Overall (%) (N=23)</th>
<th>Little contact (%) (n=0)</th>
<th>One friend (%) (n=7)</th>
<th>A group of friends (%) (n=15)</th>
<th>Popular with peers (%) (n=1)</th>
</tr>
</thead>
<tbody>
<tr>
<td>A moderate amount</td>
<td>Any</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Some</td>
<td></td>
<td>21.74</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Quite a bit</td>
<td></td>
<td>17.40</td>
<td>8.70</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Very</td>
<td></td>
<td>52.17</td>
<td>21.74</td>
<td>30.43</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unbearable amounts</td>
<td>Any</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

\( \chi^2=27.125 \text{ df}=8, p=0.001<0.05 \)

Table 4.11: Average stress level for each group of expectations on friendship
Figure 4.19: Respondents’ self-report stress levels by expectations on children’s friendship.

Hypothesis 7: Parents who have higher expectations for their children with ASD, who have higher levels of services receiving statuses, and who have higher satisfactions for the services that they receive are more likely to have higher levels of confidence in terms of planning for their children’s future.

Scores are assigned to the answer categories according levels of confidence: “Extremely not well” is assigned a score of 0, “Moderately not well” is assigned a score of 1, “Somewhat not well” is assigned a score of 2, “Somewhat well” is assigned a score of 3, “Moderately well” is assigned a score of 4, and “Extremely well” is assigned a score of 5. The scores for each category are summed and divided by the total number of respondents within the
category in order to obtain the averages; the averages of the categories are then compared (See Table 4.13 & Figure 4.20). Results show that respondents who reported higher satisfaction levels with services currently received are more likely to be more confident in making successful future plans for their children with ASD.

Chi-square analyses reveal that 1) respondents’ levels of satisfaction with services have statistically significant influence on their confidence in future planning for their children with ASD ($p = 0.002 < \alpha = 0.05$), and 2) the respondents’ statuses of service receipt have no statistically significant influence on their confidence in future planning for their children with ASD (See Table 4.12).
<table>
<thead>
<tr>
<th>Satisfaction</th>
<th>Confidence</th>
<th>Overall (%)</th>
<th>Extremely well (%)</th>
<th>Moderately well (%)</th>
<th>Somewhat well (%)</th>
<th>Somewhat not well (%)</th>
<th>Moderately not well (%)</th>
<th>Extremely not well (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(N=23)</td>
<td>(n=0)</td>
<td>(n=7)</td>
<td>(n=6)</td>
<td>(n=2)</td>
<td>(n=5)</td>
<td>(n=3)</td>
<td></td>
</tr>
<tr>
<td>Extremely satisfied</td>
<td>17.39</td>
<td>13.04</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderately satisfied</td>
<td>34.78</td>
<td>13.04</td>
<td>17.39</td>
<td>4.35</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat satisfied</td>
<td>17.39</td>
<td>4.35</td>
<td>13.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat dissatisfied</td>
<td>17.39</td>
<td>4.35</td>
<td>13.04</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderately dissatisfied</td>
<td>13.04</td>
<td>4.35</td>
<td>8.70</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Extremely dissatisfied</td>
<td>13.04</td>
<td>4.35</td>
<td>8.70</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

$\chi^2=36.859$ df=16, $p=0.002<0.05$

Table 4.12: Chi-Square Result of Respondents’ levels of satisfaction with services * respondents’ confidence levels in planning for their children’s future
Table 4.13: Average confidence level by satisfaction level categories

<table>
<thead>
<tr>
<th>Satisfaction level</th>
<th>Moderately satisfied</th>
<th>Somewhat satisfied</th>
<th>Somewhat not satisfied</th>
<th>Moderately dissatisfied</th>
<th>Extremely satisfied</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average confidence level</td>
<td>3.75</td>
<td>3.25</td>
<td>1.75</td>
<td>0.5</td>
<td>1.67</td>
</tr>
</tbody>
</table>

Figure 4.20: Respondents’ confidence in future planning for their children by their satisfaction levels with services
**Hypothesis 8:** Asian parents are more likely to have higher expectations for their children with ASD in all the four areas of expectation: education attainment, employment, friendship and intimate relationship.

Chi-square analyses reveal no significant differences in expectation levels between Asian immigrant parents and American-born parents for their children with ASD in areas of education attainment, employment, friendship, and intimate relationship. Additionally, analyses reveal no statistically significant differences in the respondents’ satisfaction levels of 1) relationships between the respondents’ and their children with ASD and 2) relationships between the children with ASD and their siblings between the two populations.

**Hypothesis 9:** Immigrant experiences of Asian parents are likely to influence their self-assessed emotional statuses and issue-handling capabilities in terms of planning for their children’s future.

Scores are assigned to the answer categories according to levels of issue-handling capabilities: “Extremely incapable” is assigned a score of 0, “Moderately incapable” is assigned a score of 1, “Somewhat incapable” is assigned a score of 2, “Somewhat capable” is assigned a score of 3, “Moderately capable” is assigned a score of 4, and “Extremely capable” is assigned a score of 5. The scores for each category are summed and divided by the total number of respondents within the category in order to obtain the averages; the averages of the categories are then compared (See Table 4.15 and Figure 4.21). Results reveal that American-born respondents reported higher levels of issue-handling capabilities than their Asian immigrant counterparts in terms of handing the issues related to the futures of their children with ASD – Asian Immigrant: \( m = 3.43 \), American-Born: \( m = 3.94 \).
Chi-square analyses reveal that 1) immigration status has statistically significant influence on the respondents’ self-reported levels of issue-handling capabilities \((p = 0.049 < \alpha = 0.05)\), and 2) immigrant status has no significant influence on the respondents’ self-reported stress levels and optimism levels.

<table>
<thead>
<tr>
<th>Population</th>
<th>Overall (%)</th>
<th>Asian Immigrant (%)</th>
<th>American Born (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Capability</td>
<td>(N=23)</td>
<td>(n=7)</td>
<td>(n=16)</td>
</tr>
<tr>
<td>Extremely incapable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderately incapable</td>
<td>8.70</td>
<td>4.35</td>
<td>4.35</td>
</tr>
<tr>
<td>Somewhat incapable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Somewhat capable</td>
<td>26.09</td>
<td>4.35</td>
<td>21.74</td>
</tr>
<tr>
<td>Moderately capable</td>
<td>34.78</td>
<td>21.74</td>
<td>13.04</td>
</tr>
<tr>
<td>Extremely capable</td>
<td>30.43</td>
<td></td>
<td>30.43</td>
</tr>
</tbody>
</table>

\(\chi^2=7.846 \ df=3, p=0.049<0.05\)
Table 4.14: Chi-Square result of immigration status * respondents’ self-assessed issue-handling capabilities (N=23)

<table>
<thead>
<tr>
<th>Population</th>
<th>Asian Immigrant</th>
<th>American Born</th>
</tr>
</thead>
<tbody>
<tr>
<td>Average</td>
<td></td>
<td></td>
</tr>
<tr>
<td>issue-handling</td>
<td>3.43</td>
<td>3.94</td>
</tr>
<tr>
<td>capability score</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 4.15: Average self-report rating of capabilities by immigration status
Figure 4.21: Respondents’ self-report issue-handling capabilities by immigration status
**Hypothesis 10:** Asian immigrant parents are more likely to start planning for their children’s future earlier than American-born parents.

Chi-square analysis reveals no statistically significant differences between Asian Immigrant respondents and American-born respondents in terms of 1) age of the respondents’ children with ASD at which the respondents started planning for their futures, and 2) how often the respondents’ think about future issues related to their children with ASD.

**Hypothesis 11:** Asian immigrant parents are more likely to self-report receiving fewer services and having higher dissatisfactions with such services.

Chi-square analysis reveals no statistically significant differences between Asian Immigrant respondents and American-born respondents in terms of 1) service receiving statuses in the past, 2) service receiving statuses currently, and 3) satisfaction levels with services.
Analysis of the Open-ended Questions

Three open-ended questions were asked to solicit the respondents’ opinions associated with future planning for their children with ASD. 20 out of all respondents (23) answered those questions.

The first question was, “What other issues do you think may influence your plan for your child’s future”. Respondents reported various factors that they anticipate to influence their future plans for their children with ASD, including their children’s health situations, their own health situations (among older respondents), family financial and employment issues, public context for people with special needs, their children’s attainment and development in study and work, their children’s abilities to adjust to the current future plan, and services currently received.

The second question concerned the kinds of services, programs and policies that would help the respondents with future planning for their families their children with ASD. The respondents listed various opinions such as:

1. A need for suggestions and experiences from peers and professionals about future planning
2. Early intervention in terms of independent living is helpful for their children with ASD; for example, participating in summer camps with peers, living in college dorms, as well as daily activities and skills training
3. One respondent suggested that if colleges / universities can provide enough support and encouragement for children with ASD during their college years, they will gain confidence that will potentially change their lives.
4. Some respondents also wish for the establishment of high-quality community living centers for their children’s future independent living.
5. Social interaction and friendship are also important in the respondents’ perspective:
they wish that their children with ASD can have more opportunities to meet more people and to get directions from their peers.

6. One respondent expressed that there should be opportunities for their children with ASD to meet with individuals of the opposite gender who match them in terms of functioning level for potential friendships or even romantic relationships.

7. Vocational training and opportunities are considered as important services and support in terms of the future independent living of the respondents’ children with ASD.

8. Some respondents suggested that there should be more job opportunities and supported positions for people with ASD.

9. Most of the respondents wish to attend more peer support groups and to share their experiences with other parents who are in similar situations.

10. Lastly, some respondents mentioned that having service / benefit coordinator(s) is necessary for them to manage all the issues and (human) resources associated with their children with ASD.

Few respondents answered question number 3, which was “Do you have any other suggestions, concerns, and thoughts on this topic?” Those respondents who did answer the question expressed their complaints about the services, as well as their confusion and worries about the future of their children with ASD.
Chapter 5: Conclusions and Implications

Discussions

Demographic data:

Even though the investigator expected to be able to collect more data samples from Asian immigrant parents, access to this population in Columbus is unfortunately limited to her. Also, parents of children with ASD are busy with the added issues in their lives, and some of them expressed that they are slightly tired of participating in researches. As the profile of respondents reveals, more female parents than their male counterparts participated in the study, which may indicate that female parents take more responsibilities of the issues related to their children with ASD than the male parents. Most of the respondents interviewed fall into the age range from 41 to 60 years old; individuals who are in this age range not only have to think about their careers, their parents and family issues, but at the same time, as parents who have children with ASD, they also have to start thinking their children’s future. Almost all families included in this study, with the exception of only one family, have at least two children in their household, who may assume responsibilities as caregiver for their siblings with ASD in the future. The respondents’ children with ASD are mostly male, consistent with the latest census data (National Centeron Birth Defects and Developmental Disabilities & Division of Birth Defects and Developmental Disabilities, 2012). Lastly, the respondents’ children with ASD have varying diagnoses and disabilities.

The respondents reported having high expectations on their children with ASD, which may contribute to the higher levels of stress observed among them; however, their children may not possess the necessary levels of abilities to meet their expectations. All the respondents reported that they expect their children with ASD to have jobs in the future, as
well as independent lives. Over half of the respondents reported that they wish their children would continue on to higher education after graduating from high school. As previous researches have shown, high expectations of parents on their children with ASD and their abilities serve as a positive factor for the children’s progress (Trute & Hauch, 1988). The respondent’s high expectations on their children’s friendships and intimate relationships indicate their wish for their children to develop social interactions and to have “normal” lives.

The respondents show high levels of worry and stress regarding their future plans for their children with ASD. They expect the availability of services that help them with future planning for their children with ASD, however there is a lack of such services as well as relevant peer support: over half of the respondents reported that they barely received any support for planning for their children’s futures. The worries and stresses that the respondents experience in their lives are influenced by their children’s situations as well as their own: for example, they may feel less optimistic about the future because the insufficient amounts of services that they receive, and they might not have extra time to plan for their children’s futures because they lack the capabilities to do so. Even when services are available that help the respondents to plan for the futures of their children with ASD, the respondents may find such services to be lacking and as a result be dissatisfied with them. The respondents reported that they hope for more supports and services associated with future planning for their children, and that service providers should address issues such as lack of peer support and alternative caregiver(s).

In terms of future caregiving when the respondents’ can no longer take care of their children with ASD, the respondents reported to rely more on their children’s siblings, their spouses/partners, as well as the government. Some respondents reported that they wish for their children to go to community living centers where they can live independent lives, while some others are still contemplating the options; over 34% of respondents reported not
knowing what to do at the moment with their children’s futures.

**Hypothesis:**

Results show that the respondents’ ages significantly influence their self-report satisfaction of their relationships with their children with ASD: respondents of ages 51 to 60 seem moderately satisfied with their relationships with their children with ASD, which may indicate they have already figured out how to effectively handle the relationships; respondent who are older than 60 years old, on average, experience lower levels of parent-sibling relationship satisfaction compared to those in preceding age range, which may be due to issues related to their children being in transitional ages as well as their own issues with aging; respondents in the 31-40 year-old age range may still be overwhelmed with issues at the onset of their children’s diagnoses.

The respondents’ education levels seem to influences their stress levels; specifically, those who have undergraduate or graduate degrees were found to have higher stressful levels. The respondents’ education levels also seem to impact their expectations on their children’s friendships in the future: the less educated the respondent is, the higher the expectations that the respondent would have on his/her child’s future friendships, and vice versa. Some possible reasons for the above observations may be because respondents with higher education levels are more knowledgeable and are more concerned about the future, and they may worry about more things farther into the future. The observation that respondents’ with lower education levels have higher expectations on their children’s future friendships than parents with higher education level may be because the latter respondents’ value and focus on education more than they do social interactions. On the other hand, the respondents’ expectations of their children’s future friendships appear to influence their stress levels: the lower the level of expectations, the less the amount of stress is caused; this might be because
respondents who expect less from their children with ASD are also less confident about their children’s abilities, who are likely to possess lower levels of abilities.

Higher levels of satisfaction with services appear to be related to cause higher levels confidence for planning the future in the respondents. This finding emphasizes the importance of receiving services and support for parents of children with ASD. Effective services will help parents gain self-confidence, which may reduce their stress levels, enable them to become more optimistic about the future, and increase their abilities to plan for their children’s future.

In terms of differences between Asian immigrant respondents and American-born respondents, the Asian immigrant respondents reported lower levels of self-assessed issue-handling capabilities than their American-born counterparts. Notably, the immigration experiences that the Asian immigrant respondents experience / have experienced culturally and environmentally may influence their issue-handling capabilities in terms of issues related to their children with ASD. Additionally, results show that the Asian immigrant respondents reported higher levels of stress and dissatisfaction with services than their American-born counterparts, though the differences were not found to be statistically significant. Generally, the situation that Asian immigrant individuals usually lack help and support from their families of origin may cause additional issues than it would in American-born individuals due to the cultural norm that Asian individuals are more family oriented and prefer to consider their families as part of their support system (Sands, 2001).

**Qualitative data:**

The respondents reported various factors that influence their future plans for their children with ASD, including the children’s health situations, the parents’ own health situations (among older parents), family financial and employment issues, public context for
individuals with special needs, the children’s attainment and development in study and work, the children’s abilities to adjust to their parents’ current plans for them, as well as the services received by the families / respondents / children.

The respondents also reported:

1. Their needs for suggestions and experiences from peers and professionals about future planning.
2. Their opinion that early intervention in terms of independent living is helpful for their children with ASD
3. Their wish for the establishment of high-quality community living centers for their children’s future independent living.
4. Their opinion that social interactions, friendships and opposite-gender friendships are also important for their children with ASD
5. Their opinion that vocational training and opportunities are important services and supports in terms of the future independent living of their children with ASD.
6. Their wish to attend more peer support groups and to share their experiences with other parents who are in similar situations.
7. Their opinion that having service / benefit coordinator(s) is necessary for them to manage all the issues and (human) resources associated with their children with ASD.

**Recommendations**

1. It is important to build networks and social support systems for parents with children with ASD, which can help the parents with coping with issues related to their children’s disabilities - Peer support was considered as a protective factor an essential need according to respondents, and a lack of peer support negatively impacts parents of children with ASD.
As a wish of participants, parents of children with ASD would like to attend more supportive peer support groups which could help them gain information, share experience, obtain emotional support, even get some caregiving, carpool support. Building a network in community would provide parents of ASD a relative supportive helping environment. As the survey shows, over half of the participants reported that they could not find someone else to help them take care of their children if they and their spouse need some help. In additional, many parents reported that they rarely have someone to talk about issues related to their children’s disability as friend.

2. Asian immigrant parents of children with ASD need more attention and assistance regarding difficulties related to cultural adaptation, such as accessing services, benefits, and the court system, due to the cultural differences and language barrier that they experience.

Asian immigrant parents are not as confident as American born parents when thinking about the children’s future as the result shows in this study. So they might have some difficulties to remain strong enough and gain as many resources as they could. Considering the language barrier, Asian immigrant parents are vulnerable to get information, apply services and advocate for their rights and benefits. Thus, more attention and special support should be provided to make sure Asian immigrant parents’ voice could be heard.

3. Effective programs and social policies are tremendously helpful for parents with planning for their children’s future, such as:
   1) Suggestions and experiences from peers and professionals about future planning
   2) Early intervention in terms of independent living
   3) High-quality community living centers for future independent living
   4) Social interaction and same-gender / opposite-gender friendship
5) Vocational training and (supported) job opportunities

6) Peer support groups for parents of children with ASD

7) Service / benefit coordinator(s) to help manage issues and (human) resources associated with children with ASD.

4. For future study and research, professionals and practitioners could investigate more Asian immigrant parents of children with ASD to see a general situation in this population. Studies to fully address Asian immigrant parents of children with ASD regarding emotional status, social and service needs, services receiving status, and difficulties when planning for the children’s future are extremely needed.

Conclusions

In conclusion, the study finds that: 1) parents have high expectations on their children with ASD, which may cause additional stress in their lives; 2) parents show high levels of worrying and stress regarding the future plans of their children with ASD; 3) parents expect the availability of services that help them with future planning for their children with ASD, however there is a lack of such services as well as relevant peer support - in addition, parents are dissatisfied with the current services that they receive; 4) while gender and race do not influence the emotional status of parents of children with ASD, the parents’ ages are significantly related to their satisfactions of their relationships with their children with ASD; 5) the parents’ education levels influences their stress levels as well as their expectations on their children’s potential friendships in the future; 6) the parent’s levels of satisfaction with the services that they currently receive influence their confidence regarding of their abilities to plan for a successful future for their children; and lastly, 7) Asian immigrant parents show themselves as having lower issue-handling capabilities than American-born parents.

Because of the limited time and the investigator’s limited access to the Asian immigrant
population in Columbus, the sample size was small and the study adopted a convenient sampling method, which may have compromised 1) the representativeness of the sample groups corresponding to the Asian immigrant parent population and American-born parent population, and 2) the significance of the across-group comparisons. In addition, the survey contains some wording problems, which may have confused the respondents and resulted in inaccurate feedback. For future studies on this topic, a larger sample should be sought, and the questionnaire should be more carefully designed – for example, the rating questions will employ numeric scales instead of unordered categories with ambiguous level comparisons.
References


Appendix A: Questionnaire

Parent Survey
For Children with Autism Spectrum Disorder

Instructions: Please choose one best answer that reflects your opinions for each question (except No. 13). If there is any question that makes you feel uncomfortable, you do not need to complete it.

Part I: Demographic Information
1. Participant’s Age: _____________________
2. Gender:  □ Female  □ Male
3. County of Residence: _____________________
4. Population Category: □ Asian Immigrants  Please specify your home country:_______
   □ American Born  Please specify your ethnicity:_______
5. If you are Asian Immigrants:
   How long have you been in the United States: _____Year(s) ____Month(s)?
6. What is your highest education level:
   □ High School  □ Undergraduate School  □ Graduate School  □ Others__
7. Age of the child with Autism: ________________
8. Gender of the child:  □ Female  □ Male
9. Diagnosis of the child: ___________________________
10. Education Status of the child:
    □ Preschool or younger  □ Primary School  □ High School
    □ Undergraduate School  □ Graduate School  □ Others______
11. How many children you have in your family? ___________________
12. Do you have a spouse/partner?  □ Yes  □ No
13. Do you have anyone else besides your spouse/partner who can help you take care of the child who has Autism Spectrum Disorder?  □ Yes  □ No

Part II: Survey
1. Overall, how satisfied are you about your relationship with your child who has Autism Spectrum Disorder currently?
   a) □ Extremely Satisfied
b) □ Moderately Satisfied
c) □ Somewhat Satisfied
d) □ Somewhat Dissatisfied
e) □ Moderately Dissatisfied
f) □ Extremely Dissatisfied

2. What are your expectations for your child who has Autism Spectrum Disorder in the following areas?

(1) Educational attainment
   a) □ 4-year full time undergraduate college
   b) □ Graduate education
   c) □ Community college
   d) □ Vocational school
   e) □ Job training

(2) Employment
   a) □ Full-time job
   b) □ Part-time job
   c) □ Supported
   d) □ Sheltered workshop
   e) □ Don’t want the child to work

(3) Intimate relationships
   a) □ Have romantic relationships
   b) □ Get married
   c) □ Only have romantic relationships, don’t expect to get married
   d) □ Whatever the child wants will be Ok with me.

(4) Friendship
   a) □ Have at least one friend
   b) □ Have a group of friends
   c) □ Are popular with their peers
   d) □ Would prefer the child have little contact with their peers

(5) Other areas about your expectations that you would like to share:

________________________________________________________________________
________________________________________________________________________
________________________________________________________________________

3. If the child with Autism has any siblings, to what extent are you satisfied with their sibling relationship? If the child has no sibling, please go to question 4.

a) □ Extremely Satisfied
b) □ Moderately Satisfied
c) □ Somewhat Satisfied
d) □ Somewhat Dissatisfied
e) □ Moderately Dissatisfied
4. How capable do you think you could deal with your child’s issues related to the Disorder?
   a) Extremely Capable
   b) Moderately Capable
   c) Somewhat Capable
   d) Somewhat Incapable
   e) Moderately Incapable
   f) Extremely Incapable

5. How often do you think about your child’s independent living issues?
   a) Frequently
   b) Many times
   c) Sometimes
   d) A little
   e) Rarely
   f) Almost never

6. How old was your child when you started thinking about their independent living issues?
   a) Preschool age
   b) Primary school age
   c) Teen
   d) Young adult
   e) Not yet

7. How stressful do you feel when you think about your child’s future independent living issues?
   a) Very
   b) Some
   c) Quite a bit
   d) A moderate amount
   e) A great deal
   f) Unbearable amounts

8. How well do you feel you could prepare a successful future plan for your child right now?
   a) Extremely well
   b) Moderately well
   c) Somewhat well
   d) Somewhat not well
   e) Moderately not well
   f) Extremely not well

9. Currently, how optimistic are you about your child’s future?
a) ☐ The future looks very bright
b) ☐ The future looks somewhat bright
c) ☐ The future looks OK
d) ☐ The future looks both good and bad
e) ☐ The future looks bad
f) ☐ The future looks very bad

10. To what extent did you receive services in areas related to helping parents to plan for an independent life for their child who has Autism Spectrum Disorder?
   a) ☐ A great deal
   b) ☐ Moderately
   c) ☐ Quite a bit
   d) ☐ Somewhat
   e) ☐ A little
   f) ☐ Not at all

11. How would you rate your level of satisfaction on services that prepare parents to make future plans for their child?
   a) ☐ Extremely Satisfied
   b) ☐ Moderately Satisfied
   c) ☐ Somewhat Satisfied
   d) ☐ Somewhat Dissatisfied
   e) ☐ Moderately Dissatisfied
   f) ☐ Extremely Dissatisfied

12. How often do you talk about related issues of planning for your child’s future with other people who also have a child with special needs?
   a) ☐ A great deal
   b) ☐ Moderately
   c) ☐ Quite a bit
   d) ☐ Somewhat
   e) ☐ A little
   f) ☐ Not at all

13. Currently, what is your plan for your child’s future independent living?
   (Please choose all the answers that match your plan.)
   a) ☐ Siblings will take care of this.
   b) ☐ Other relatives will take care of this.
   c) ☐ Spouse/partner of the child will take care of this.
   d) ☐ I will let the government and agencies to take care of this by using benefits and Medicaid at home.
   e) ☐ I will save money for the child and then hire a private caregiver to take care of it.
f) [ ] I will arrange my child to a community living center for people with special needs.
g) [ ] I don’t know what to do and don’t have any idea about this.
h) Others:

______________________________________________________________

14. To what extent you have received ongoing support to help you plan and support your child’s future independent living?
   a) [ ] A great deal
   b) [ ] Moderately
   c) [ ] Quite a bit
   d) [ ] Somewhat
   e) [ ] A little
   f) [ ] Not at all

15. What other issues do you think may influence your plan for your child’s future?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

16. What kind of services, programs, and policies do you think will be helpful for your family and your child in planning for their future regarding independent living?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

17. Do you have any other suggestions, concerns, and thoughts on this topic?

________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________
________________________________________________________________

THANK YOU!
Appendix B: Written script sent to participants

Written Script

Subject: Invitation to participate in a survey about Autism Spectrum Disorder

Dear Parents:

I am an intern in OSU Nisonger Center. I am also a graduate student at the OSU College of Social Work. I am writing to invite you to participate in a study that explores parents’ future plan for children with Autism Spectrum Disorder. The research is titled, How Parents Plan for the Future of Their Children with Autism Spectrum Disorder--A Comparison between Asian Immigrant population and American Born population. The study will explore parents’ expectation and future plan for their children with Autism Spectrum Disorder on independent living. The study will also explore cultural factors relating to the research topic and include participants from Asian immigrant populations and American population. Findings of the study will provide social work practitioners and general population increase understanding of the studied phenomenon that should have implications for service provision to clients with Autism Spectrum Disorders.

If you wish to participate in our study, you will complete a survey and return it back to us for analysis purpose. Your personal information will not appear on any documents during the data collection, data analysis, or dissemination process. The survey will be only used for research purpose. You have the right to terminate your participation at any time during the study. Your participation in the study will not bring any risk to you and your children. Findings of the study will potentially help you gain increase understanding of independent issues in your child as a part of your parental plan for children.
If you would like to participate in the survey, you will find the consent form and the parent survey. Please sign the consent form and complete the parent survey. After you finish it, please email or mail me back. My email address is liu.1682@osu.edu or baiziyanglc@gmail.com; my mail address is 2275 Antigua Dr., Apt 3C, Columbus, OH. 43235. If it is possible, please help me send them back in one or two weeks. Thank you very much.

Sincerely

Chang Liu

MSW-II Graduate student, OSU
Appendix C: Email script sent to personnel of agencies

Email Script

From: Investigator

Sent To: Personnel from agencies

Subject: Invitation to participate in a survey about Autism Spectrum Disorder

Dear XXX (personnel from agencies),

I am conducting a research study titled: “How Parents Plan for the Future of Their Children with Autism Spectrum Disorder--A Comparison between Asian Immigrant population and American population”. I am going to recruit clients who have a child diagnosed with Autism Spectrum Disorders. On behalf of clients’ confidentiality, could you please help me forward this email to client’s contact list to see whether they will be interested to participant in this survey? The Email script for parents is included below. Thank you very much.

Hello Dear Parents:

I am a graduate student at the OSU College of Social Work. I am writing to invite you to participate in a study that explores parents’ future plan for children with Autism Spectrum Disorder. The research is titled, How Parents Plan for the Future of Their Children with Autism Spectrum Disorder--A Comparison between Asian Immigrant population and American population. The study will explore parents’ expectation and future plan for their children who have an Autism Spectrum Disorder on independent living. The study will also explore cultural factors relating to the research topic and include participants from Asian immigrant populations and American population. Findings of the study will provide social
work practitioners and general population increase understanding of the studied phenomenon that should have implications for service provision to clients with Autism Spectrum Disorder.

If you wish to participate in our study, you will complete a survey and return it back to us for analysis purpose. Your personal information will not appear on any documents during the data collection, data analysis, or dissemination process. The survey will be only used for research purpose. You have the right to terminate your participation at any time during the study. Your participation in the study will not bring any risk to you and your children. Findings of the study will potentially help you gain increase understanding of independent issues in your child as a part of your parental plan for children. If you would like to participate in the survey, you will receive a consent form that will inform you about your rights during the study. Please sign and return the consent form to us and the questionnaire will be sent to you directly, through email or mail.

Sincerely

Chang Liu

MSW-II Graduate student, OSU