THE EXCHANGE OF SOCIAL SUPPORT VIA SOCIAL NETWORKS OF MATERNAL CAREGIVERS FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

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Dedicated to my husband, David Coates, and my parents, Scott & Karen Pritchett.

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I am sincerely grateful to my husband for his love, patience, and gentle reminders of the fun to be had out in the world, to my parents for their unwavering support and belief that I can achieve anything I set out to do, and for the unselfish love and devotion I receive every day from Sydney, Lumpy, and Sebastian. I could not have done this without you.

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ABSTRACT

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THE EXCHANGE OF SOCIAL SUPPORT VIA SOCIAL NETWORKS OF MATERNAL CAREGIVERS FOR CHILDREN WITH AUTISM SPECTRUM DISORDERS

The role of social support in the lives of the16.8 million caregivers for children with special needs in the U.S. is not adequately understood. Many studies have explored seeking health information online, but failed to consider information exchanged through social networks (i.e., family, friends, colleagues, neighbors, etc.). Caregivers of children with special needs spend on average 30 hours per week providing such care. The burden of caregiving can negatively affect caregivers physically, mentally and emotionally, socially, and financially. Social support is one potential mediator for the effects of caregiver burden. The objective of this study was to explore the flow of four dimensions of social support within the social networks of maternal caregivers for children diagnosed with an autism spectrum disorder (ASD). A convenience sample was gathered via electronic distribution lists for Indiana parents of children with special needs. Participants could elect to complete a face-to-face interview or an anonymous online survey. The typical participant was Caucasian, married, college-educated, and located in Central Indiana. Respondent social networks are composed of multiplex relations, indicating strong ties. Significant correlations were found for participant age, child age, and the age of diagnosis, and network members for various networks. Specifically, a later age of child diagnosis is associated with fewer network members for the caregiver. Correlational analyses between dimensions of social support and network characteristics suggest options for further study. Overall, the results of this exploratory study are inconclusive, but can provide direction for future research.

INTRODUCTION

Problem Statement

The most recent CDC data (Rice, 2006) suggests a national prevalence average for ASDs of 1 in 110 children, while the Child Count Data provided by the Indiana Department of Education (Pratt, 2009) estimates that 1 in 101 children in the public school system have Autism Spectrum Disorder as an educational classification. A conservative estimate based on the approximate enrollment of one million children in Indiana public schools is that 100,000 school-aged children (or 1 in 101) in Indiana are affected by an ASD (Pratt, 2009). Caregivers of these children are faced with heavy burdens of care due to the unique and often challenging social and behavioral issues associated with this spectrum of disorders. This burden can be characterized in three ways: physical, emotional, and social. According to the National Alliance for Caregiving (NAC; National Alliance for Caregiving, 2009), the caregiver burden is perhaps heaviest for mothers. However, it has an impact on the entire family, including extended family members such as grandparents (Interactive Autism Network, 2010a, 2010b). The negative impact of caregiver burden manifests in several ways – physical strain, emotional strain, depression, guilt, anxiety, and anger, among others. Almost a quarter of respondents to the NAC survey (2009) indicated that they felt caregiving had negatively impacted their health. One quarter of the 16.8 million caregivers in the United States, or 4.2 million people may be experiencing a reduced ability to care for their child(ren) as a result of caregiver burden. Within Indiana, this problem may affect as many as 25,000 caregivers and 18,000 families (i.e., one quarter of those with a school-aged child with the educational classification of ASD). There is potential for this burden and its effects to be counteracted through effective programs, services, and personal resources such as family, friends, colleagues, and neighbors.

Social support is thought to be a potential mediator in the effect of caregiver burden and stress. Sarasohn-Kahn (2008) summarizes the conclusions of the social support literature thus far in saying “A stable and supportive social network improves health outcomes for people with a wide range of conditions from heart failure to post-partum depression.” Although the specific impact of social support varies by study and population, there is strong evidence that social support is a fruitful area of study for informing the development of new intervention services and resources (Smith & Christakis, 2008).

Aim

The aim of this study is to explore the relationships between the functional (i.e., four dimensions of social support) and the structural (i.e., ties and density) characteristics of the social networks of mothers providing care for children who have been diagnosed with one of the three Autism Spectrum Disorders, with the ultimate goal of developing interventions and services that meet their particular health information needs.

BACKGROUND

This chapter summarizes the literature pertinent to the scope and aim of this study. Major concepts addressed in the research will be defined for use here and throughout this manuscript. The literature review comprises three core areas: caregiving, social support, and social networks. Information describing the population of interest, mothers providing care for a child with an ASD, is also provided for context. Finally, the research questions are specified.

Terminology

Actor: The social entity of interest in social network analysis. Actors are discrete individual, corporate, or collective social units (Wasserman & Faust, 1994). In this study, actors are individuals named by the ego, or participant.

Caregiver: The adult who is primarily responsible for the day-to-day care of a child diagnosed with an ASD.

Caregiver burden/strain: The physical, emotional, financial, and social impact of the stress of caregiving.

Density: A structural characteristic of social networks that is a measure of the relative connectedness of the network members. It is specifically the proportion of existing ties out of all possible ties (Wasserman & Faust, 1994).

Ego: The focus of egocentric analysis and typically the source (i.e., a study participant) of egocentric network data.

Multiplexity: A term used to describe the connection between two actors that are composed of more than one type of relation or exchange. For example, two individuals who provide emotional support through face-to-face and telephone interactions would be considered multiplex.

Node: The representation for a network member in a sociogram.

Relation/Relational ties: Linkages between actors that "are channels for transfer or 'flow' of resources (either materials or nonmaterial)." (Wasserman & Faust, 1994)

Social network: A social environment structure that is expressed as patterns or regularities in relationships. A social network "consists of a finite set or sets of actors and the relation or relations defined on them." (Wasserman & Faust, 1994)

Social network analysis (SNA): A set of techniques that is "based on the assumption of the importance of relationships among interacting units (Wasserman & Faust, 1994)."

Social support: A multidimensional concept that describes social contacts who provide access to "socioemotional aid, instrumental aid, and informational aid" (Agneessens, Waege, & Lievens, 2006) through qualitative exchanges.

Sociogram: "A means for depicting the interpersonal structure of groups." (Wasserman & Faust, 1994)

Autism Spectrum Disorders

ASD is a spectrum of disorders distinguished from other developmental disorders (i.e., specific developmental disorders including learning disorders, communication disorders, and disorders of motor skills) by the presence of impairments in social relating. The spectrum includes three disorders: autistic disorder (commonly referred to as autism), Asperger's Disorder, and Pervasive Developmental Disorder – Not Otherwise Specified (typically shortened to PDD-NOS). This grouping of disorders is due in part to the lack of a known cause. Some researchers believe that the autism spectrum disorders may be caused by disparate biological mechanisms as a result of environmental exposure and genetic susceptibility (El-Fishawy & State, 2010; Landrigan, 2010; Piggot, Shirinyan, Shemmassian, Vazirian, & Alarcon, 2009). The common criterion across the spectrum is the presence of substantial impairments in social relating, although behavioral issues are often present.

The prevalence of autism reported varies by agency and region. The latest data from the CDC (Rice, 2006) indicate that 1 in 110 children have an ASD. The rates are higher for boys than for girls at an approximate 4:1 ratio. In addition, some regions seem to have higher prevalence. Child Count Data provided by the Indiana Department of Education suggests that 1 in 101 children attending public school in Indiana have an educational classification of ASD (Pratt, 2009). Although the process of determining a medical diagnosis and educational classification are different, both facilitate access to relevant services in their respective systems; thus, both estimates are informative. Specifically, the educational classification figure is a strong indicator of services provided within the public school system. Based on these figures, a conservative estimate suggests that 100,000 children in Indiana are receiving services for an ASD. As some families have more than one child on the spectrum, approximately 75,000 families in Indiana with school-aged children are affected by ASD. When considering the cost of caring for these children can be as much as 2.5-20 times more than that of a typical child (Tsai & Wang, 2009), the need for effective services and resources is clearly important not only to the families but to the communities in which they live.

The complex nature of ASD and the need for multiple, simultaneous interventions to overcome developmental delay place a heavy burden on parents and families. While home-based early intervention and school-based services for children with special needs are federally and state mandated, schools and districts vary across the state in their capacity to provide such services. Furthermore, these systems are administered separately, forcing caregivers to navigate multiple complex systems such as those for public education, healthcare, insurance, waiver programs, and Medicare or Medicaid. The way in which these systems provide services is not easily understood by families new to the diagnosis, who are struggling also to deal with the familial and societal ramifications of caring for a child with a developmental disability. These challenges contribute to the heavy burden of care, which is discussed further in the next section.

Caregiving

A 2009 survey of the NAC estimates that 16.8 million adults are unpaid caregivers for a child (under 18 years of age) with special needs (National Alliance for Caregiving, 2009). Approximately half are caring for one child, while the rest are caring for two or more children with special needs. The average American caregiver is Caucasian (60% Caucasian, 17% African American, 19% Hispanic, 2% Asian American, and 1% other), female (72%), on average is 40.6 years old. 59% of caregivers are caring for a male child. Just over half (53%) of respondents were married. 53% of respondents reported they were employed, with 35% working full-time and 18% working part-time. The majority of caregivers spend an average of 30 hours per week, while 24% spend 40 hours or more providing care (National Alliance for Caregiving, 2009). Almost three-quarters (74%) of respondents indicate they are the primary caregiver, although 67% also report using paid services.

The NAC survey attempted to quantify the activities and reasons for special care. These reasons include a learning disability or educational issue (61%), emotional or mental health issue (57%), a long-term physical condition (52%), behavioral issues (45%), and developmental delay (41%) (National Alliance for Caregiving, 2009). The activities the survey identified as associated with providing care for a child with special needs include the following:

- monitoring the child's condition;
- ensuring others know how to deal with him/her;
- advocating on his/her behalf;
- performing treatments or therapies for learning, emotional, or behavioral issues;
- giving medicines or injections;
- giving physical or medical therapies;
- preparing a special diet; and
- arranging or supervising outside services.

The burden which caregiving places on the lives of these adults varies, but can be described using three dimensions: physical, emotional, financial, and social strain. The term caregiver burden is often used to describe the impact of the stress of caregiving (Phillips, Gallagher, Hunt, Der, & Carroll, 2009). 64% of survey respondents report experiencing physical strain, while 34% experience emotional strain (National Alliance for Caregiving, 2009). Six out of ten report that the responsibilities of caregiving places limits on the time they spend with other family and friends. However, the impact of caregiving on physical health remains unclear. Responses to the NAC survey (National Alliance for Caregiving, 2009) suggest that a quarter of caregivers feel caregiving has had a negative impact on their health, while 63% report that it has had no effect. Other studies have suggested that the severity of a child's disability (i.e., their level of functioning) has an adverse effect on caregiver mental health (Tadema & Vlaskamp, 2009). Specifically, problems such as behavioral issues add to caregiver stress (Tadema & Vlaskamp, 2009; citing Beresford, 1995 & Sloper, 1999). The severity of a child's disability and the nature of their condition mediates the impact on caregiver mental health (Tadema & Vlaskamp, 2009; citing Hoare et al, 1998). More severe conditions, behavioral issues, and conditions such as reflux, constipation, or organ diseases have a negative impact on parental mental health and increase their stress. Children with an ASD diagnosis, by definition, often exhibit such behavioral symptoms. Furthermore, one study estimates that 29% of children with autism are dependent on their caregivers for assistance during all waking hours of the day (Olsson & Hwang, 2003). All of this suggests that maternal caregivers for children with an ASD are at particular risk for heavy caregiver strain or burden. Some research reports that strain can reduce a caregiver's ability to provide care, which affects functioning of the family (Tsai & Wang, 2009; citing Pelchat & Lefebvre, 2004 and Perlick et al., 2007).

Male and female caregivers do not appear to share burden equally or to respond to it in the same ways. On average, women spend significantly more time providing care than men, experience greater burden (Phillips, et al., 2009), and express greater need (Ellis et al., 2002). This seems to result in greater anxiety, but not greater depression, than men. Additionally, women report seeing fewer close friends within the past four weeks (Phillips, et al., 2009). A needs assessment of families in Massachusetts reported that the greatest need of parents caring for children (aged 8-10 years) on the autism spectrum was information (47%), followed by community services (32%), and support (31%) (Ellis, et al., 2002). Results from Ellis' (2002) study indicate that child age was the best predictor of overall parental need. Needs statements used to gauge such need that were ranked highest included information about teaching strategies, behavior management, child rights, and availability of present and future services. A study using the Battelle Development Inventory detected only one significant relationship between parental stress and a dimension of child functioning – personal/social development (Bishop, Richler, Cain, & Lord, 2007; citing Smith et al., 2001). Angold et al., (1998) found that parents of children with externalizing behaviors and tic disorders reported greater caregiver burden. Although Bishop et al., (2007) examined many child characteristics for correlation with perceived burden, only the correlation with child adaptive behavior was significant. In the same study, scores on the social domain of the ADI-R (Autism Diagnostic Interview-Revised) were not correlated with burden, though the score for repetitive/restricted behaviors was significantly correlated.

The research conducted on social support suggests that it may be an important factor related to caregiver burden, but the exact relationship at this time is unclear. It appears that caregiver burden may be influenced or mediated by many variables, which Marsh, Kersel, Havill, & Sleigh, (1998) suggest can be categorized into child characteristics, parent characteristics, and environmental characteristics.

An aspect of caregiving that is of particular interest to library and information science professionals is the set of information needs associated with providing care. The Pew Research Center's Internet & American Life Project has examined the way in which Americans seek and access health information. A recent study entitled The Social Life of Health Information (2009) reports the widespread practice of seeking health information online (61% of adults, 81% of internet users reported this behavior). However, this does not negate the importance of people as sources of information. When asked about sources they would turn to for information or assistance, 86% indicate they would ask a health professional, 68% would ask a friend or family member, and 54% would turn to books or other print resources. Of those who are seeking health information online, 66% are looking for information on a specific condition. In comparison, 85% of respondents to the NAC survey (2009) indicate they need more information or help about at least one topic of caregiving. This suggests that caregivers are comparable to the general population, except perhaps for a greater need for caregiving information. Results of the NAC child caregiver survey (2009) indicate that 67% of caregivers have gone online in the past year to find caregiving information, while 81% seek information about a specific condition or treatment, 63% seek information about services, 44% want information on how to perform specific caregiving tasks, and 43% seeking doctors or other health professionals.

While the information needs and seeking of particular groups have long been studied, they are usually studied outside the context of caregiving and social support. Examining the information needs of caregivers within the context of caregiving responsibilities and burden may lend insight into the patterns of information exchange associated with caregiving and types of sources caregivers rely upon. In addition, patterns of information exchange can be compared with the exchange of other dimensions of social support. Insights into these phenomena may facilitate development of tools and resources that are more usable and easily integrated into daily caregiving practices.

Social Support

The term social support is defined in several ways in the literature, but the concept is generally consistent, if not operationally defined. Agneessens (2006) describes it as social contacts that are made up of qualitative exchanges such "socioemotional, instrumental, and informational aid." Tsai and Wang (2009) classify four dimensions: emotional, informational, instrumental, and appraisal support. Generally, researchers agree on the distinction between informational, emotional, and instrumental support. There is less agreement on other dimensions, such as appraisal support and social companionship.

The importance of social support is well documented. Several studies suggest the importance of an individual's social support network in dealing with stress, emotional and psychological well-being, physical well-being, health, and longevity (Agneessens, et al., 2006; Sarasohn-Kahn, 2008). For instance, it may serve as a buffer in stress alleviation (Lin, 2009). Sarasohn-Kahn (2008; p. 4) states, "A stable and supportive social network improves health outcomes for people with a wide range of conditions from heart failure to post-partum depression."

Social support can be characterized as coming from formal or informal sources. Formal sources include professionals and organizations such as physicians, nurses, educators, social workers, community health agencies, schools, among many others. Informal sources of social support include family, friends, colleagues, neighbors, and other acquaintances. There is some evidence to suggest that the role and effect of these sources differs, particularly in American culture (Plickert, Cote, & Wellman, 2007). Agneessens, et al., (2006) report that immediate kin are a main source of support during financial crisis. Kin are also important in times of illness and for emotional support. The same study by Agneessens, et al., (2006) suggests that friends are far less important than kin for instrumental support. A study by Plickert et al., (2007) indicates that many North Americans have different expectations for receiving social support from friends and kin, even distinguishing between immediate kin and relations that are more distant.

Despite the depth of research on social support, there have been few studies of social support in caregivers with a school-aged developmentally or intellectually disabled child. Furthermore, these studies have provided contradictory findings. Some indicate that greater parental stress is common in families of a child with an ASD (Ellis, et al., 2002), and is greater than that of parents of a child with another developmental disability (Bishop, et al., 2007). Moes & Frea (2002) proposes that five sources of stress are linked to the caregiver burden of a child with autism:

1. inconsistent pattern of cognitive development;

2. dependency needs persisting across the lifespan of the child;
3. demands of managing extreme problem behaviors;
4. limitations placed on family opportunities; and
5. financial responsibilities for present and future child-related expenses.

Results from the few studies out there suggest that parent caregivers receive more support from informal sources, such as family and friends, than from formal sources. One reason for this might be that parents with young children may still be learning their way through the formal support network. Tsai and Wang (2009) suggest that greater social support is associated with a lower level of caregiver strain. However, other significant predictors of perceived strain included health of the mother, time spent as a caregiver, and the child's degree of dependent daily activity. These factors, along with social support, accounted for 38% of the variation in perceived caregiver strain. Tsai and Wang (2009) also report results that suggest instrumental support was the most significant dimension of social support influencing mothers' perceived strain.

The multidimensional nature of social support may be illuminated by the study of its exchange through social networks. Social support in all its dimensions is a quantifiable item. Social network analysis (SNA) is particularly well suited to studying the flow of social support among the members of caregiver social networks. A few such studies have been conducted. These indicate that strong ties are more likely than weak ties to be supportive, and that close friends are an important source for sociable companionship (Plickert, et al., 2007). Lin (2009) discusses several studies confirming that social networks are related to both social support and stress reduction. Hampton and Wellman (2001), through SNA techniques, demonstrate that people use the internet to access social support. The use of SNA techniques to study the exchange of social support in caregiver networks was not discovered in the literature. The strengths and weaknesses of SNA in examining the exchange of social support will be discussed in Chapter Three. Further background information on the application of SNA is provided in the next section.

Social Network Analysis (SNA)

SNA is a set of techniques that allow researchers to analyze social structures that deal specifically with relational aspects of the structure. SNA facilitates the expression of the social environment as patterns or regularities in relationships among interacting units (Wasserman & Faust, 1994). SNA has been used to study many phenomena, such as occupational mobility, group problem solving, diffusion and adoption of innovations, corporate interlocking, social support (Wasserman & Faust, 1994), and information seeking (Pettigrew, 1997). Rather than a united theoretical framework, SNA is an advanced set of techniques with which researchers can examine the structural properties of relations. SNA began to evolve from the work of several researchers in the 1930s, finally becoming a well-developed set of techniques in the 1960s. It arises from three traditions: sociometric analysis and graph theory, interpersonal configurations and cliques, and networks – total and partial. A full consideration of the origins of SNA is beyond the scope of this manuscript. However, key features of the methods and their application relevant to the study at hand are described next.

SNA generally refers to two types of networks studies – ego-centric and socio-centric studies. These are distinguished by the availability of relational data for a network. Egocentric networks include relational data for a particular ego and the individuals in the ego's network(s). Socio-centric networks include data for all members of a defined group, or network. A requirement for socio-centric network studies is a clearly defined and bounded group. Where the boundaries of a group are less clear, an egocentric study is often more appropriate. Social networks have both structural and functional characteristics. Structural characteristics include the following: number of network members (or actors), network density, homogeneity of network members, frequency of contact, and geographic proximity (Ashida & Heaney, 2008; citing Heaney & Israel, 2002). Functional characteristics include social connectedness, social support, social influence, and social comparison (Ashida & Heaney, 2008; citing Berkman & Glass, 2000). Of these concepts, this study will focus only with the number of network members, number of ties, network density, and social support due to the loosely defined population. This is one of the methodological considerations in selecting an egocentric study, which is discussed further in Chapter Three.

Assumptions

The following assumptions were made in designing the study protocols that are described in Chapter 3.

1. Information behaviors are shaped by the burdens of being a caregiver, the social support available to them, and their particular social networks;
2. Caregivers need special support in seeking and sharing information relevant to their caregiving responsibilities;
3. In order to provide effective support, we need to understand the way their caregiving burdens shape information seeking and sharing;

4. That the social networks of mothers caregiving for a child with an ASD are shaped by the responsibilities of providing care;
5. Child characteristics such as age, diagnosis, and age of diagnosis may be related to social support and social network characteristics of the caregiver.

CHAPTER THREE: RESEARCH DESIGN

This chapter outlines the methods used to describe the demographics, social support, and social networks of mothers caring for a child diagnosed with an ASD. The purpose of the study will be set forth in several research questions. A discussion of the potential methods for addressing these questions follows. The rationale for the methods selected is presented in conjunction with an account of instrument design for both the interview and survey. Procedures for the study, including planned recruitment and data processing protocols as well as obstacles faced in both, are then detailed. Finally, a thorough rationale and description of the analyses conducted is provided, broken down into the four set of variables: demographics, technology use, social support, and social networks.

Research Questions

Consideration of the literature discussed in Chapter Two led to the development of the following research questions. The possible mediating effect of social support exchange upon caregiver burden can be effectively studied by applying social network analysis techniques used to study social support in other populations.

1. Capture and describe the basic features/characteristics of their social network structure.
2. What types of social support are embedded within these social networks?
3. What relationships exist between participant demographics and social support?

4. What relationships exist between participant demographics and the structural characteristics of the network?
5. What relationships exist between the provision of specific types of social support and the structural characteristics of the network?

Participants

The protocol for this study was reviewed and approved by the IUPUI/Clarian Institutional Review Board in July 2009. Participants represent a convenience sample of 61 mothers living in Indiana and caring for a child (or more) diagnosed with an ASD. The interview was the first option to participate offered. Individuals were recruited via two electronic distribution lists for families of children with special needs living in Indiana. Both distribution lists are actively used by its members for information seeking and sharing, advice, and emotional support. One list has an estimated membership of more than 1,000 members, while the second list is used by a parent support group consisting of more than 500 members. Due to restrictions on recruitment for non-clinic (Christian Sarkine Autism Treatment Center) studies and a lack of study resources, it was not possible for the investigator to contact patients or individuals served via outreach program via other methods.

Those indicating interest in completing the interview were invited to contact the investigator for basic study information and to provide consent. The interview was conducted at a safe public location mutually convenient for both the participant and investigator. Six potential participants contacted the investigator for further information. Due to difficulty recruiting and scheduling participants for the interview, an anonymous online survey was developed as an additional option for participation. Again, information about the two study options was distributed via two electronic distribution lists. Individuals willing to complete the online survey were able to follow the link within the advertisement to participate. Several interview participants were asked to share information about the study with other mothers, while several survey participants notified the investigator that they had voluntarily shared information about the study with other mothers.

Previous studies

An interview incorporating social network questions along with contextual data regarding the health obstacles and related information seeking strategies and resources was the initial design for this study (see Appendix A). Additional information about the family, technology access and use, and a brief assessment of health literacy were included to provide relevant demographic characteristics about the sample. Specifically, open-ended questions regarding the information seeking strategies and resources were included so that content analysis could be performed to extract common themes. Questions addressing the core areas of interest were developed by the investigator and reviewed by other researchers for readability and bias. These areas of interest included demographics, child characteristics, family characteristics, patterns of technology access and use, social network members and relations, and social support provided by social network members. Specifically, questions to elicit network members or actors (i.e., name generators) and those which capture the function of the relations (i.e., name interpreters) were developed based primarily on a study conducted by Carrasco, et al., (2006) as well as the text by Wasserman and Faust (1994).

However, the difficulty in recruiting participants willing and able to complete the 60-90 minute interview necessitated the development of a more feasible option for participation. Due to the differences in collecting data during an interview versus via an online survey, there was a substantial reduction in the quantity of data collected by the survey. This reduction consisted primarily of the elimination of open-ended questions to decrease the amount of time necessary to complete the study. Thus, a shortened and focused online survey was designed as an alternative for those unable to complete a face-to-face interview.

The online survey was designed to address the core research questions by eliminating the time required to address less vital contextual questions. It was clear after completing the interviews that the level of detail elicited regarding the social networks was not sufficient to examine the differences that may exist between those supported by various communication technologies. In addition, the interview questions did not capture the necessary between-actor information to document a complete social network. The focus of the online survey became the documentation of the caregiver's social network and the social support provided within that network. One advantage of the online survey was the ability to reduce the likelihood of interviewer error or omission in collecting network data. The social network questions were streamlined and standardized as much as possible to reduce responder burden and minimize confusion. Meaningful differences in data collection between the interview and online survey make it extremely difficult to provide comparison of the data. Relevant insights from the interview data are discussed as it informed the design of the online survey.

Procedures

Instrument Design

The most common option for studying social networks or social support is the questionnaire (Heitzmann & Kaplan, 1988; Wasserman & Faust, 1994). Other relatively common methods reported in the literature include interview, observation, diaries, and archival records. A preliminary study was conducted via interview, but observation and diaries were ruled out due to the time burden. Interest in exploring the use of multiple technologies to maintain social network relationships eliminated data collection via electronic records of specific tools or systems. Thus, a single online survey was selected to obtain the necessary level of detail without overburdening the participants.

Demographics

Common demographic questions such as age, education, and employment were included to characterize participants in relation to the population. In addition, demographic variables that the literature suggests may play a role in understanding social support (marital status, diagnosis, child age, school placement) and social networks (internet connection type, frequency of internet use, and time spent on the internet) were included.

Social support

Social support is typically measured via questionnaires, such as the Interpersonal Support Evaluation List (ISEL; Cohen & Hoberman, 1983), the Social Support Questionnaire (SSQ; Sarason, Levine, Basham, & Sarason, 1983), and the Network Social Support Interview (NSSI; Norbeck, Lindsey, & Carrieri, 1981). Although several of the available measures have reasonably good reliability and validity (Heitzmann &

Kaplan, 1988), the focus of this study is on the exchange of the various dimensions of social support, rather than the perception of or satisfaction with social support. This focus circumvents some of the difficulties common to social support research, such as varied and vague definitions that are difficult to operationalize, confusion regarding the interplay of social support and stress, and the lack of comprehensive validity data for many measures (Heitzmann & Kaplan, 1988). Thus, questions about receiving and providing social support were incorporated into the social analysis section of the interview and online survey.

These questions address the exchange of four commonly described dimensions of social support that are of interest in this study: informational, emotional, instrumental, and appraisal support. Within the interview, the informational support questions were handled separately from the three other types of social support. During the design of the online survey, the literature was consulted and a change in the presentation of social support questions was implemented. In light of the questions excluded from the online survey, specifically those regarding health-related informational needs and resources, the incorporation of information exchange as a dimension of social support seemed appropriate and consistent with the traditions of social support research. Internal consistency reliability for the five social support questions was good ($\alpha = .789$).

The four dimensions were selected for both their common use in research and the relative ease in conveying their meaning to participants in a clear and understandable way. When deemed necessary or unfamiliar, the dimensions were operationalized into commonly understood behaviors. However, emotional support was not operationalized for two reasons. First, it was judged that these terms were sufficiently familiar that participants would have prior exposure to the concept. Second, emotional support likely means different specific behaviors to different people. Advice is used as an example of appraisal support, while assistance in providing care for the child is the operational definition for instrumental support. These questions were designed to capture the exchange of support in both directions. Unfortunately, a typographical error in the phrasing of this series of questions that was not caught until after data collection had ceased limits the data to the receipt of support by the participant (see Appendix B). This data did not affect the informational support dimension data. The investigator was particularly interested in the possible asymmetry of information exchange to and from caregivers, so data was collected distinguishing between receiving and sharing informational support.

Social networks

The purpose of the online survey was three-fold: elicit the names of participants' networks members, characterize the technologies used to maintain the relationships, and characteristics the types of social support exchanged within the networks. The technologies selected represent a variety of traditional technologies (telephone) and new media technologies including those widely used by Americans (Fox & Jones, 2009; email and social networking sites) and some that are less commonly used (texting and chat).

Self-report data was selected both for ease and due to the lack of resources available for this study. However, Haythornthwaite (2005) suggests that self-report data is reliable for indicating the general state of a network or a particular relationship rather than characterizing particular instances of interaction. An ego-centered approach was selected to study this population for two reasons. First, the bounds of the population are not clearly delineated (Wasserman & Faust, 1994). Second, the investigator lacked the resources to seek out all connected members of a subgroup of the population. While this limits the depth of analyses, Garton et al., (1997) report that the egocentric approach can be well suited to the study of how people use computer-mediated communications to maintain relations. Furthermore, ego-centered analysis can demonstrate the range of connectivity for individuals and identify those with access to greater resources (Garton, et al., 1997). The relationships within the captured networks will be characterized by their content (i.e., social support) and strength (i.e., multiplexity based on technologies used to maintain the relationship). Density, one of the most common metrics in SNA, will be calculated for each network. Unfortunately, the egocentric approach does not allow us to characterize the networks using such metrics as centrality, closeness, betweenness, or structural equivalence.

Data Analysis

All data were characterized using appropriate measures of central tendency, measures of variability, and measures of shape using the PASW Statistics 18 package ("PASW Statistics 18," 2009). In general, this was done through calculating the mean and median, applying the Kolmogorov-Smirnov test of normality, creating histograms and box plots, and calculating the standard deviation, range, and variance. The specific tests conducted for each group of variables are described further in the following sections.

Group differences

The Mann-Whitney test was applied to examine the demographics between social network non-responders and responders for significant differences. Assumptions for the

Mann-Whitney are that the data are at least ordinal, the distribution is non-parametric, and the groups are independent. In order to examine the differences between two sets of results from the same participants, the Wilcoxon Signed-Rank test will be applied. The assumptions of this test are that the variable is measured at least at the interval level and that the distribution is non-normal.

Association of variables

Relationships between variables were explored through measures of association and correlation. Due to the non-normal distribution of the variables, non-parametric tests were applied. Lambda (λ) is a measure of association that can be used for any type of data as long as the variables have a small number of distinct values. Thus, lambda was applied to pairs of variables in which one of them is nominal and the second has a limited number of values. Lambda can only indicate the strength of the association, not the direction since the source data are nominal. It is a measure of the proportional reduction in error when a variable is used to predict the value of another (0 indicates no reduction in error, 1 indicates perfect prediction). Association between variables with too many values and that are not measured nominally will be detected using Kendall’s tau-b. Kendall’s tau-b should be used instead of Spearman’s coefficient in the case of a small data set with many tied ranks (Field, 2005). Correlation, or the measure of a linear relationship between variables, requires that both be at least ordinal in nature. Spearman’s correlation coefficient is the non-parametric option, but is not appropriate for these data due to the small sample size. These tests provide an indication of the associative and correlative relationships between the variables of interest. The possible relationship between network members (nodes) and network relations (ties) is potentially more direct than that of network density with demographic and social support variables, simply due to the nature of the density calculation. Thus, association and correlation analyses were conducted for all three network characteristics.

Social network analysis

Density values are calculated differently for egocentric networks than sociocentric or whole networks. Egocentric networks by definition focus on the individual responding, so density calculations will be artificially inflated if ego connections are included. Thus, the ego itself and ties between the ego and actors are excluded from density calculations.

$$\Delta = \frac{2L}{g\,(g-1)}$$

The formula for calculating density is above, where L = arcs (i.e., lines or connections), g = nodes (i.e., network members).

This chapter has reviewed the common methods used in studying social support and social networks. The design and use of the interview protocol is provided, along with reasons for changing the method of data collection. The design of an online survey as an abbreviated, alternative method for participation is also described. Finally, a summary of situations in which traditional statistical tools and structural analysis of social networks was applied to the data is outlined. The following chapter will present the results of the data collected and analyzed via the procedures described above.

CHAPTER FOUR: RESULTS

In this chapter, results are provided for two groups of participants (social network responders and non-responders) who participated in the study. The characteristics of the data, the analyses conducted, and the results are described in order to elucidate the role of social support and social networks in the life of these maternal caregivers. How these results address the research questions proposed in Chapter Three is explained. Chapter Five expounds upon these explanations to provide reasonable interpretation of the results.

Descriptive statistics, group differences, and correlational analyses are reported in this chapter with relevant tables and figures cited. Additional samples of data and analyses are available for review in Appendix C. The majority of the results reported and discussed come from participants completing the online survey. Participant demographics are reported for both social network responders and non-responders, while analyses of social support and social networks are presented only for social network responders (see Figure 1). Finally, the results are summarized to provide an overview of the relationships detected between the three sets of variables: demographics, social support, and social networks. Greater participation via the survey option offered improved statistical power of the results; thus, the modified survey was elected over fewer participants despite the potential for rich contextual information collected via face-to-face interview.

Participants

A convenience sample of 61 mothers of children diagnosed with an ASD was recruited via electronic distribution lists for families of special needs children in Indiana. Participants followed the link to the online survey or contacted the investigator to express interest in completing a face-to-face interview after being exposed to the email advertisements. The investigator had access to two regional and statewide distribution lists as an employee of the Christian Sarkine Autism Treatment Center, which provides clinical and outreach services to families of children with ASDs. The investigator distributed an advertisement describing the options for participation via these lists approximately monthly during the 8-month period spanning July 2009 through February 2010.

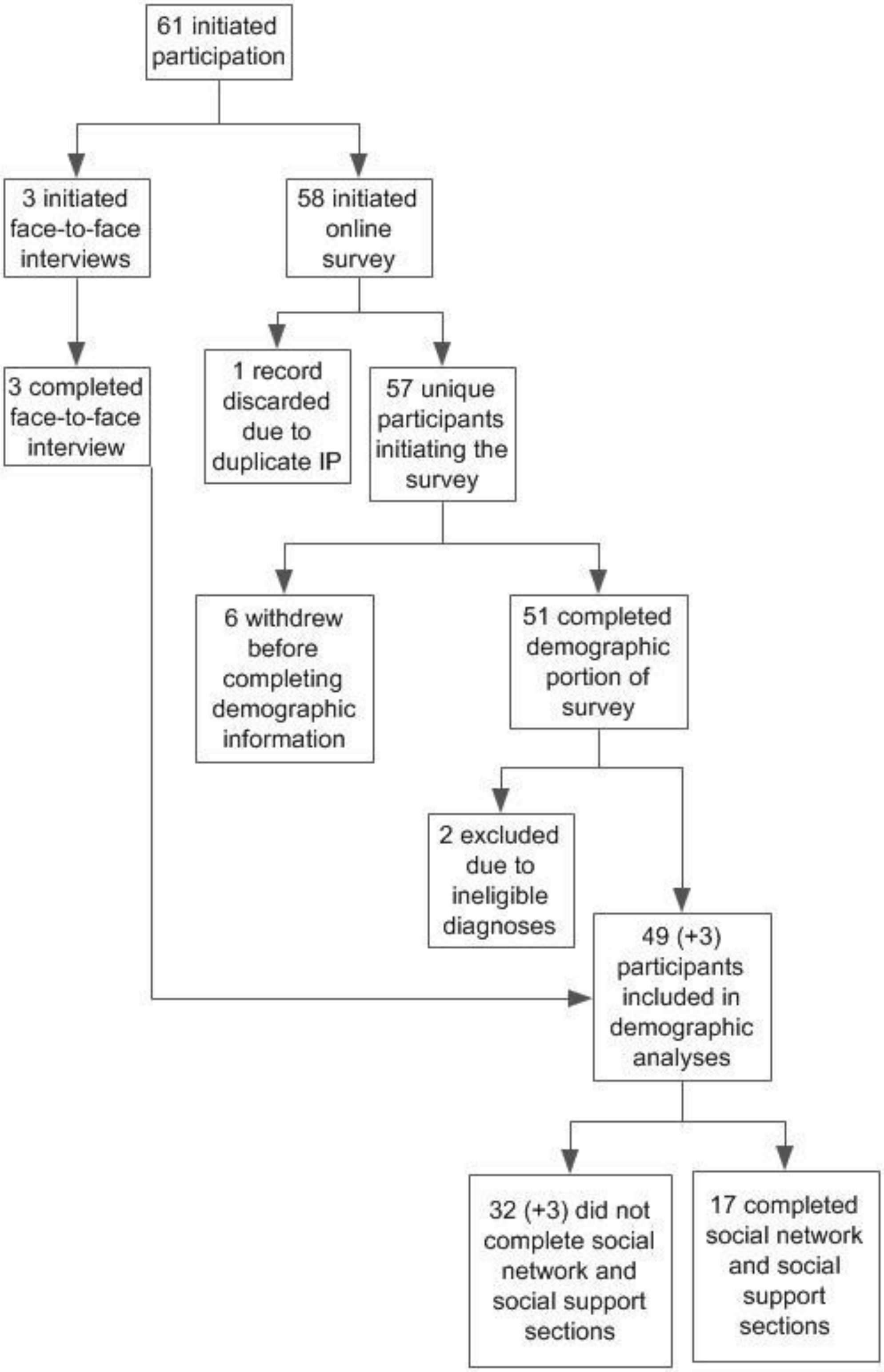

Figure 1: Participant response rate and inclusion in analyses

Results

The analyses revealed in this chapter are organized into three sections: demographics, social support, and social networks. Results for all participants (both social network responders and non-responders) are described in the demographics section, while only data from participants who completed the interview or online survey (social network responders) are discussed in the social support and social network sections.

Demographics

In all, 61 participants consented to participate, two of whom completed a face-to-face interview, one completed a phone interview, and 58 started the anonymous online survey. Of those 58 who began the online survey, 51 submitted complete or nearly complete demographic and technology information. Only 17 of the 51 with eligible diagnoses submitted complete social network data; one participant who completed social network data was eliminated due to an ineligible diagnosis. The demographic and technology results are reported for the 49 online respondents as well as the 3 who participated in the interview. However, the social support and social network results reported can describe only those who eligible participants who completed the online survey in its entirety (n = 17); these individuals are hereafter referred to as social network responders. Those who did not complete the majority of the survey are referred to as social network non-responders, including the three participants who completed the interview. Such a high rate of attrition was not expected, so the demographic responses from incomplete surveys were used to determine whether social network non-responders were different from responders. All significant differences between the groups are reported with the demographic and technology variables in the subsequent sections.

Overall, participants who provided demographic data (n = 52) were generally Caucasian, non-Hispanic, college-educated married mothers living in Central Indiana, specifically Hamilton (n=21, 41%; missing = 2) and Hendricks (n=10, 19%; missing = 2) counties. The average age of the mothers was 35-44 (see Table 1), while 92% of participants fell between the ages 25-54 years. All responding participants completed high school, with more than half completing a bachelor's degree or higher (see Table 1). More than two-thirds (71%; missing = 4) of respondents are married and the majority are employed full-time (33%) or part-time (27%), although a quarter (25%) of respondents are currently full-time mothers. There was little racial diversity (96% Caucasian) and no ethnic diversity (100% non-Hispanic) within the sample. These four variables (age, education, employment, and marital status) along with child diagnosis and two technology variables (frequency of internet use, and time spent weekly using the internet) were the used for association and correlation results reported in the social support and social network sections. Other demographic information is summarized in Table 2. The *n* for child characteristics is higher due to four mothers caring for more than one child with an ASD. Histograms and the Kolmogorov-Smirnov test were conducted to determine whether the distribution of these variables were normal. The results of the Kolmogorov-Smirnov test for all demographic variables indicate significant differences ($p < .05$) from normal distribution (see Table 3), which is supported by the histograms (see Appendix C), the distributions of all demographic variables are non-normal.

Variables (n = 54)	**Frequency (%)**	**Mean (stdev)**
Age (missing = 0)		2.23 (0.88)
18-24 (0)	0 (0%)	
25-34 (1)	11 (21%)	
35-44 (2)	22 (42%)	
45-54 (3)	15 (29%)	
55-64 (4)	4 (8%)	
Highest Level of Education Completed (missing = 0)		3.33 (1.40)
8th Grade (0)	0 (0%)	
High School (1)	10 (19%)	
Associates (2)	5 (10%)	
Vocational/Professional Certification (3)	4 (8%)	
Bachelors (4)	24 (46%)	
Masters (5)	9 (17%)	
Doctoral (6)	0 (0%)	
Marital Status (missing = 4)		1.33 (0.83)
Single (0)	2 (4%)	
Married (1)	37 (71%)	
Married, separated (2)	0 (0%)	
Divorced (3)	9 (17%)	
Widowed (4)	0 (0%)	
Prefer not to respond (5)	0 (0%)	
Current Employment Status (missing = 0)		3.02 (1.16)
Unemployed, looking (0)	2 (4%)	
Unemployed, not looking (1)	1 (2%)	
Employed, part-time (2)	14 (27%)	
Employed, full-time (3)	11 (33%)	
Full-time mother (4)	13 (25%)	
Self-employed (5)	5 (10%)	
Retired (6)	0 (0%)	

Table 1: Frequency, mean, and standard deviation (stdev) of core demographic variables

(includes both social network responders and non-responders)

Variables (n = 54)	**Frequency (%)**	**Mean**	**Median**	**Standard Deviation**
Current child age (missing = 0)	---	10.58	---	5.23
Child diagnosis (missing = 2)		---	1.00	1.51
PDD-NOS	10 (19%)			
Autistic Disorder	21 (41%)			
Asperger's Disorder	20 (38%)			
Autism Spectrum Disorder – Not Specified	3 (6%)			
Other				
Age of diagnosis (missing = 2)	---	5.63	---	4.43
School placement (missing = 7)		---	1.33	1.34
General Education	22 (43%)			
Resource Room - 80% or more of the day	4 (8%)			
Resource Room – less than 80% of the day	9 (18%)			
Self-contained	13 (25%)			
Prefer not to respond	1 (2%)			

Table 2: Frequency, mean, median, and standard deviation for child characteristics

(includes social network responders and non-responders)

Tests of Normality

	Kolmogorov-Smirnov[a]			Shapiro-Wilk		
	Statistic	df	Sig.	Statistic	df	Sig.
Participant Age	.224	45	.000	.868	45	.000
MaritalStatus	.484	45	.000	.532	45	.000
Education	.312	45	.000	.819	45	.000
Employment	.159	45	.006	.903	45	.001
Diagnosis	.279	45	.000	.790	45	.000
Child Age	.204	45	.000	.881	45	.000
DiagnosisAge	.214	45	.000	.714	45	.000
SchoolPlacement	.325	45	.000	.743	45	.000
InternetConnection	.275	45	.000	.667	45	.000
InternetFrequency	.517	45	.000	.368	45	.000
InternetTime	.252	45	.000	.811	45	.000

a. Lilliefors Significance Correction

Table 3: Results of the tests of normality for demographic variables, including both participant and child characteristics

These caregivers are frequent internet users; particularly those who are social network responders (see Table 5). A large majority of participants report daily use of the internet (83%) for at least one hour daily (96%). Most participants spend on average 1-14 hours per week on the internet. All participants are connecting via broadband connections (as defined by the FCC), 46% of who access the internet via DSL, while 40% connect through cable service.

Variables	**Frequency (%)**
InternetConnection	
Dial-up (0)	0 (0%)
DSL (1)	24 (46%)
Cable modem (2)	21 (40%)
Satellite (3)	2 (4%)
Other (5)	3 (6%)
InternetFrequency	
Daily (0)	43 (83%)
Weekly (1)	7 (13%)
Monthly (2)	2 (4%)
Less than once per month (3)	3 (6%)
InternetTime-weekly	
<1 hour (0)	2 (4%)
1-7 hours (1)	24 (44%)
8-14 hours (2)	16 (31%)
15-21 hours (3)	3 (6%)
22+ hours (4)	7 (13%)

Table 4: Overview of participant internet access and use

Differences between social network responders and non-responders

Since a large proportion of participants initiating the online survey did not complete the social network questions, it is informative to examine whether the respondents differ in some way from non-respondents. The groups appear to be similar in age (U = 311.00, p = .38, r = .13), education (U = 297.50, p = .57, r = .08), employment (U = 261.50, p = .82, r = -.03), and marital status (U = 246.00, p = .77, r = -.04). Respondents and non-respondents do not differ significantly for type of internet connection (U = 313.50, p = .97, r = -.01), frequency of internet use (U = 304.50, p = .97, r = -.01), or time spent using the internet (U = 311.00, p = .64, r = .07).

Social support

The social support variables were explored in similar ways to the demographic variables. Histograms were produced and the Kolmogorov-Smirnov test was conducted for the five social support variables. These tests revealed non-normal distributions, thus non-parametric measures for association (lambda) and correlation (Kendall’s tau-b) were used. Sharing information and emotional support were the most prevalent forms of social support within the networks (see Tables 5 & 6). Generally, most participants received all dimensions of social support through their caregiving social networks.

Social support connections (n = 17)	**Mean (stdev)**
Advice	3.12 (2.74)
Assistance	3.65 (2.52)
Emotional support	4.47 (2.98)

Get info	2.76 (2.33)
Share info	4.94 (2.86)

Table 5: Mean and standard deviation (stdev) for the number of ties for each dimension of social support (social network responders); minimum = 2, maximum = 10

Social support connections (n = 17)	**Mean (stdev)**
Advice%	14% (0.12)
Assistance%	23% (0.16)
Emotional support%	25% (0.11)
Get info%	13% (0.10)
Share info%	26% (0.12)

Table 6: Percentage of ties providing specific dimensions of social support as a percentage of each respondent's overall social support (social network responders only)

The results of the association and correlational analyses with demographic variables are shown in Table 7. These values were calculated based on the assumption that the demographic variables are independent. Since Kendall's tau-b requires at least ordinal data, lambda only was calculated for nominal variables. While the results for lambda are helpful in creating models to predict values for particular variables, the results of tau are more intuitively understood as a linear association between two variables. As a whole, the values for lambda suggest that child characteristics such as child age and age of diagnosis may result in proportional reduction in error (PRE) for a particular dimension of social support in a caregiver's network. When looking at the results for tau, it appears that the correlations are generally small and non-significant. However, the age of diagnosis is significantly correlated with sharing information (r = -.445, p < .01), assistance (r = -.362, p < .05), and social support as a whole (r = -.388, p < .05). No other correlations between demographic variables and social support were found to be significant in this population.

Social Support dimension	**Demographic variables**	**Lambda (range: 0 - 1)**	**Tau (range -1 – 1)**
Get information	Participant Age	.231 (.156)	-.039 (.071)
	Education	.231 (.056)	N/A
	Employment	.077 (.303)	N/A
	Diagnosis	.154 (.303)	N/A
	ChildAge	.385 (.008)**	-.197 (.303)
	DiagnosisAge	.462 (.013)*	-.310 (.062)
	InternetFreq	.154 (.405)	N/A
	InternetTime	.154 (.303)	-.038 (.876)
Share information	Participant Age	.000 (.000)$^{\pm}$	.075 (.633)
	Education	.167 (.132)	N/A
	Employment	.250 (.056)	N/A
	Diagnosis	.083 (.303)	N/A
	ChildAge	.500 (.013)*	-.130 (.564)
	DiagnosisAge	.333 (.075)	-.445 (.006)**
	InternetFreq	.083 (.560)	N/A
	InternetTime	.083 (.303)	.066 (.750)
Advice	Participant Age	.167 (.303)	.227 (.284)
	Education	.083 (.560)	N/A
	Employment	.083 (.560)	N/A
	Diagnosis	.083 (.560)	N/A
	ChildAge	.417 (.008)**	-.131 (.521)
	DiagnosisAge	.417 (.008)**	-.089 (.649)
	InternetFreq	.083 (.303)	N/A
	InternetTime	.083 (.303)	-.019 (.934)
Emotional Support	Participant Age	.154 (.405)	.142 (.466)
	Education	.154 (.100)	N/A
	Employment	.231 (.156)	N/A
	Diagnosis	.308 (.132)	N/A
	ChildAge	.538 (.001)$^{\pm}$	-.139 (.566)

	DiagnosisAge	.462 (.002)**	-.203 (.275)
	InternetFreq	.154 (.303)	N/A
	InternetTime	.231 (.056)	.142 (.520)
Assistance	Participant Age	.167 (.303)	-.039 (.833)
	Education	.250 (.156)	N/A
	Employment	.250 (.156)	N/A
	Diagnosis	.250 (.156)	N/A
	ChildAge	.583 (.005)**	.101 (.540)
	DiagnosisAge	.417 (.068)	-.362 (.026)*
	InternetFreq	.083 (.303)	N/A
	InternetTime	.167 (.303)	.000 (1.000)
Social Support – all dimensions	Participant Age	.133 (.303)	.270 (.101)
	Education	.267 (.022)*	N/A
	Employment	.200 (.238)	N/A
	Diagnosis	.200 (.238)	N/A
	ChildAge	.467 (.005)**	-.055 (.812)
	DiagnosisAge	.467 (.005)**	-.388 (.016)*
	InternetFreq	.067 (.653)	N/A
	InternetTime	.133 (.405)	.108 (.658)

Table 7: Values of association (lambda) & correlation (tau) measures for social support variables (social network responders only); * $p < .05$, ** $p < .01$, $^{\pm}$ $p < .001$

Social networks

A brief summary of the data included in social network analysis is provided in Table 8. Although 17 participants completed the social network portion of the survey, not all participants reported use of all six technologies for network maintenance. Network size (or the sum of nodes), network ties (or the number of relations), and density, the relative proportion of ties that exist out of all possible ties, are the three reliable social network analysis statistics that could be calculated from the network data collected. Basic network characteristics such as network size, network ties, and density can provide information regarding the way that networks differ by the technology used and what particular demographic characteristics are associated with patterns of use. Statistics for each ego's whole caregiving network were included the analysis. While technology-specific network data may indicate the role of a technology for a particular demographic or dimension of social support, data for an ego's whole network can provide a more comprehensive perspective on the functional and structural characteristics of the social networks of maternal caregivers.

The available network data was also used to produce sociograms, or graph representations of the egocentric networks for visual comparison. Both the density calculations as well as the sociograms (see Appendix D) illustrate the relative low density of these networks, particularly when egocentric connections are disregarded. Sample sociograms are provided in Figures 1 – 4 to demonstrate the range of nodes and ties reported. Other informative network statistics, such as centrality and betweenness, could not be calculated due to the lack of sociocentric (whole-network) network data. Given sufficient overlap of egocentric networks, it is possible to construct a reasonably accurate sociocentric network. However, the egocentric networks available do not provide the necessary overlap to produce a clear picture of sociocentric network.

An important note is that the *n* for both of the Chat and Texting network types was relatively low (n = 4 and n = 6, respectively) as shown in Table 8. The results for these networks presented throughout the remainder of this chapter should be considered with that in mind.

Prevalence of Technologies	
Participants reporting F2F interactions	17
Participants reporting Telephone interactions	16
Participants reporting Texting interactions	6
Participants reporting Email interactions	13
Data points used to calculate Chat-density	4
Data points used to calculate SNS-density	9

Table 8: Prevalence of specific technologies in participant social networks (social network responders only)

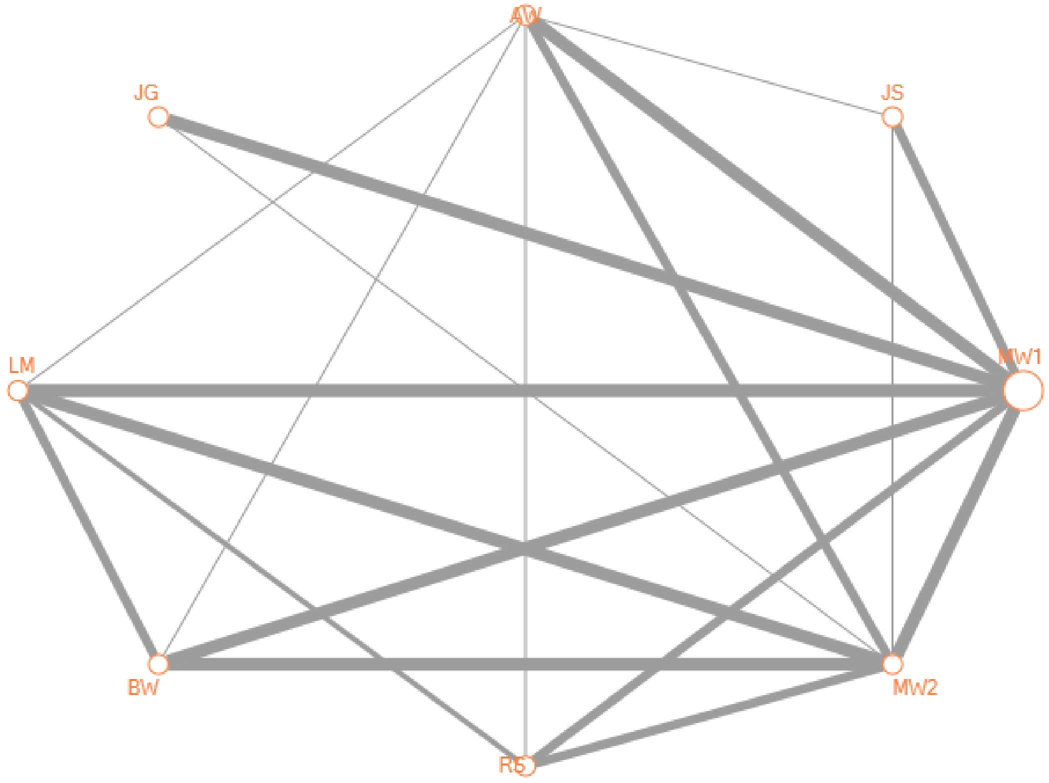

Figure 2: Sample sociogram of a participant's whole network with relatively few actor-actor ties (thickness of the line corresponds to greater multiplexity of the tie, or the number of technologies used to maintain the relationship)

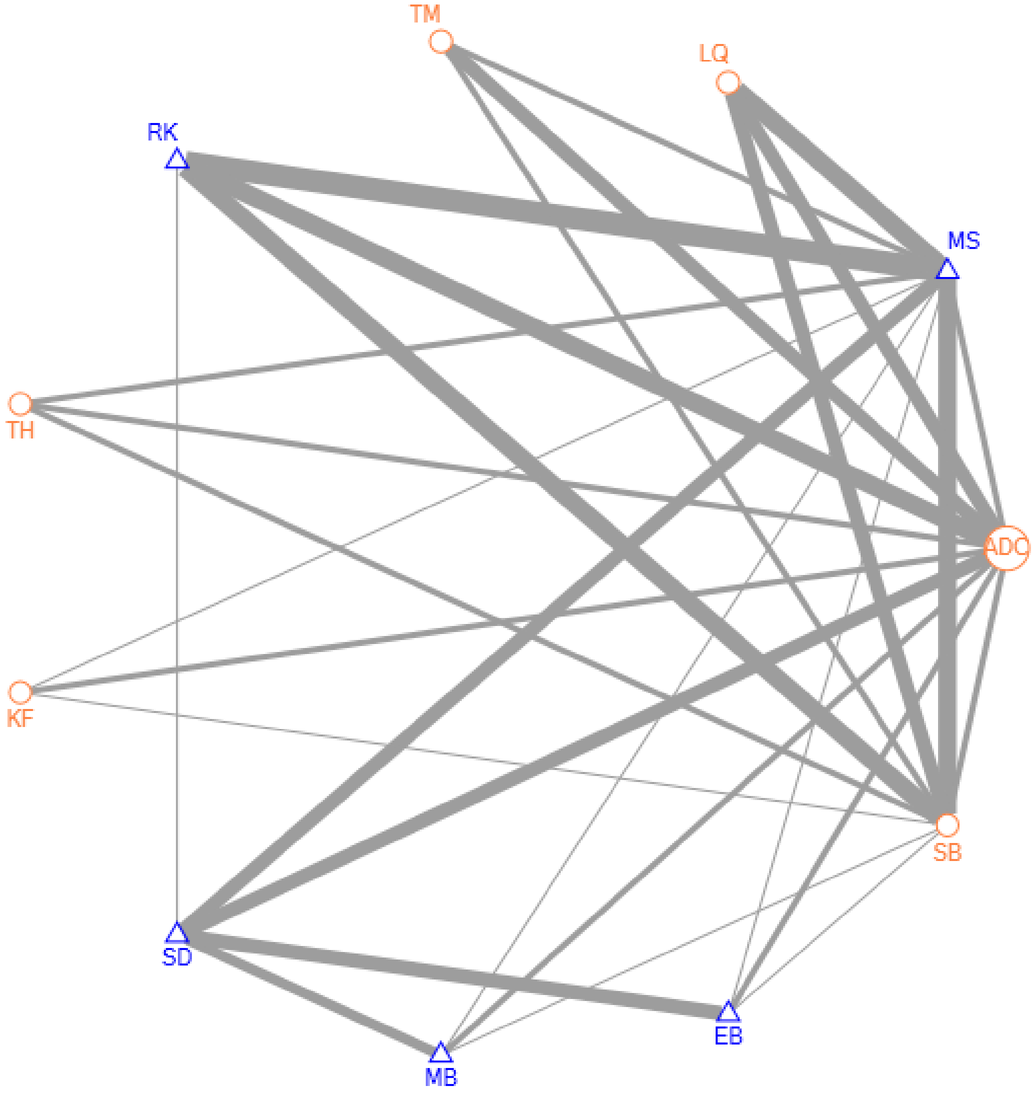

Figure 3: Sample sociogram of a participant's whole network with relatively many actor-actor ties (thickness of the line corresponds to greater multiplexity of the tie, or the number of technologies used to maintain the relationship)

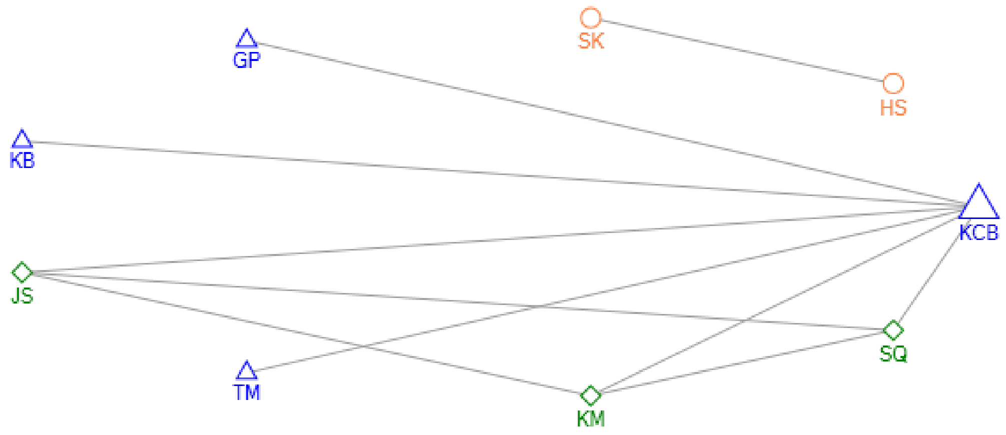

Figure 4: Sample sociogram for a telephone network with relatively few non-ego ties (thickness of each line is one since this sociogram represents only one network)

The range for the number of network members, or nodes, is 8 (min = 3, max = 11). This range is constrained in part by the limit placed on the ego within the survey of naming ten network members. The distribution of the mean nodes for all types of networks is relatively close (range: 7.47 – 8.50). If the means for the Chat and Texting networks are disregarded, the range becomes closer (7.47 – 8.22). This agrees with the results of the Wilcoxon Signed-Rank test discussed at the end of the chapter and presented in Table 16.

Network type	**Mean nodes (stdev)**
Chat	8.50 (2.08)
Email	8.00 (2.74)
F2F	7.47 (2.83)
SNS	8.22 (2.54)
Telephone	7.50 (2.92)
Texting	8.50 (3.02)

Table 9: Mean and standard deviation for nodes (network members) by network types for social network respondents; Note: values for the whole networks are not provided since the number of network members is simply the average of the individual network types

The range for the number of ties across all networks is 25 (min = 3, max = 28). The average sum of ties (excluding ties to the ego) varied widely across the type of network. Chat networks averaged the greatest ties across participants ($\sum_{\text{chat}} = 9.0$). F2F networks averaged the second highest sum of ties ($\sum_{\text{F2F}} = 7.06$), followed in decreasing order by telephone, SNS, email, and texting networks respectively (see Table 10). Each mean of ties by network type was examined for association with demographic and social support variables. The significant associations can be seen in Table 11. The results for lambda reflect the resulting proportional reduction in error in predicting the number of nodes, ties, and network density when demographic characteristics or social support value are known. The values for Kendall's tau-b reflect the strength of correlation between the demographic or social support variable and the network characteristics.

Network type	**Mean ties (stdev)**
Chat	9.00 (13.04)
Email	3.54 (3.78)
F2F	7.06 (9.33)
SNS	5.33 (2.54)
Telephone	5.50 (7.76)
Texting	1.83 (2.14)
Whole	20.53 (29.06)

Table 10: Mean ties and standard deviation (i.e., relationships) by network type for social network respondents

The range of density is one, or the full range of its possible values (min = .00, max = 1.00). The mean densities by network type are listed in Table 11. The networks with the highest reported activity are those relying on face-to-face, telephone, and email interactions. Technologies supporting networks with the highest mean density are the Chat (Δ = .24, n = 5) and Face-to-Face (Δ = .22, n = 17) networks. The density of the remaining networks is in decreasing order: Telephone (Δ = .18, n = 16), SNS (Δ = .17, n = 9), Email (Δ = .12, n = 13), and Texting (Δ = .10, n = 6). For individual participants, mean is generally less than .30, with only a few individual networks exceeding that value. As shown in table 11, the mean density for all networks falls below .30. These findings generally agree with low densities reported in other studies.

Network type	**Mean density (Δ)**
Chat	.24 (.36)
Email	.12 (.12)

F2F	.22 (.22)
SNS	.17 (.24)
Telephone	.18 (.20)
Texting	.10 (.13)
Whole	.17 (.19)

Table 11: Average density by network type; the range for density values is 0 to 1 since it is the percentage of existing ties to possible ties in a network

Correlation between demographics and social network characteristics

Network members (nodes), relations (ties), and densities by network type were examined for relationships with demographic variables and social support variables using cross tabulation. Due to the non-normal distribution of these data, as detected by histograms and the Kolmogorov-Smirnov test (see Appendix C), non-parametric tests were used to detect significant differences between means (Wilcoxon Signed-Rank test), association (lambda) between variables, and correlation (Kendall’s tau-b) between variables. Since Kendall’s tau-b requires at least ordinal data, lambda only was calculated for nominal variables.

As shown in Table 12, variables that significantly reduced the error in predicting nodes in a network include the following. For Chat networks, age, employment, child age, and age of diagnosis all resulted in significant proportional reduction in error (PRE) of the number of nodes. For Email, F2F, and Telephone networks, education, child age, and age of diagnosis resulted in significant PRE of the number of nodes. For SNS networks, education, diagnosis, and child age resulted in significant PRE of the number of nodes. Interestingly, for Texting networks, only age of diagnosis resulted in significant

PRE of the number of nodes. For the whole network, employment, diagnosis, child age, and diagnosis age resulted in significant PRE of the number of nodes.

There are far fewer significant correlations between demographics and network nodes. The results shown in Table 12 indicate that both participant age and the age of diagnosis for the child are correlated with the number of nodes in a caregiver network. More specifically, participant age is significantly correlated with nodes in Email networks (r = .384, p < .05) and SNS networks (r = .468, p < .05). The age of diagnosis is strongly negatively correlated with nodes in Email networks (r = -.443, p < .05), F2F networks (r = -.444, p < .05), SNS networks (r = -.627, p < .001), Telephone networks (r = -.442, p < .05), Texting networks (r = -.617, p < .001), but not with the network as a whole (r = -.211, p = .204). The only other significant correlation detected is a negative one between time spent on the internet and nodes in Texting networks (r = -.560, p < .001).

Network Type	**Nodes**		
	Demographics	**Lambda**	**Tau**
Chat	Participant Age	1.000 (.014)*	--
	Education	--	N/A
	Employment	1.000 (.014)*	N/A
	MaritalStatus	.500 (.221)	N/A
	Diagnosis	.500 (.221)	N/A
	ChildAge	1.000 (.014)*	.333 (.540)
	DiagnosisAge	1.000 (.014)*	--
	InternetFreq	--	N/A
	InternetTime	.500 (.221)	.000 (1.000)
Email	Participant Age	.222 (.471)	.384 (.016)*
	Education	.444 (.018)*	N/A

	Employment	.222 (.403)	N/A
	MaritalStatus	.111 (.298)	N/A
	Diagnosis	.333 (.234)	N/A
	ChildAge	.667 (.010)**	.288 (.286)
	DiagnosisAge	.556 (.029)*	-.443 (.034)*
	InternetFreq	.111 (.559)	N/A
	InternetTime	.111 (.704)	.157 (.503)
F2F	Participant Age	.167 (.718)	.282 (.119)
	Education	.417 (.008)**	N/A
	Employment	.250 (.238)	N/A
	MaritalStatus	.083 (.704)	N/A
	Diagnosis	.333 (.132)	N/A
	ChildAge	.500 (.033)*	.135 (.590)
	DiagnosisAge	.500 (.013)*	-.444 (.012)*
	InternetFreq	.167 (.303)	N/A
	InternetTime	.167 (.560)	.165 (.443)
SNS	Participant Age	.286 (.398)	.468 (.011)*
	Education	.571 (.010)**	N/A
	Employment	.286 (.398)	N/A
	MaritalStatus	.143 (.292)	N/A
	Diagnosis	.571 (.010)**	N/A
	ChildAge	.429 (.224)	-.026 (.937)
	DiagnosisAge	.714 (.018)*	-.627 (.000)$^{\pm}$
	InternetFreq	.143 (.292)	N/A
	InternetTime	.286 (.468)	-.140 (.624)
Telephone	Participant Age	.182 (.472)	.280 (.094)
	Education	.455 (.007)**	N/A
	Employment	.273 (.237)	N/A
	MaritalStatus	.091 (.301)	N/A
	Diagnosis	.364 (.131)	N/A
	ChildAge	.545 (.031)*	.094 (.721)
	DiagnosisAge	.545 (.012)*	-.442 (.013)*
	InternetFreq	.091 (.560)	N/A
	InternetTime	.091 (.762)	.175 (.403)
Texting	Participant Age	.667 (.083)	.500 (.180)
	Education	.333 (.273)	N/A

	Employment	.333 (.649)	N/A
	MaritalStatus	.333 (.264)	N/A
	Diagnosis	.333 (.273)	N/A
	ChildAge	.667 (.083)	.694 (.000)$^{\pm}$
	DiagnosisAge	1.000 (.014)*	-.617 (.000)$^{\pm}$
	InternetFreq	--	N/A
	InternetTime	.667 (.273)	-.560 (.000)$^{\pm}$
Whole	Participant Age	.133 (.303)	.236 (.187)
	Education	.267 (.075)	N/A
	Employment	.267 (.022)*	N/A
	MaritalStatus	.071 (.302)	N/A
	Diagnosis	.267 (.022)*	N/A
	ChildAge	.467 (.001)**	.086 (.731)
	DiagnosisAge	.533 (.000)$^{\pm}$	-.211 (.204)
	InternetFreq	.133 (.405)	N/A
	InternetTime	.133 (.303)	.272 (.123)

Table 12: Association and correlation coefficients for demographics and social network members (or nodes); * $p < .05$, ** $p < .01$, $^{\pm}$ $p < .001$

Table 13 displays the results for associative and correlational analyses between demographics and network ties. As in Table 12, there are many more significant results for lambda than for tau. These analyses are consistent with the results in Table 12 for network nodes that child age and age of diagnosis demonstrate significant PRE in predicting the structural characteristics of a network. The analysis for network ties also demonstrates a possible role for education and employment. For Chat networks, age, employment, child age, and age of diagnosis resulted in significant PRE for network ties. For Email networks, child age and age of diagnosis resulted in significant PRE for network ties. For F2F networks and Texting networks, employment, child age, and age of diagnosis resulted in significant PRE for network ties. For SNS networks, education and age of diagnosis resulted in significant PRE for network ties. For Telephone networks, employment, diagnosis, child age, and age of diagnosis resulted in significant PRE for network ties. For the whole network, education, child age, and age of diagnosis resulted in significant PRE for network ties.

Again, there are fewer significant correlations than associations. Only time spent on the internet appears to be correlated with demographic variables in this sample. Time spent on the internet is negatively correlated with ties in Chat networks ($r = -.816$, $p < .05$) and positively correlated with Email networks ($r = .384$, $p < .01$).

Network Type	**Network Ties**		
	Demographics	**Lambda**	**Tau**
Chat	Participant Age	1.000 (.014)*	.333 (.540)
	Education	--	N/A
	Employment	1.000 (.014)*	N/A
	MaritalStatus	.500 (.221)	N/A
	Diagnosis	.500 (.221)	N/A
	ChildAge	1.000 (.014)*	--
	DiagnosisAge	1.000 (.014)*	-.333 (.540)
	InternetFreq	--	N/A
	InternetTime	.500 (.221)	-.816 (.014)*
Email	Participant Age	.200 (.127)	.110 (.689)
	Education	.200 (.299)	N/A
	Employment	.100 (.299)	N/A
	MaritalStatus	--	N/A
	Diagnosis	.200 (.127)	N/A
	ChildAge	.500 (.005)$^{\pm}$	.253 (.281)
	DiagnosisAge	.400 (.018)*	-.134 (.549)
	InternetFreq	--	N/A
	InternetTime	.200 (.127)	.384 (.004)**

F2F	Participant Age	.214 (.056)	-.130 (.573)
	Education	.214 (.056)	N/A
	Employment	.286 (.022)*	N/A
	MaritalStatus	.077 (.302)	N/A
	Diagnosis	.286 (.132)	N/A
	ChildAge	.429 (.002)**	.272 (.168)
	DiagnosisAge	.500 (.001)$^{\pm}$	-.112 (.408)
	InternetFreq	.071 (.560)	N/A
	InternetTime	.143 (.132)	-.065 (.772)
SNS	Participant Age	.333 (.114)	-.139 (.602)
	Education	.500 (.038)*	N/A
	Employment	.333 (.114)	N/A
	MaritalStatus	--	N/A
	Diagnosis	.333 (.114)	N/A
	ChildAge	.333 (.114)	.211 (.522)
	DiagnosisAge	.667 (.010)**	-.366 (.167)
	InternetFreq	--	N/A
	InternetTime	.167 (.292)	-.311 (.229)
Telephone	Participant Age	.167 (.302)	-.198 (.269)
	Education	.250 (.154)	N/A
	Employment	.333 (.021)*	N/A
	MaritalStatus	.000 (1.000)	N/A
	Diagnosis	.333 (.021)*	N/A
	ChildAge	.417 (.007)**	.174 (.424)
	DiagnosisAge	.500 (.012)*	-.191 (.320)
	InternetFreq	.083 (.560)	N/A
	InternetTime	.250 (.302)	.042 (.857)
Texting	Participant Age	.500 (.083)	.000 (1.000)
	Education	.250 (.273)	N/A
	Employment	.750 (.014)*	N/A
	MaritalStatus	.333 (.264)	N/A
	Diagnosis	.250 (.273)	N/A
	ChildAge	.750 (.014)*	.148 (.665)
	DiagnosisAge	.750 (.014)*	.296 (.460)
	InternetFreq	.250 (.552)	N/A
	InternetTime	.500 (.083)	-.077 (.854)

Whole	Participant Age	.143 (.473)	-.137 (.493)
	Education	.286 (.022)*	N/A
	Employment	.143 (.473)	N/A
	MaritalStatus	.077 (.302)	N/A
	Diagnosis	.143 (.473)	N/A
	ChildAge	.429 (.013)*	.142 (.528)
	DiagnosisAge	.500 (.005)**	-.220 (.222)
	InternetFreq	.143 (.132)	N/A
	InternetTime	.143 (.405)	.109 (.599)

Table 13: Association and correlation coefficients for demographics and social network ties (or relations); * $p < .05$, ** $p < .01$, $^{\pm}$ $p < .001$

Table 14 displays the results for associative and correlational analyses between demographics and network density. As in Tables 12 and 13, there are many more significant results for lambda than for tau. The same variables that appear to be significant in reducing PRE for network nodes and ties - child age and age of diagnosis - also seem to be significant in reducing PRE for network density, while education and employment are less frequently significant. For Chat networks, age, employment, child age, and age of diagnosis resulted in significant PRE for network density. For Email networks and F2F networks, child age and age of diagnosis resulted in significant PRE for network density. For SNS networks, education and age of diagnosis resulted in significant PRE for network density. For Texting networks, employment, child age, and age of diagnosis resulted in significant PRE for network density. For the whole network, child age and age of diagnosis resulted in significant PRE for network density.

As may be expected with a complex variable such as network density, there are fewer significant correlations detected than for network nodes or ties. Age appears to be negatively correlated to both Telephone network (r = -.478, p < .001) and Whole network density (r = -.529, p < .001).

Network Type	**Network Density**		
	Demographics	**Lambda**	**Tau**
Chat	Participant Age	1.000 (.014)*	.333 (.540)
	Education	--	N/A
	Employment	1.000 (.014)*	N/A
	MaritalStatus	.500 (.221)	N/A
	Diagnosis	.500 (.221)	N/A
	ChildAge	1.000 (.014)*	--
	DiagnosisAge	1.000 (.014)	-.333 (.540)
	InternetFreq	--	N/A
	InternetTime	.500 (.221)	-.816 (.014)*
Email	Participant Age	.200 (.127)	-.161 (.507)
	Education	.100 (.299)	N/A
	Employment	.100 (.299)	N/A
	MaritalStatus	--	N/A
	Diagnosis	.200 (.127)	N/A
	ChildAge	.500 (.005)**	.095 (.653)
	DiagnosisAge	.400 (.018)*	.072 (.766)
	InternetFreq	--	N/A
	InternetTime	.200 (.127)	.377 (.001) ±
F2F	Participant Age	.077 (.738)	-.334 (.119)
	Education	.154 (.473)	N/A
	Employment	.308 (.132)	N/A
	MaritalStatus	.083 (.302)	N/A
	Diagnosis	.154 (.303)	N/A
	ChildAge	.462 (.013)*	.209 (.329)
	DiagnosisAge	.538 (.005)**	.016 (.933)
	InternetFreq	.154 (.132)	N/A
	InternetTime	.154 (.405)	-.288 (.154)
SNS	Participant Age	.333 (.114)	-.362 (.036)*

	Education	.500 (.038)*	N/A
	Employment	.333 (.114)	N/A
	MaritalStatus	--	N/A
	Diagnosis	.333 (.114)	N/A
	ChildAge	.333 (.114)	-.211 (.493)
	DiagnosisAge	.667 (.010)**	-.171 (.560)
	InternetFreq	--	N/A
	InternetTime	.167 (.292)	-.028 (.931)
Tele	Participant Age	.154 (.302)	-.478 (.000)$^{\pm}$
	Education	.231 (.055)	N/A
	Employment	.385 (.007)**	N/A
	MaritalStatus	.083 (.301)	N/A
	Diagnosis	.231 (.154)	N/A
	ChildAge	.462 (.002)**	.179 (.462)
	DiagnosisAge	.538 (.000) $^{\pm}$	.196 (.323)
	InternetFreq	.077 (.560)	N/A
	InternetTime	.231 (.055)	-.041 (.860)
Text	Participant Age	.500 (.083)	-.231 (.343)
	Education	.250 (.273)	N/A
	Employment	.750 (.014)	N/A
	MaritalStatus	.250 (.264)	N/A
	Diagnosis	.250 (.273)	N/A
	ChildAge	.750 (.014)*	-.071 (.820)
	DiagnosisAge	.750 (.014)*	.500 (.181)
	InternetFreq	--	N/A
	InternetTime	.500 (.083)	.148 (.721)
Whole	Participant Age	.133 (.132)	-.529 (.000)$^{\pm}$
	Education	.200 (.056)	N/A
	Employment	.200 (.056)	N/A
	MaritalStatus	.071 (.302)	N/A
	Diagnosis	.133 (.132)	N/A
	ChildAge	.467 (.001)$^{\pm}$	.093 (.633)
	DiagnosisAge	.467 (.001)$^{\pm}$	.100 (.566)
	InternetFreq	.067 (.303)	N/A
	InternetTime	.200 (.056)	-.072 (.713)

Table 14: Association and correlation coefficients for demographics and social network density (or percentage of existing ties to possible ties); * $p < .05$, ** $p < .01$, $^{\pm}$ $p < .001$

Correlation between social support and social network density

As shown in Table 15, the correlations between network nodes and social support variables was not conducted due to the way in which social support was measured as an exchange between two nodes. Thus, the number of nodes constrains the values for the social support variables. Correlation analysis was conducted for network ties and density. The results of tau suggest that assistance is the most commonly correlated dimension of social support with network ties. More specifically, advice is negatively correlated with Chat ties (r = -.816, p < .05). Assistance is positively correlated with Email ties (r = .325, p < .05), F2F ties (r = .474, p < .01), SNS ties (r = .560, p < .01), Telephone ties (r = .566, p < .001), and Whole network ties (r = .516, p < .001). Emotional support is positively correlated with Email ties (r = .432, p < .05), and SNS ties (r = .532, p < .001). Sharing information is positively correlated with F2F ties (r = .344, p < .05), Telephone ties (r = .413, p < .001), and Whole network ties (r = .378, p < .01), but negatively correlated with Texting ties (r = -.296, p < .05). Social support as a whole is positively correlated with Email ties (r = .328, p < .05), F2F ties (r = .483, p < .01), and Whole network ties (r = .491, p < .01).

The few correlations detected between dimensions of social support and network density can be seen in Table 15. Advice is negatively correlated with Chat network density (r = -.816, p < .014). Assistance is positively correlated with SNS network density (r = .507, p < .05). Emotional support is positively correlated with Email network density (r = .291, p < .05). Both sharing information and social support as a whole are negatively correlated with Texting network density (r = -.357, p < .001; r = -.500, p < .01).

Network Type	Social Support dimensions	Tau – Network ties	Tau - Network density (Δ)
Chat	Advice	-.816 (.014)	-.816 (.014)*
	Assistance (instrumental)	.333 (.540)	.333 (.540)
	Emotional support	.333 (.540)	.333 (.540)
	Get info	-.333 (.540)	-.333 (.540)
	Share info	--	--
	Social Support (all)	-.333 (.540)	-.333 (.540)
Email	Advice	.110 (.584)	.024 (.911)
	Assistance (instrumental)	.325 (.048)*	.209 (.224)
	Emotional support	.432 (.027)*	.291 (.033)*
	Get info	.099 (.670)	-.036 (.880)
	Share info	.289 (.081)	.107 (.523)
	Social Support (all)	.328 (.046)	.103 (.591)
F2F	Advice	.249 (.228)	.097 (.684)
	Assistance (instrumental)	.474 (.008)**	.317 (.066)
	Emotional support	.241 (.251)	.024 (.903)
	Get info	.218 (.283)	-.032 (.893)
	Share info	.344 (.011)*	.072 (.694)
	Social Support (all)	.483 (.005)**	.139 (.528)
SNS	Advice	.338 (.185)	.182 (.543)
	Assistance (instrumental)	.560 (.013)*	.507 (.014)*
	Emotional support	.532 (.000)$^{\pm}$	.177 (.446)
	Get info	.250 (.365)	.000 (1.000)
	Share info	.225 (.372)	.075 (.767)
	Social Support (all)	.406 (.074)	.119 (.689)
Telephone	Advice	.221 (.286)	-.009 (.970)
	Assistance (instrumental)	.566 (.000)$^{\pm}$	.259 (.128)

	Emotional support	.343 (.109)	.054 (.786)
	Get info	.194 (.340)	-.154 (.525)
	Share info	.413 (.001)$^{\pm}$	.018 (.930)
	Social Support (all)	.474 (.005)**	.026 (.917)
Texting	Advice	.148 (.460)	-.071 (.820)
	Assistance (instrumental)	.000 (1.000)	-.071 (.876)
	Emotional support	.231 (.502)	0.000 (1.000)
	Get info	-.215 (.289)	-.414 (.034)
	Share info	-.296 (.028)*	-.357 (.000)$^{\pm}$
	Social Support (all)	-.296 (.140)	-.500 (.010)**
Whole	Advice	.245 (.205)	-.039 (.862)
	Assistance (instrumental)	.516 (.001)$^{\pm}$	.202 (.284)
	Emotional support	.340 (.087)	-.055 (.772)
	Get info	.214 (.259)	-.078 (.734)
	Share info	.378 (.006)**	-.016 (.930)
	Social Support (all)	.491 (.002)**	-.067 (.753)

Table 15: Correlation between social support variables and network characteristics - ties and density; * p < .05, ** p < .01, $^{\pm}$ p < .001

As shown in Table 16, there are some significant differences between network types. The mean density for email networks is significantly different from that of SNS networks (Z = -2.20, p = .03) and Texting networks (Z = 2.02, p = .04). The mean density for Telephone networks is significantly different from that of SNS networks (Z = -2.38, p = .02) and that of texting networks (Z = -2.02, p = .04).

	Chat	**Email**	**F2F**	**SNS**	**Telephone**	**Texting**
Chat	-----	-1.60 (.11)	-1.60 (.11)	1.00 (.32)	-1.07 (.29)	-0.45 (.66)
Email	-1.60 (.11)	-----	-1.77 (.08)	-2.20 (.03)*	-1.07 (.29)	2.02 (.04)*

F2F	-1.60 (.11)	-1.77 (.08)	-----	-1.83 (.07)	-0.97 (.33)	-1.15 (.25)
SNS	1.00 (.32)	-2.20 (.03)*	-1.83 (.07)	-----	-2.38 (.02)*	.00 (1.00)
Tele	-1.07 (.29)	-1.07 (.29)	-0.97 (.33)	-2.38 (.02)*	-----	-2.02 (.04)*
Text	-.45 (.66)	2.02 (.04)*	-1.15 (.25)	.00 (1.00)	-2.02 (.04)*	-----

Table 16: Results of Wilcoxon Signed-Rank test for differences between mean densities by network type; * $p < .05$, ** $p < .01$, $^{\pm}$ $p < .001$

CHAPTER FIVE: DISCUSSION

In Chapter Two, current research on social support and the social networks of caregivers was discussed. The research on ASD and other developmental disabilities suggests that specific health and behavioral issues have a greater impact on perceived caregiver burden than others. These include externalized behaviors and tic disorders, reflux, constipation, and organ disorders, among others (Tadema & Vlaskamp, 2009). Other variables influencing caregiver burden are time spent providing care and dependency of the child on the caregiver to perform daily adaptive functioning skills (Bishop, et al., 2007; Tsai & Wang, 2009). It may be that child age is a significant predictor of caregiver needs, perhaps because families new to a diagnosis and those less experienced in providing care may need more social support across all dimensions. Other important points from Chapter Two include the inverse relationship between social support and caregiver burden, which is generally explained by the presence of social support mediating the effect of caregiver burden on the caregiver’s physical and emotional health and social functioning. The results of this study will be compared and contrasted with previous research in the following sections.

Characterizing the population

Data describing the racial, ethnic, educational, and employment characterization of Indiana mothers caring for children with an ASD is not available in the research literature. The sample may not be representative of the racial and ethnic diversity of the residents of Indiana, nor the level of education, employment status, technology access, and marital status characteristic of the general population. Further study is needed to characterize this population. Thus, the results obtained from this sample may not be generalizable to the larger population of Indiana mothers providing care for a child with an ASD.

Research questions

Research Question 1: Capture and describe the basic features/characteristics of their social network structure.

An examination of the summary network sociograms for the 18 responders suggests the following. First, the density of respondents' networks is relatively low, with two exceptions. This may be due either to a lack of awareness of the ties between network members or to under-reporting due to respondent fatigue. Second, respondent networks are composed of multiplex relations, which is one indicator of the presence of strong ties. While not all ties are so strongly multiplex, generally the presence of strong ties is greater than that of weak ties across participants. Finally, the face-to-face (F2F), chat, and telephone networks (Tele) appear to have the greatest density. However, since the chat network density is calculated on only five respondents, it is likely less representative than the data for face-to-face and telephone networks. The relative prevalence of face-to-face interactions is consistent with results from a 2009 report by the Pew Internet and American Life Project (2009) suggesting that face-to-face is still the most important means of interactions for core social networks. The results reported for this study also suggests that network members interacting face-to-face and via telephone with the ego are more likely to know each other well. Those with whom the ego interacts via email, texting, and SNS are possibly less integrated into the daily lives of other members of the network. Another explanation is that these less dense networks support more distant contacts than do the face-to-face and telephone networks. Unfortunately, data on the proximity of network members was not collected. Although there is wide variation in the number of technologies (i.e., multiplexity) used to maintain ties, the large majority of participants use at least three technologies to communicate with several network members.

Research Question 2: What types of social support are embedded within these social networks?

All four dimensions of social support (informational, emotional, instrumental, and appraisal) are received by the respondents in this sample. However, some are more prevalent than others. The results in Table 5 show that the most commonly received dimensions of social support within each are informational (specifically sharing) and emotional support, although instrumental support is a close third. These figures add up to more than 100% since they were calculated as the mean of the percentage of the social support ties within each respondent’s network. These results confirm the findings by Ellis et al., (2002) that informational support was the greatest need for the caregiver sample in Massachusetts. Also consistent with the Ellis et al., (2002) study, child age was a significant predictor in network structural characteristics.

Another surprising finding is that these caregivers appear to engage in sharing informational support more than they receive it. A possible explanation is that caregivers seek information from professionals, organizations, and online or print resources more so than from network members. However, they appear to engage in social support by sharing what they have found with their network members. After receiving informational support, appraisal support in the form of advice is the least prevalent dimension in these networks. It may be that caregivers are hesitant to engage in this behavior out of fear of offending or harming the relationship. It is also possible that advice is not an appropriate or clear operational definition for appraisal support for these caregivers. Overall, it appears that all dimensions of social support are deeply embedded into the networks of caregivers responding to this survey.

Research Question 3: What relationships exist between participant demographics and social support?

In exploring the relationships between social support and demographic characteristics, two variables appear in both associative and correlational results repeatedly: child age and age of diagnosis. These child characteristics conceivably have a great impact on caregiver burden in that they may determine the level of care required by the child as well as how well-supported the mother is by her social network, services, and interventions. A child's age is one factor in his/her level of functioning, which has been shown to affect caregiver burden critically (Ellis, et al., 2002; Phillips, et al., 2009; Tadema & Vlaskamp, 2009; Tsai & Wang, 2009). The correlations with age of diagnosis may actually reflect the amount of a time a family has had since diagnosis to adjust and begin to implement coping strategies and make use of services. On the other hand, it is possible that adjusting to a diagnosis simply is more challenging at a later age, when familial and societal expectations for that child have already been set. At an older age, a diagnosis of developmental disorder may be seen as the fault of the parents, rather than a biological or genetic condition. An alternative explanation is that despite red flags, a diagnosis is not received until the family has reached a crisis point for behavioral, physical, mental, and social challenges that have escalated for some time.

This study did not collect role relation data that would allow distinction between informal and formal sources of social support. The relative lack of significant results may be due to the small sample size.

Research Question 4: What relationships exist between participant demographics and the structural characteristics of the network?

A few participant and child characteristics appear to be significantly related to properties of social network structure – participant age, child age, age of diagnosis, education, and employment. Analysis of nodes, ties, and density suggest that two of these correlations may be worth further examination in future studies. First is the age of diagnosis, which is negatively correlated with the nodes, but not ties or density of many network types: Email, F2F, SNS, Telephone, and Texting. This suggests that the age of diagnosis may significantly affect the size of a caregiver’s social network. For this sample, the older a child was at diagnosis is associated with his/her caregiver having fewer social network contacts available to them for social support. These results do not suggest causality, but it is an important finding for further study.

Participant age is negatively correlated with network nodes and density for Email and SNS networks. This suggests that younger parents may be less likely to use these technologies. Time spent on the internet is positively correlated with network ties for Email networks, but negatively correlated with network ties for Chat networks. Time spent on the internet is similarly positively correlated with network density for Email networks, but negatively correlated with network density for Chat networks. Although the *n* for Chat networks is quite low, this may suggest that some caregivers are relying more on mobile technologies to communicate and may have different patterns of seeking social support via technologies than those who primarily relying on desktop technologies.

Research Question 5: What relationships exist between the provision of specific types of social support and the structural characteristics of the network?

After performing correlational analyses on network density and social support variables and seeing the scarcity of relationships, the number of nodes and ties as characteristics of network structure were selected for inclusion in these analyses. While social support may not be directly related to structural features such as nodes, ties, or density, others have proposed that social support is tied to the functional characteristics of networks (i.e., role relations; Haythornthwaite, 2005); thus, it is plausible that social support may be related to other structural characteristics of networks not measured in this study.

Assistance appears to be correlated with network ties for all network types, except Chat and Texting. Surprisingly, assistance seems to be spread out across multiple technologies instead of constrained to F2F interactions, as was expected. This is likely due to participant confusion of what assistance meant. While the investigator used the term to indicate actual tangible instrumental support, participants may have understood it to mean less tangible forms of support, such as planning or perhaps arranging to provide tangible forms of support. Sharing information is also widely distributed across the various network types.

The relationship between network density and the dimensions of social support appear to be less direct than that between ties and social support. Analyses detected only three correlations with densities meeting significance. There is a positive correlation between provision of emotional support and both network ties and density for Email networks. In contrast, provision of emotional support is correlated only with network ties for SNS networks. One possibility is that network density is less important for a broadcast type of technology, such as social networking sites. In contrast, email is more often a one-on-one exchange.

Getting information is not significantly correlated with any network property. Perhaps this because receiving information is an inherent feature of all communications, regardless of mode. In contrast, sharing information is positively correlated with network ties for F2F, Telephone, Texting, and Whole networks, while network density is only positively correlated with Texting networks. It is possible that texting, as a relatively information-poor technology, is not appropriate for sharing complex health information.

Social support as a whole is positively correlated with network ties for Email, F2F, Telephone, and Whole networks. However, the correlations for all but Texting networks are positive. The negative correlation between Texting network density and all dimensions of social support is also significant. Similar to the non-significant results for Chat network ties, there appears to be an inverse relationship between receiving social support (generally) and the number of Texting network ties. This may suggest that texting is an inappropriate technology to consider for interventions and services to meet the needs of caregivers.

These results confirm that caregivers engage in many types of interactions to maintain their social support networks, as did the students described in Haythornthwaite (2001) and the adults described in (Hampton, et al., 2009). The results of this exploratory study of social support and social networks in the lives of caregivers for children with an ASD are somewhat inconclusive. Much of the literature on social support suggests that its impact depends upon the context and culture of the population being studied. My hope is that this study will be an early study in a growing body of research characterizing the needs and behaviors of caregivers for children with ASD (and special needs in general) so that services and interventions can be appropriately tailored.

CHAPTER SIX: CONCLUSIONS

In general, the results indicate that further study of the exchange of social support within caregiver social networks could be informative in developing services and interventions that fit into the daily lives of these caregivers. Since there has been little social support or social network analysis research done on caregivers for children with an ASD, the results of this study can offer direction for future research. Due to the small sample size for social support and social network analyses, there may exist relationships that were not detected by these analyses. Consideration of the strengths and limitations of the data discussed previously as well as suggestions for future research follow.

Strengths

As this was a small pilot study exploring familiar concepts in an unexamined population, the results are inconclusive. However, some positive elements of study design and potentially fruitful relationships have been demonstrated. Rather than examining information exchange as an isolated element or behavior, this study examined it as a dimension of social support within the context of caregiving. Specifically, the study compares information exchange to other dimensions of social support in caregiver networks. The study suggests that information may be more or less significant as a dimension of social support needed by caregivers at various stages of their child’s development. However, the exact relationship between information need and child age has not been determined. Finally, this is the first study of maternal caregivers of children with an ASD and their social networks. Given the growing prevalence of autism and the burden it is placing on families, schools, and the healthcare system, this is an important population to study.

Limitations

As this was an exploratory study with few resources available, there are many limitations of the data. The first and most significant is the small sample size, which limits the ability to generalize results beyond this sample to a larger population and which may have resulted in Type II statistical errors. More specifically, the results may be generalizable to a similar demographic group – Caucasian, non-Hispanic, college-educated, aged 25-54, and employed part- or full-time. As the sample was a convenience sample, it may not represent the diversity of the population in Indiana. Since this population has not been sufficiently studied on a national or local level, generalizability is difficult to determine at this time. While 61 participants initiated the study, only 17 eligible participants completed the social network and social support questions. Basic non-parametric analyses were conducted to detect significant group differences between non-responders and responders. These did not detect major differences between the two groups. Further research is needed to characterize this population's racial and ethnic diversity, educational level, employment status, marital status, frequency of internet use, time spent on the internet, among other characteristics.

A standardized measure for social support was not used in this study. The focus instead was the exchange of four dimensions of social support rather than perception of or satisfaction with the social support available. However, these dimensions may not be clearly operationalized or described in the survey, causing respondents to provide inaccurate data. Also significant was a typographical error in the phrasing of the social support questions, which limited to data for three of the four dimensions to support received by the ego. This may have skewed the data collected to the extent that it does not accurately reflect existing relationships.

For the social network portion of the survey, participants were limited to naming ten network members. This was done to limit the time required to complete the survey. In addition, much previous research has shown that most people have relatively few close ties (Wasserman & Faust, 1994). However, this artificial limit may be an underestimation that distorts the structural network characteristics measured.

Future Research

Suggestions for future research in this area include the following. First, as there are many reasonably reliable and valid measures of social support, it is recommended that these be used in conjunction with social support exchange data to characterize fully the dimensions. It would be helpful in future studies to include a control group of maternal caregivers of typical children for comparison of social network and social network characteristics. Studies addressing the flow of social support throughout social networks should include a survey instrument that collects detailed information about the actor-actor connections of the ego, including directional social support information, technologies used to maintain the relationships, as well as frequency of contact, proximity of network members, and role relations.

Second, role relations, or the description of the many roles of network members, whether they are broadly categorized into formal and informal sources or more specifically categorized by their relation to each other (i.e., kin, friend, colleague, etc.)

may provide additional context for clarifying the relationship between social support and the functional and structural characteristics of social networks. Third, additional data regarding caregiver burden could be incorporated to provide richer context for the needs and flow of social support through their networks. Perhaps rather than age of diagnosis, a more informative variable to study would be time since diagnosis, which may provide a better indication of the opportunities for the family to seek and receive services. Angold et al., (1998) suggest that particular disorders or behaviors may have a greater impact on caregiver burden, while Bishop et al., (2007) suggest that child adaptive behavior is an important factor. Both of these relationships are worthy of further study for their potential mediation in caregiver burden and overall family functioning.

Fourth, in regards to the technologies studied, it may be more useful to focus on mobile versus desktop computing patterns, given the trends in cheaper and faster mobile computing power. Finally, future studies should consider the need to generalize insights to the broader caregiving population so that models of behavior can eventually lead to improved services and interventions. Rather than convenience sampling, a list of caregivers served by educational services within a particular region could be used to recruit a sample that is representative of the national or regional caregiver population. In sum, this population is largely uncharacterized, but deserving of further study as the caregivers of millions of American children with special needs.

One interesting question is the nature of the relationship between social support and social network properties – do these results reflect inherent characteristics of the channel(s) selected to maintain the relationships or the way that these participants chose to use them? How can professionals make use of the best features of each technology to improve the access of caregivers to the support they need?

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APPENDICES

Appendix A: Semi-structured Interview Script

Interview procedure

- Interviews will be audio recorded to reduce the likelihood of investigator error when collecting data during the interview. Relevant portions of the audio recordings will then be transcribed for analysis.
- Digital photos of the sociograms created by research participants will be taken to back up the visualized network data constructed during the interview.

Instructions to participants

"There will be three parts to this interview. You can ask for a break at any time. You can also decide not to answer any of the questions if you are uncomfortable or just prefer not to answer. The questions in this interview will help me understand how you get and share information with the people in your life.

The first part includes questions about your basic history. The second part is a survey that will tell me about your knowledge of health terms; don't worry, it isn't a pass or fail kind of test. The last part will include several questions about people in your life who provide information and support that helps you care for your child."

Demographic information (5 minutes)

Race: African-American | American Indian or Alaska Native | Asian | Native Hawaiian or Other Pacific Islander | Caucasian | Other
Ethnicity: Hispanic | Non-hispanic
Age:
Residence (Town, State):
Highest level of education completed:
Profession:
How many people live in your household? How many are children?

Background questions (15 minutes)

Tell me about [*name of individual cared for*] with autism:

- What are his/her favorite activities?
- Does s/he live with you?
- How old is s/he?
- What is the diagnosis?
- When was s/he diagnosed?

Tell me about a recent health problem related to autism that [*name of individual cared for*] has experienced:

- What questions did you have because of this health problem?
- How did you find the information you needed to make a decision?
- Were you able to find useful information?
- What did you do with the information you found/retrieved?
- How did you use the information to make your decision?
- Were you happy with the decision?

Tell me a little about your family and how they interact with [*name of individual cared for*]:

- Are there other family members with a developmental disability or autism?
- Do they ask questions about autism?
- Does your family ask about the interventions and strategies for [*name of individual cared for*]?

- Do you take [*name of individual cared for*] to family gatherings?
- Do they participate in interventions, if appropriate, when they are around [*name of individual cared for*]?
- Do they interfere with [*name of individual cared for*] treatments or interventions?
- Do they share information with you about autism?
    - current events and news items
    - local or state policies
    - research
    - community programs

Technology Use

- Access
    - Do you have a computer with internet access at home?
    - What type of internet connection do you have?
    - Do you have a phone with internet access?
    - If no home access, where do you go to get online?
- What is the main tool you use to go online? (Online defined as using email, browsing the web, IM/IRC, etc.)
- How frequently do you go online? (Online defined as using email, browsing the web, IM/IRC, etc.)

Autism-specific Information

Tell me how you get information about caring for [*name of individual cared for*], especially topics associated with autism:

- Which of these [technologies] do you use to get health information on autism?
    - email
    - Which [technologies] do you use the most (at least 1, no more than 3)?
- What type of autism [health] information do you look for, in general?
    - Do you browse or search the web? What tools do you use?
    - What are your favorite sources?
        - Why?
        - How long have you been using them?
        - How often do you check them?
- What type of [health] information about autism do you get from others?
    - Are you signed up for emails from national/local autism organizations?
    - Are you on any parent discussion lists?
    - Do you receive updates from national or local news organizations?
    - Do you attend parent support groups?
- What questions do you typically ask people in your network?
- What questions do you typically search for on the web or in books, magazines, or the library?
- Do you use one source for health information related to autism more than others? Tell me what you like about it?
- What type of resource (book, specific search engine, specific website, specific person, newsletter, etc.) do you use the most?
    - Please describe how you use it?
    - Why do you like and use it?

Health Literacy Survey – REALM (10 minutes)
(separate instrument)

Network Questions (60 minutes)
Instructions to participant: *"When answering the following questions, please consider only the past six months."*

Name Generators
1. Who else helps you care for [*name of individual cared for*]? (Not paid professionals)
2. Who is usually providing information when you get health information about autism from someone - without asking for an answer to a specific question?
   a. [prompters: friends/other parents, family, support groups, advocacy groups, etc.]
3. When you have a specific question related to [*name of individual cared for*] that isn't urgent, who do you go to first? How do you usually contact him/her/them?
4. When you have an urgent question related to [*name of individual cared for*], who do you go to first? How do you usually contact him/her/them?
5. When it comes to information about autism, who do you communicate with (f2f, phone, email, chat, etc.) most frequently or for the most time?
6. If [*name of individual cared for*] had a great day, learned something new, or did something that was really hard, who would you go out of your way to tell about it?

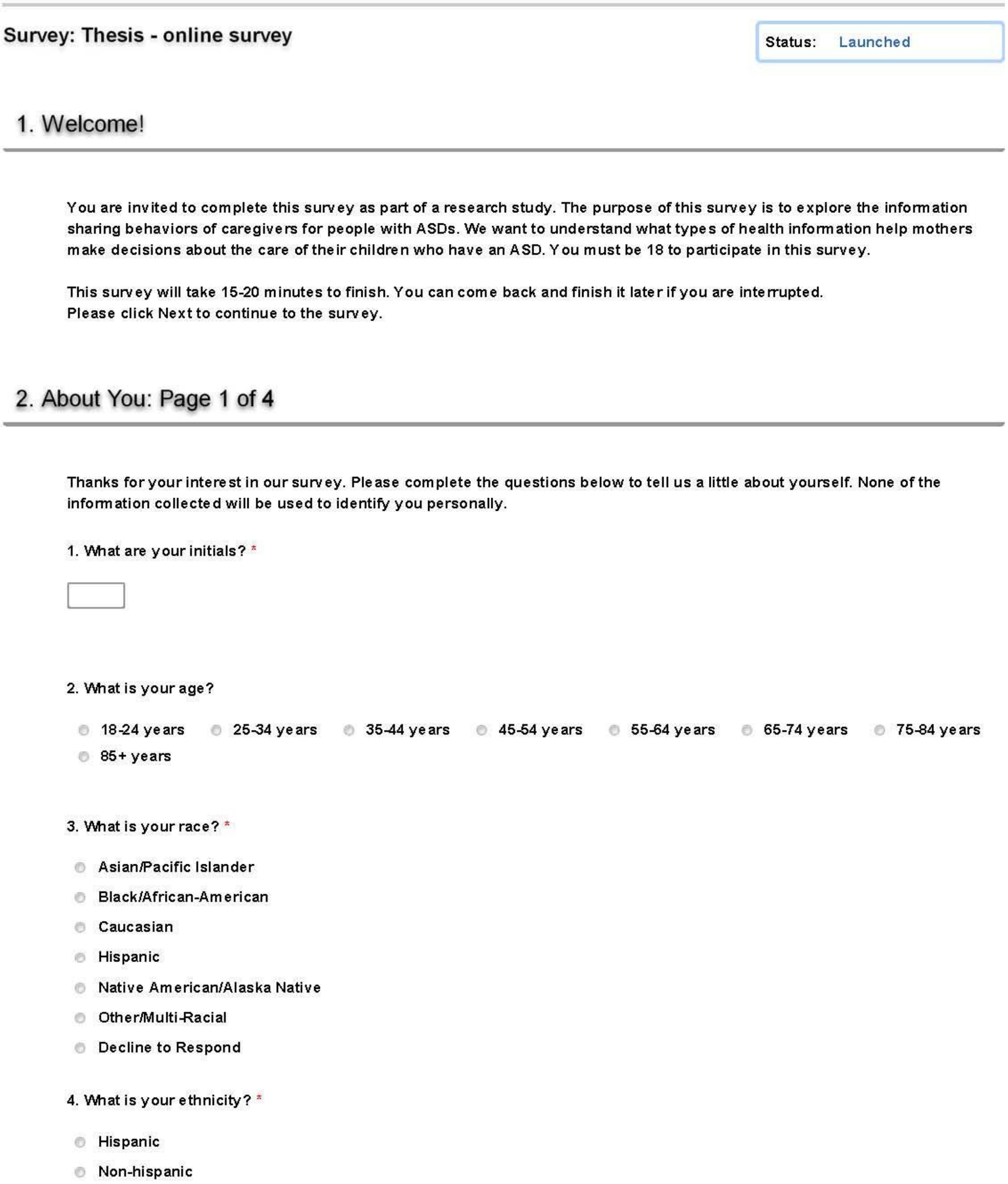
Building the sociogram
Instruction for participant: *"A sociogram is basically a drawing that will let us create a diagram of your social network. It will include each person's name and the ties among them. We'll use four concentric circles, where you are at the centre and people in your network are placed around you."*

The sociogram will be built in three steps:
1. Generating names
   a. Write on post-it papers, in no particular order, the people in your life (we'll call it your social network).
   b. Answering the Name Interpreter questions, add or mark those already on the list of people in your social network.
2. The participant will place each post-it paper (representing each alter) in one of four concentric circles, according to how "close" s/he feels about each person. They will be asked to place people who know each other nearby, to make the next step easier.
3. Finally, the participant will be asked to draw circles around groups of people who s/he thinks are very close, groups who were all somewhat close among them, and lines among pairs of very close or somewhat close people.

Name Interpreters (for each of the 10 selected alters, or all if fewer than 10 total alter)
1. Alter characteristics
   a. Age
   b. Gender
   c. Parent/caregiver for an individual with an ASD
   d. Residence
2. Face-to-face
   a. Frequency of interaction
   b. Length of interaction
   c. Who initiates
   d. Who goes to see the other person
3. Telephone
   a. Frequency of interaction
   b. Length of interaction
   c. Who initiates the call

4. Email
    a. Frequency of interaction
    b. Length of interaction
    c. Who initiates the call
5. Instant Messaging
    a. Frequency of interaction
    b. Length of interaction
    c. Who initiates the call
6. Text Messaging
    a. Frequency of interaction
    b. Length of interaction
    c. Who initiates the call
7. Information sharing/exchange of social capital
    a. Do you rely upon X for health information about ASD and related concerns? [rating scale – 5: frequently…1: never]
    b. Do you think that X relies upon you for health information about ASD and related concerns? [rating scale – 5: frequently…1: never]
    c. Do you rely upon X for other health information? [rating scale – 5: frequently…1: never]
    d. Do you actively share information about ASD and related concerns with X? [rating scale – 5: frequently…1: never]
    e. Do you actively share other health information with X regularly? [rating scale – 5: frequently…1: never]
8. Social support
    a. Do you discuss your concerns and seek advice about ASD and related issues with X? [rating scale – 5: frequently…1: never]
    b. Does X come to you to address concerns or seek advice about ASD and related issues? [rating scale – 5: frequently…1: never]
    c. Do you rely on X for emotional support when you encounter obstacles or challenges caring for [*name of individual cared for*]? [rating scale – 5: frequently…1: never]
    d. Does X come to you for emotional support when s/he encounters obstacles or challenges caring for his/her loved one? [rating scale – 5: frequently…1: never]
    e. Do you rely on X for assistance in providing care when you need help caring for [*name of individual cared for*]? [rating scale – 5: frequently…1: never]
    f. Does X rely on your for assistance in providing care when s/he needs help caring for his/her loved one? [rating scale – 5: frequently…1: never]

Appendix B: Online Survey



Survey: Thesis - online survey

Status: Launched

1. Welcome!

You are invited to complete this survey as part of a research study. The purpose of this survey is to explore the information sharing behaviors of caregivers for people with ASDs. We want to understand what types of health information help mothers make decisions about the care of their children who have an ASD. You must be 18 to participate in this survey.

This survey will take 15-20 minutes to finish. You can come back and finish it later if you are interrupted.
Please click Next to continue to the survey.

2. About You: Page 1 of 4

Thanks for your interest in our survey. Please complete the questions below to tell us a little about yourself. None of the information collected will be used to identify you personally.

1. What are your initials? *

☐

2. What is your age?

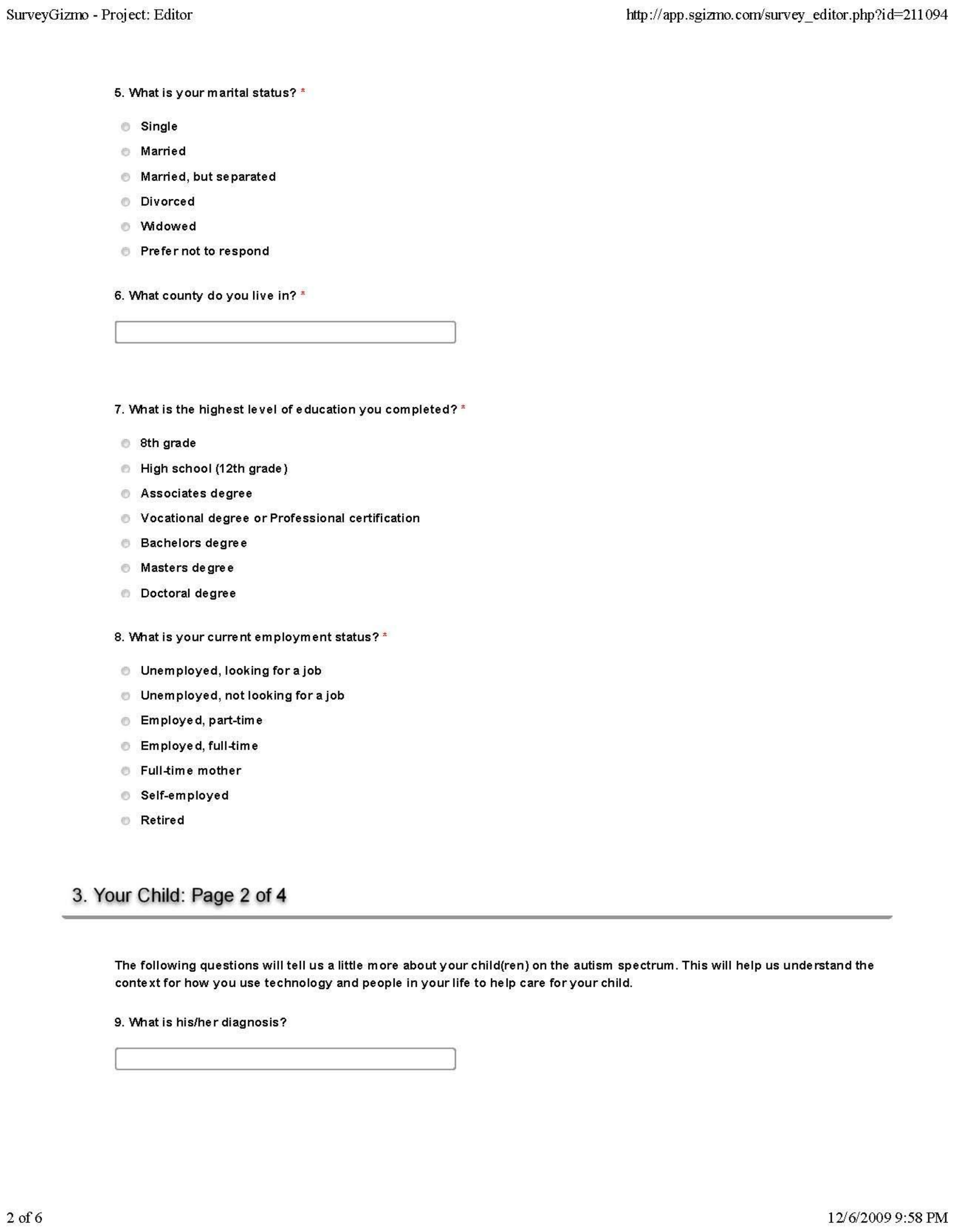
○ 18-24 years ○ 25-34 years ○ 35-44 years ○ 45-54 years ○ 55-64 years ○ 65-74 years ○ 75-84 years
○ 85+ years

3. What is your race? *

○ Asian/Pacific Islander
○ Black/African-American
○ Caucasian
○ Hispanic
○ Native American/Alaska Native
○ Other/Multi-Racial
○ Decline to Respond

4. What is your ethnicity? *

○ Hispanic
○ Non-hispanic



SurveyGizmo - Project: Editor http://app.sgizmo.com/survey_editor.php?id=211094

5. What is your marital status? *

○ Single
○ Married
○ Married, but separated
○ Divorced
○ Widowed
○ Prefer not to respond

6. What county do you live in? *

7. What is the highest level of education you completed? *

○ 8th grade
○ High school (12th grade)
○ Associates degree
○ Vocational degree or Professional certification
○ Bachelors degree
○ Masters degree
○ Doctoral degree

8. What is your current employment status? *

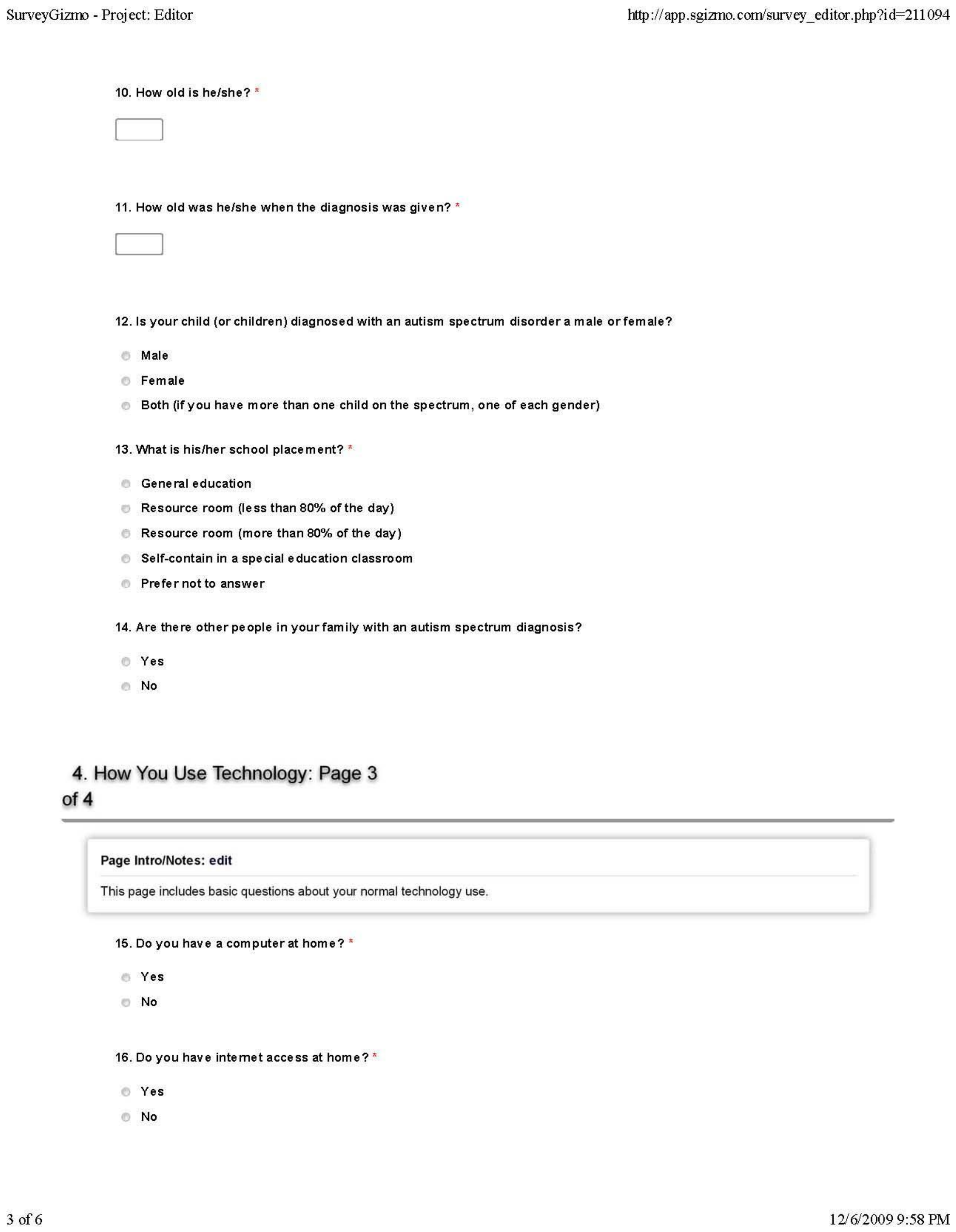
○ Unemployed, looking for a job
○ Unemployed, not looking for a job
○ Employed, part-time
○ Employed, full-time
○ Full-time mother
○ Self-employed
○ Retired

3. Your Child: Page 2 of 4

The following questions will tell us a little more about your child(ren) on the autism spectrum. This will help us understand the context for how you use technology and people in your life to help care for your child.

9. What is his/her diagnosis?

2 of 6 12/6/2009 9:58 PM



10. How old is he/she? *

11. How old was he/she when the diagnosis was given? *

12. Is your child (or children) diagnosed with an autism spectrum disorder a male or female?

○ Male
○ Female
○ Both (if you have more than one child on the spectrum, one of each gender)

13. What is his/her school placement? *

○ General education
○ Resource room (less than 80% of the day)
○ Resource room (more than 80% of the day)
○ Self-contain in a special education classroom
○ Prefer not to answer

14. Are there other people in your family with an autism spectrum diagnosis?

○ Yes
○ No

4. How You Use Technology: Page 3 of 4

Page Intro/Notes: edit

This page includes basic questions about your normal technology use.

15. Do you have a computer at home? *

○ Yes
○ No

16. Do you have internet access at home? *

○ Yes
○ No

17. What type of internet connection do you have?

○ Dial-up
○ DSL
○ Cable-modem
○ Satellite
○ T line
○ Other

18. How often do you get on the internet (use a browser)? This does not include email. *

○ Less than once a month
○ Monthly
○ Weekly
○ Daily

19. How much time do you spend on the internet each week? *

○ Less than 1 hour
○ 1-7 hours (average 1 hour a day)
○ 8-14 hours (average 2 hours a day)
○ 14-21 hours (average 3 hours a day)
○ 22+ hours

20. Which do you use most? Pick up to three. *

☐ browsers (Internet Explorer, Firefox, Opera, Safari, etc.)
☐ email
☐ chat/instant messaging
☐ social networking sites (Facebook, MySpace, Flickr, etc.)
☐ telephone
☐ text messaging

5. People in Your Life: Page 4 of 4

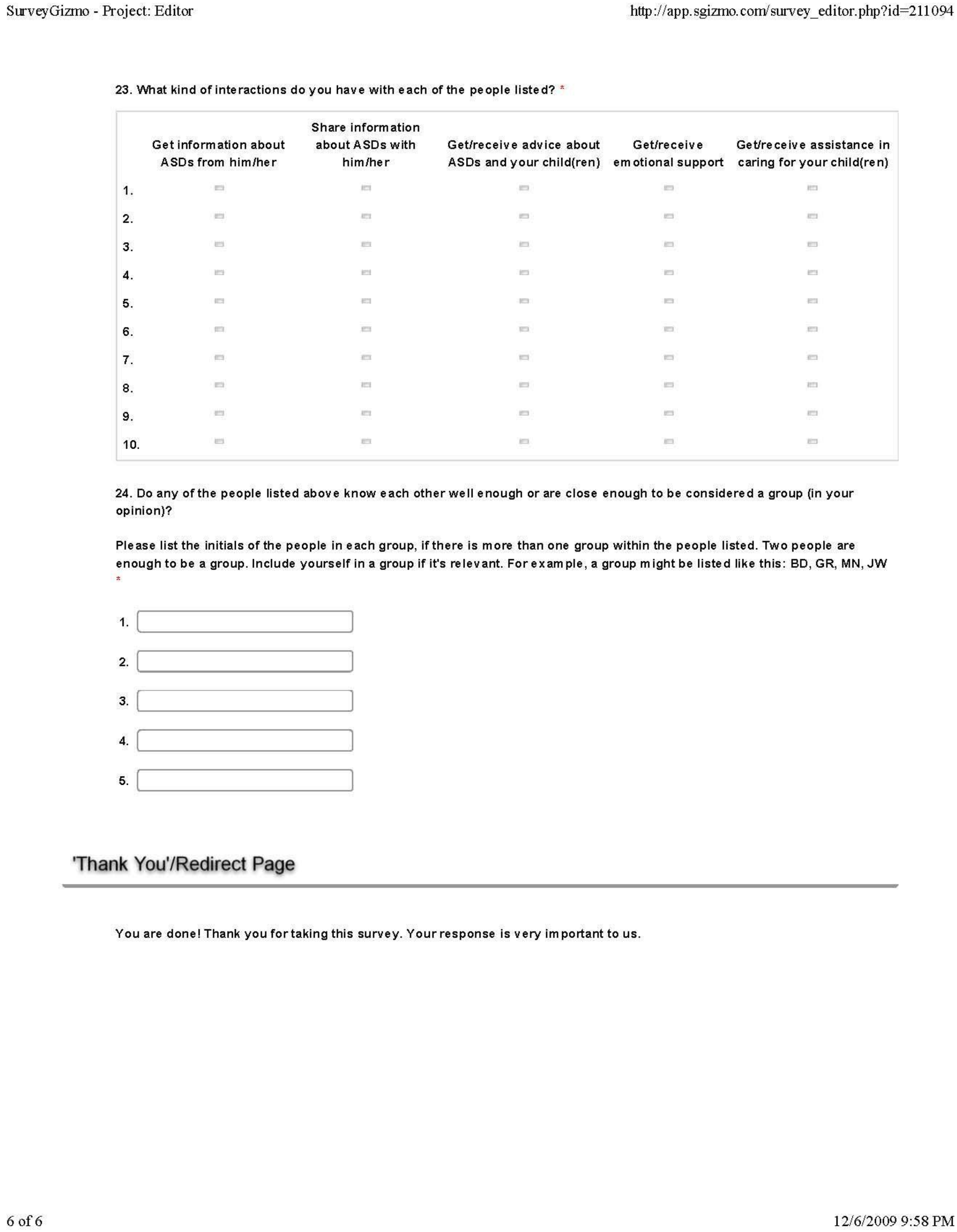
21. Please list the initials of all of the people in your life who:
-help you care for your child diagnosed with an ASD
-share information with you about ASDs
-who you share information with about ASDs
-who provide emotional support when you need it.

The next two questions should be answered for each of the people you list here. If your best friend is number 2 in this question, please enter the answers for him/her under number 2.
*

1. ☐
2. ☐
3. ☐
4. ☐
5. ☐
6. ☐
7. ☐
8. ☐
9. ☐
10. ☐

22. How do you communicate with each of the people listed below? *

	Face-to-Face	Telephone	Texting	Email	Chat/Instant Messaging	Social Networking Sites (Facebook, MySpace, etc.)	N/A
1.	☐	☐	☐	☐	☐	☐	☐
2.	☐	☐	☐	☐	☐	☐	☐
3.	☐	☐	☐	☐	☐	☐	☐
4.	☐	☐	☐	☐	☐	☐	☐
5.	☐	☐	☐	☐	☐	☐	☐
6.	☐	☐	☐	☐	☐	☐	☐
7.	☐	☐	☐	☐	☐	☐	☐
8.	☐	☐	☐	☐	☐	☐	☐
9.	☐	☐	☐	☐	☐	☐	☐
10.	☐	☐	☐	☐	☐	☐	☐



23. What kind of interactions do you have with each of the people listed? *

	Get information about ASDs from him/her	Share information about ASDs with him/her	Get/receive advice about ASDs and your child(ren)	Get/receive emotional support	Get/receive assistance in caring for your child(ren)
1.	☐	☐	☐	☐	☐
2.	☐	☐	☐	☐	☐
3.	☐	☐	☐	☐	☐
4.	☐	☐	☐	☐	☐
5.	☐	☐	☐	☐	☐
6.	☐	☐	☐	☐	☐
7.	☐	☐	☐	☐	☐
8.	☐	☐	☐	☐	☐
9.	☐	☐	☐	☐	☐
10.	☐	☐	☐	☐	☐

24. Do any of the people listed above know each other well enough or are close enough to be considered a group (in your opinion)?

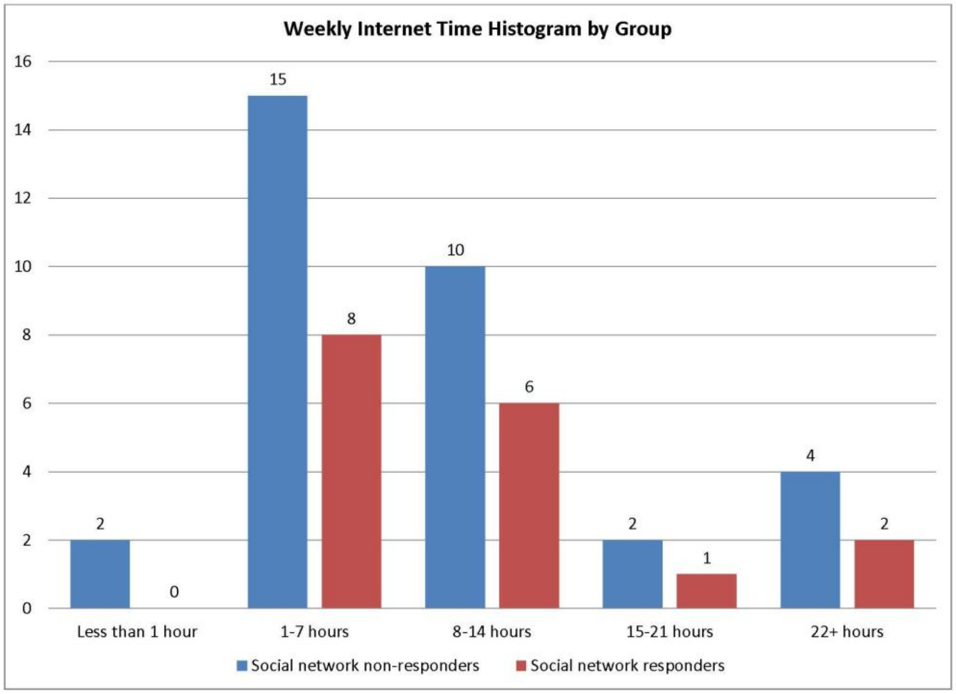
Please list the initials of the people in each group, if there is more than one group within the people listed. Two people are enough to be a group. Include yourself in a group if it's relevant. For example, a group might be listed like this: BD, GR, MN, JW *

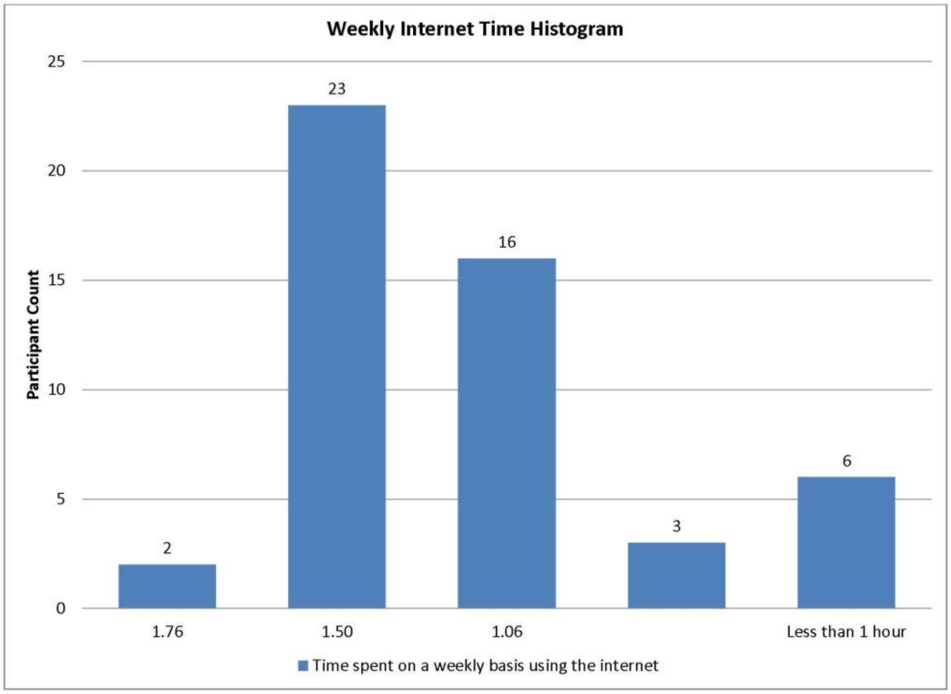
1. ______
2. ______
3. ______
4. ______
5. ______

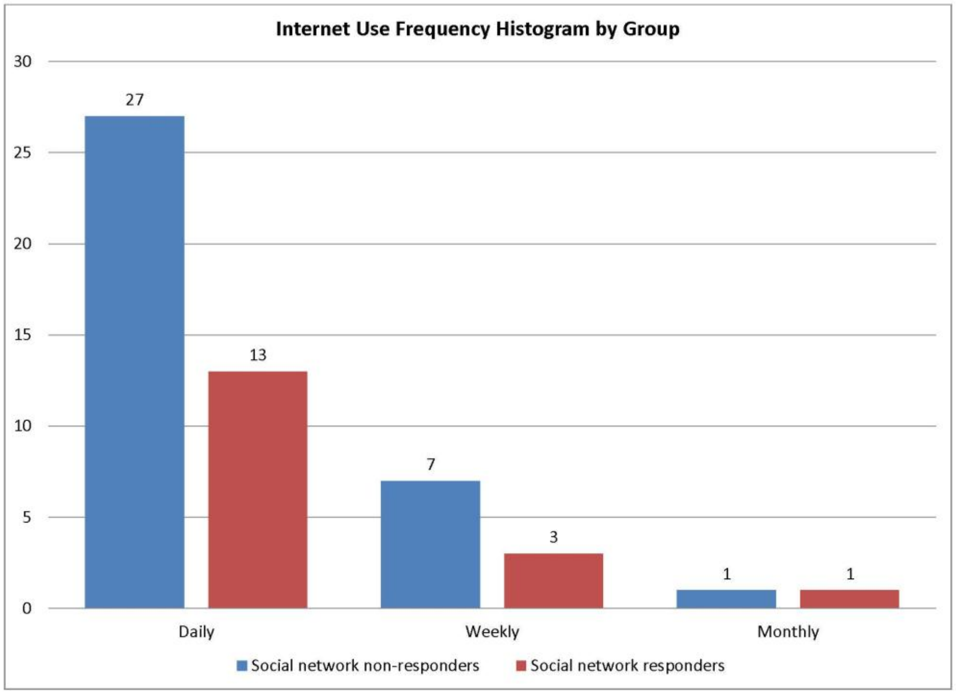
'Thank You'/Redirect Page

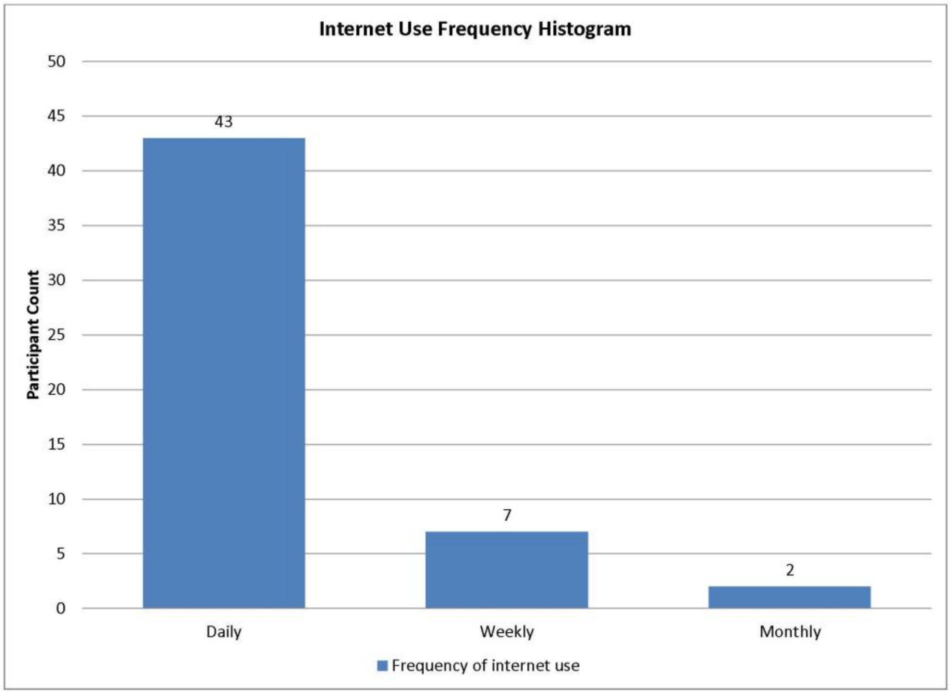
You are done! Thank you for taking this survey. Your response is very important to us.

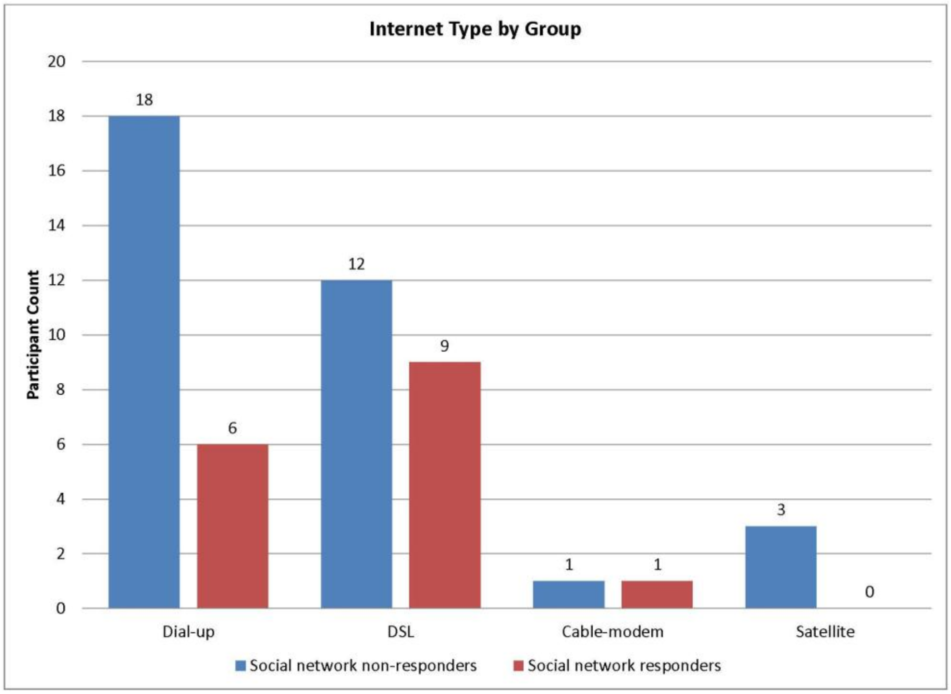
Appendix C: Additional Demographic Graphs and Tables

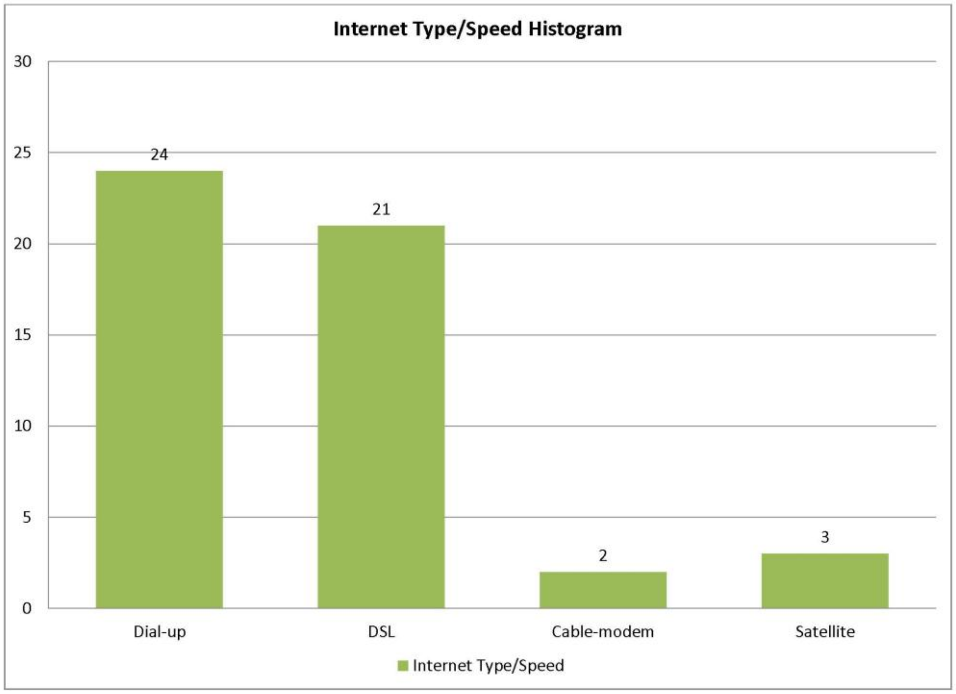

Weekly Internet Time Histogram by Group
16
14
12
10
8
6
4
2
0
2
0
15
8
10
6
2
1
4
2
Less than 1 hour
1-7 hours
8-14 hours
15-21 hours
22+ hours
Social network non-responders
Social network responders

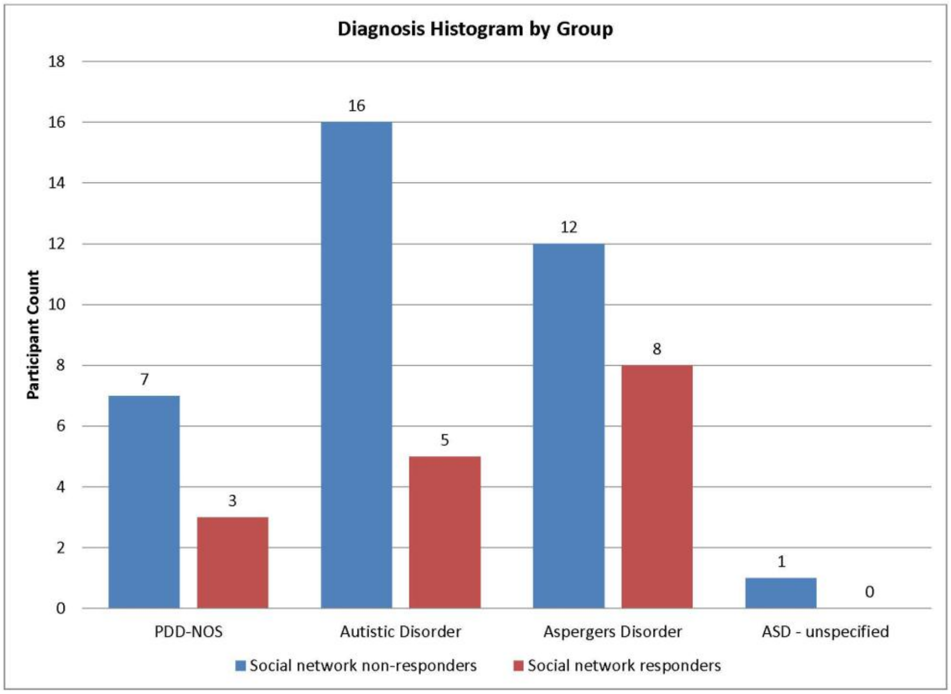

Weekly Internet Time Histogram
25
20
15
10
5
0
Participant Count
2
23
16
3
6
1.76
1.50
1.06
Less than 1 hour
Time spent on a weekly basis using the internet

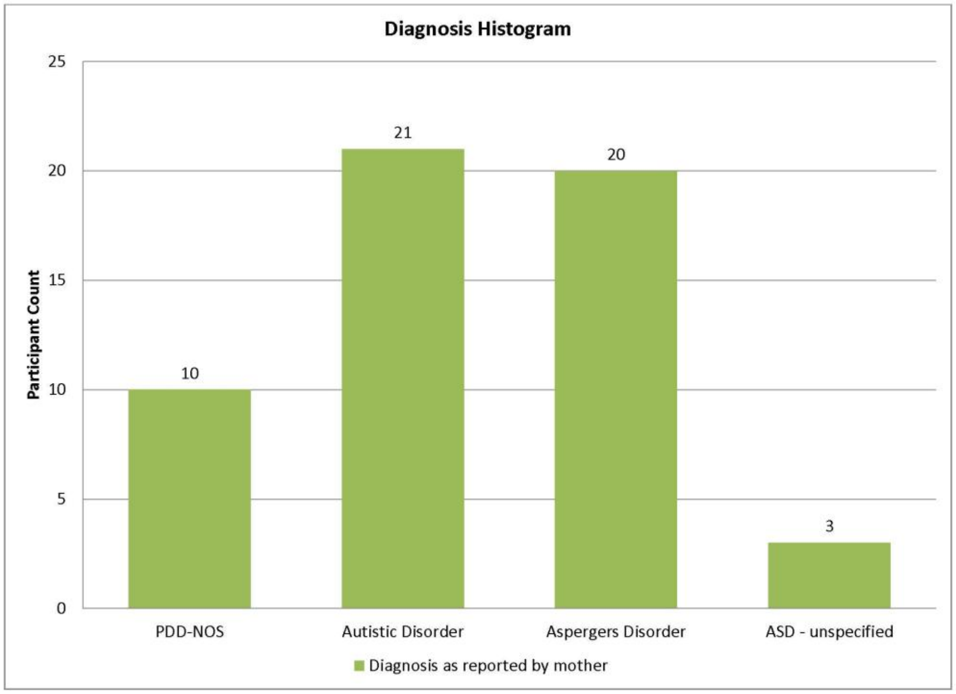

Internet Use Frequency Histogram by Group
30
25
20
15
10
5
0
27
13
7
3
1
1
Daily
Weekly
Monthly
Social network non-responders
Social network responders

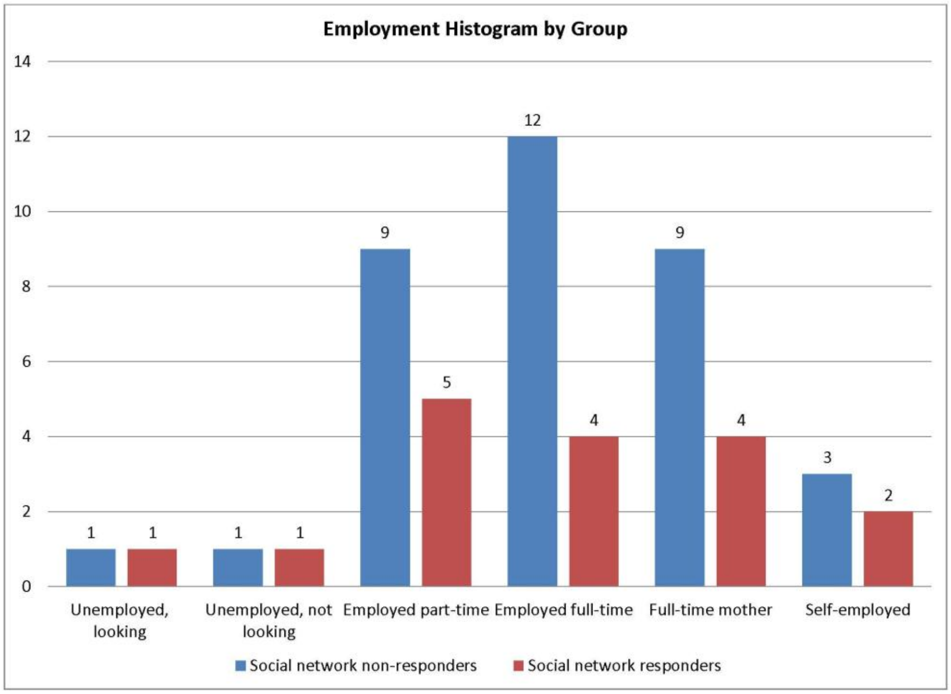

Internet Use Frequency Histogram
Participant Count
50
45
40
35
30
25
20
15
10
5
0
43
7
2
Daily
Weekly
Monthly
Frequency of internet use

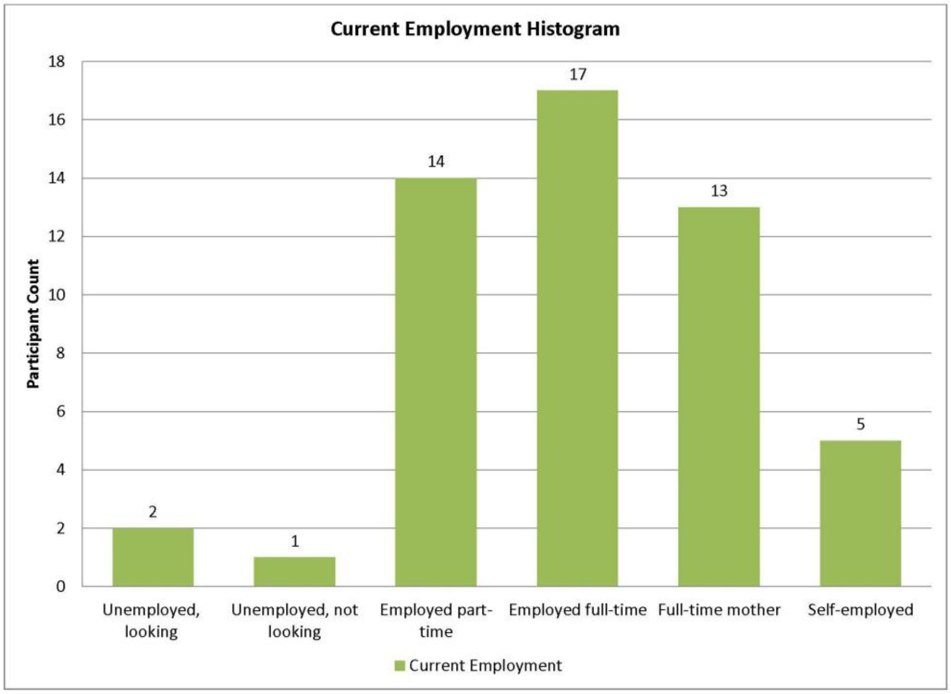

Internet Type by Group
Participant Count
20
18
16
14
12
10
8
6
4
2
0
18
6
12
9
1
1
3
0
Dial-up
DSL
Cable-modem
Satellite
🟦 Social network non-responders
🟥 Social network responders

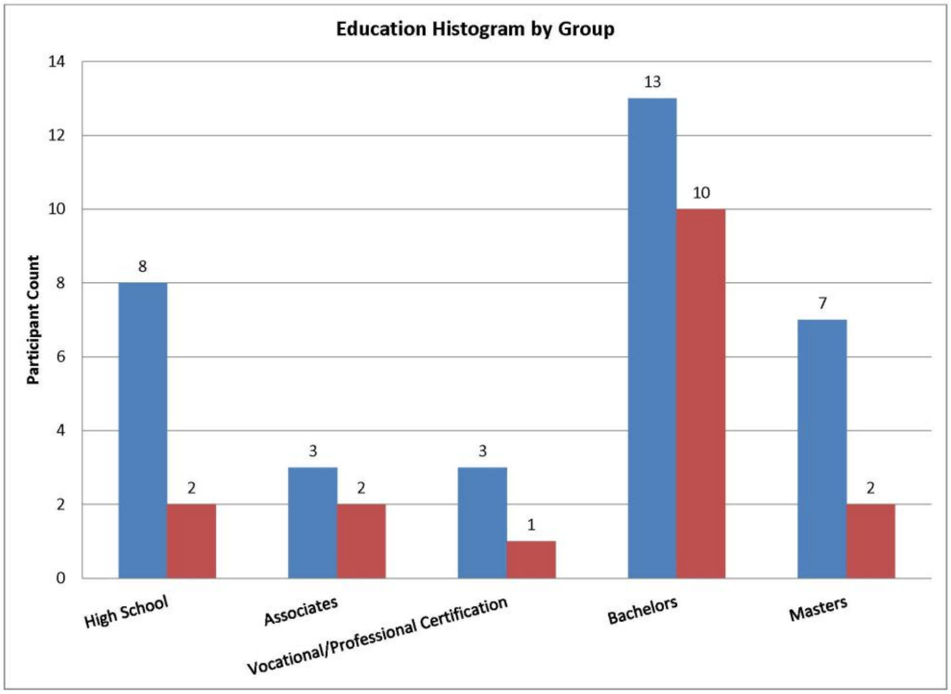

Internet Type/Speed Histogram
30
25
20
15
10
5
0
24
21
2
3
Dial-up
DSL
Cable-modem
Satellite
🟩 Internet Type/Speed

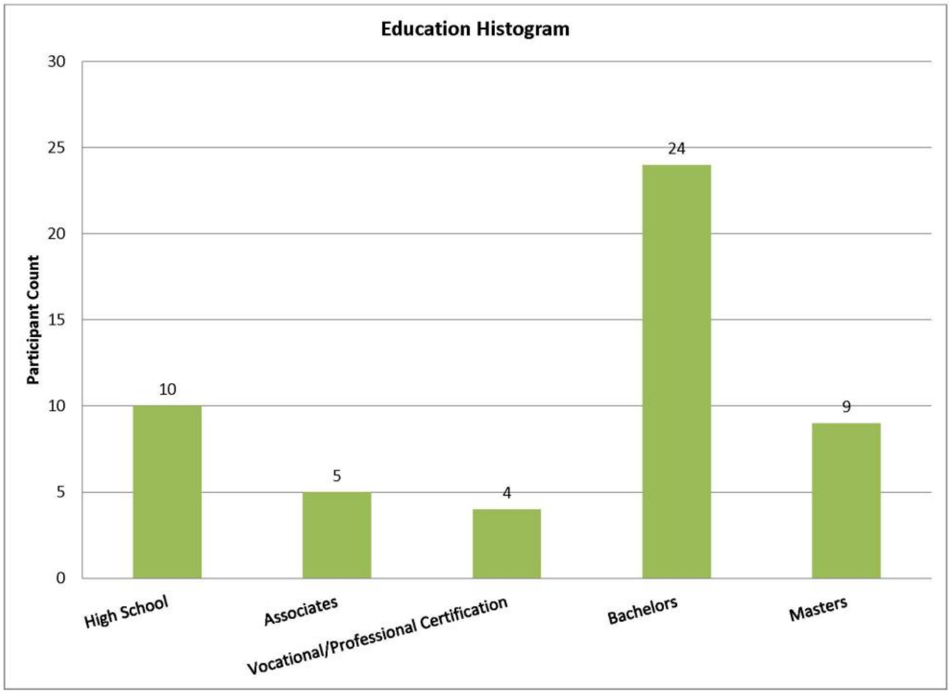

Diagnosis Histogram by Group
Participant Count
18
16
14
12
10
8
6
4
2
0
7
3
16
5
12
8
1
0
PDD-NOS
Autistic Disorder
Aspergers Disorder
ASD - unspecified
Social network non-responders
Social network responders

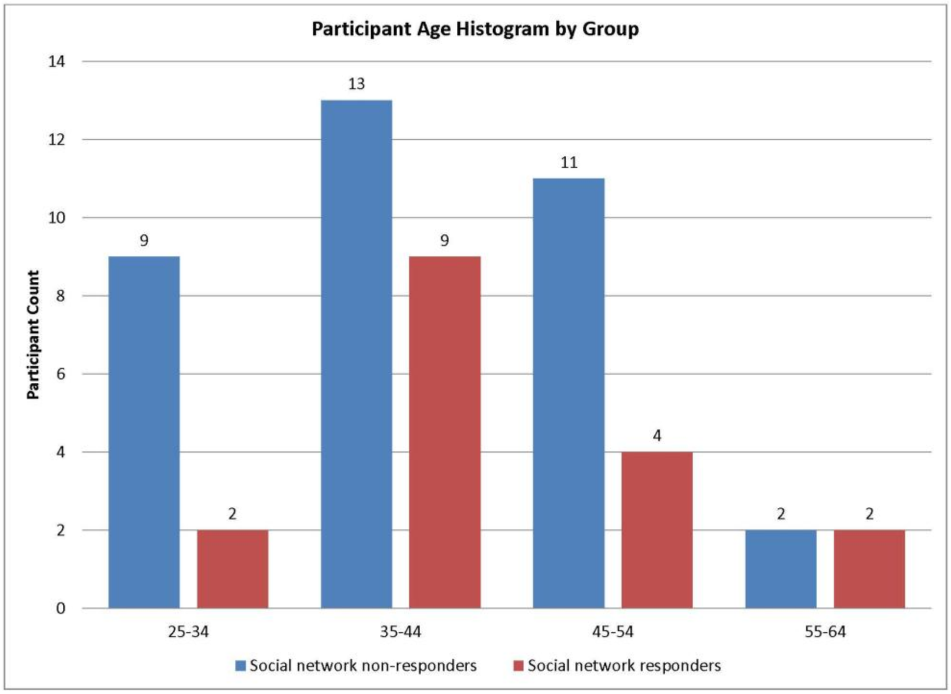

Diagnosis Histogram
Participant Count
25
20
15
10
5
0
10
21
20
3
PDD-NOS
Autistic Disorder
Aspergers Disorder
ASD - unspecified
Diagnosis as reported by mother

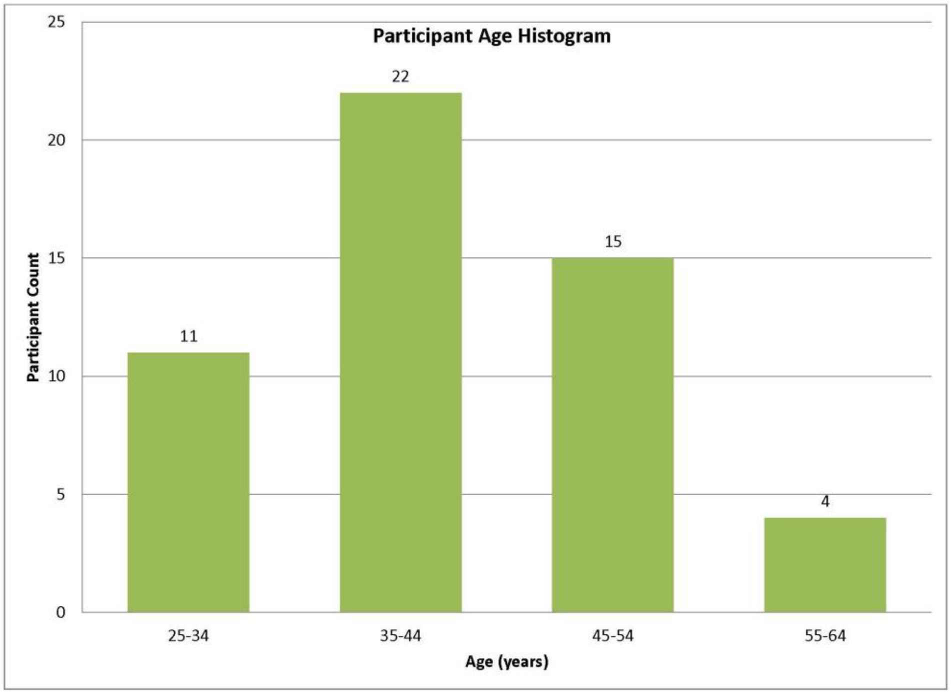

Employment Histogram by Group
14
12
10
8
6
4
2
0
1
1
1
1
9
5
12
4
9
4
3
2
Unemployed, looking
Unemployed, not looking
Employed part-time
Employed full-time
Full-time mother
Self-employed
Social network non-responders
Social network responders

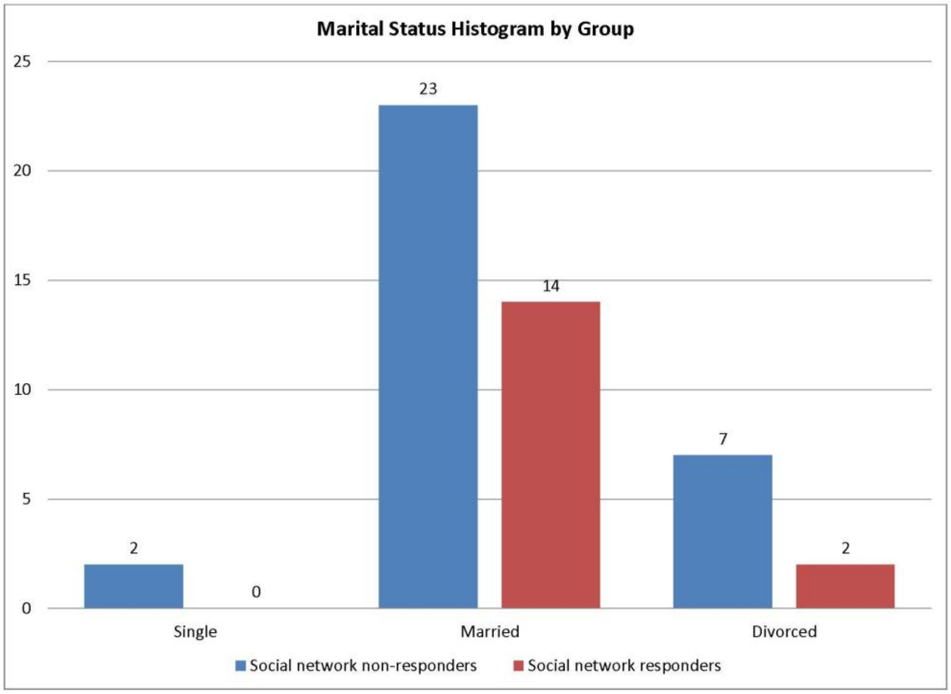

Current Employment Histogram
Participant Count
18
16
14
12
10
8
6
4
2
0
2
1
14
17
13
5
Unemployed, looking
Unemployed, not looking
Employed part-time
Employed full-time
Full-time mother
Self-employed
Current Employment

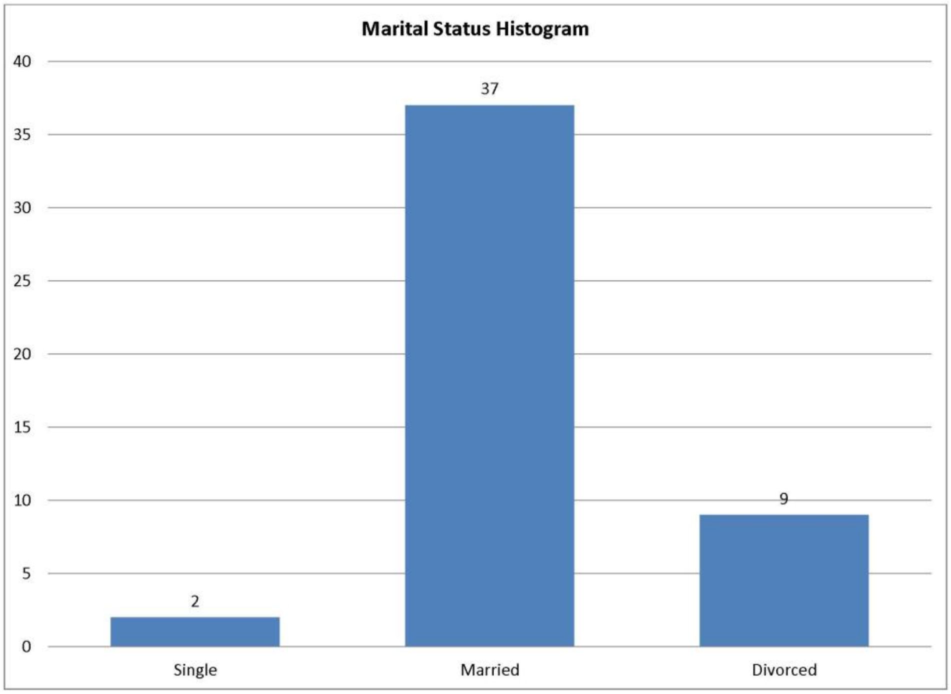

Education Histogram by Group
Participant Count
14
12
10
8
6
4
2
0
8
2
3
2
3
1
13
10
7
2
High School
Associates
Vocational/Professional Certification
Bachelors
Masters

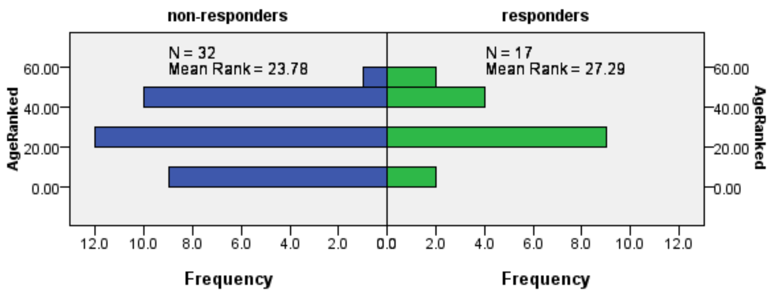

Education Histogram
Participant Count
30
25
20
15
10
5
0
10
5
4
24
9
High School
Associates
Vocational/Professional Certification
Bachelors
Masters


Participant Age Histogram by Group
Participant Count
14
12
10
8
6
4
2
0
9
2
13
9
11
4
2
2
25-34
35-44
45-54
55-64
Social network non-responders
Social network responders


Participant Age Histogram
Participant Count
25
20
15
10
5
0
11
22
15
4
25-34
35-44
45-54
55-64
Age (years)


Marital Status Histogram by Group
25
20
15
10
5
0
23
14
7
2
0
2
Single
Married
Divorced
Social network non-responders
Social network responders

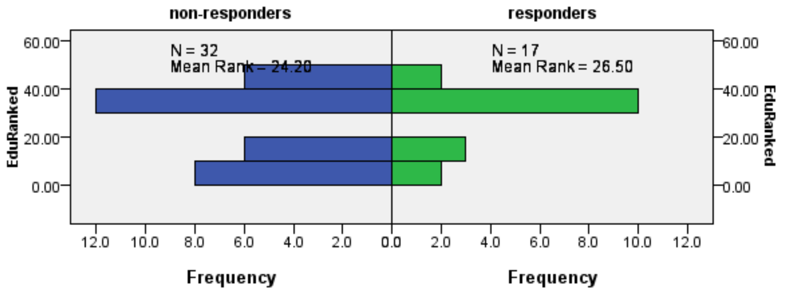

Marital Status Histogram
40
35
30
25
20
15
10
5
0
37
9
2
Single
Married
Divorced



Independent-Samples Mann-Whitney U Test

Groups (SN data completed)

Total N	49
Mann-Whitney U	311.000
Wilcoxon W	464.000
Test Statistic	311.000
Standard Error	44.834
Standardized Test Statistic	.870
Asymptotic Sig. (2-sided test)	.384



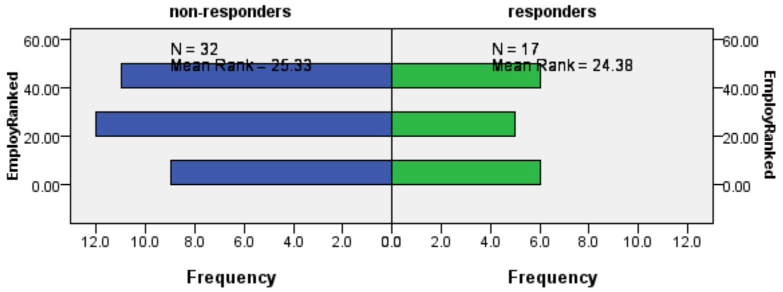
Independent-Samples Mann-Whitney U Test

Groups (SN data completed)

Total N	49
Mann-Whitney U	297.500
Wilcoxon W	450.500
Test Statistic	297.500
Standard Error	45.051
Standardized Test Statistic	.566
Asymptotic Sig. (2-sided test)	.571

Independent-Samples Mann-Whitney U Test

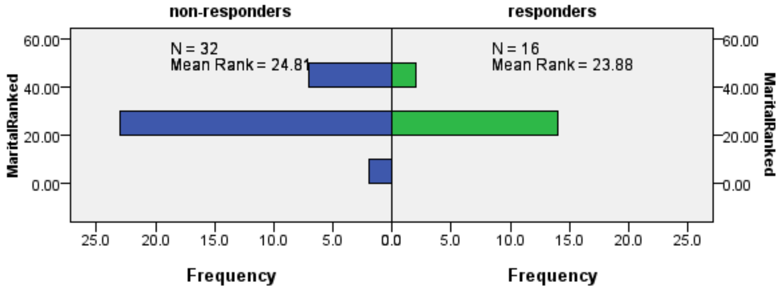
Groups (SN data completed)



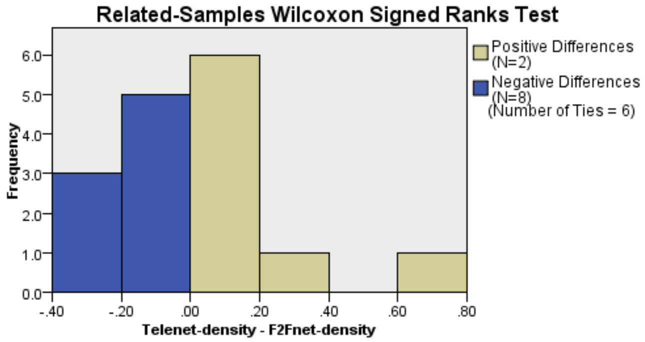
Total N	49
Mann-Whitney U	261.500
Wilcoxon W	414.500
Test Statistic	261.500
Standard Error	45.768
Standardized Test Statistic	-.229
Asymptotic Sig. (2-sided test)	.819

Independent-Samples Mann-Whitney U Test

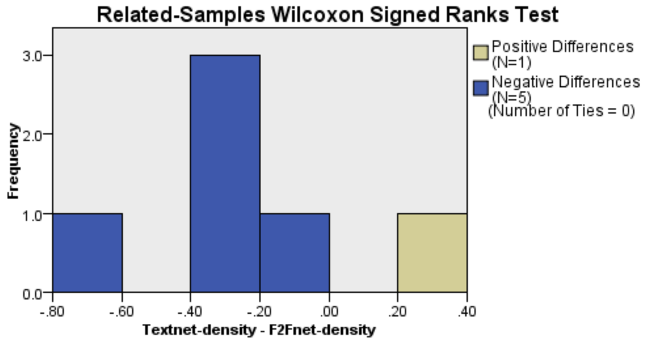
Groups (SN data completed)



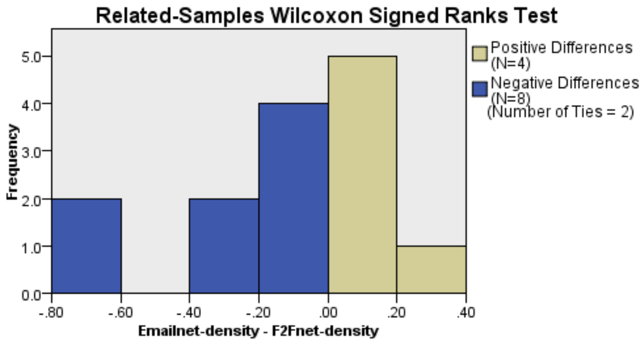
Total N	48
Mann-Whitney U	246.000
Wilcoxon W	382.000
Test Statistic	246.000
Standard Error	33.461
Standardized Test Statistic	-.299
Asymptotic Sig. (2-sided test)	.765



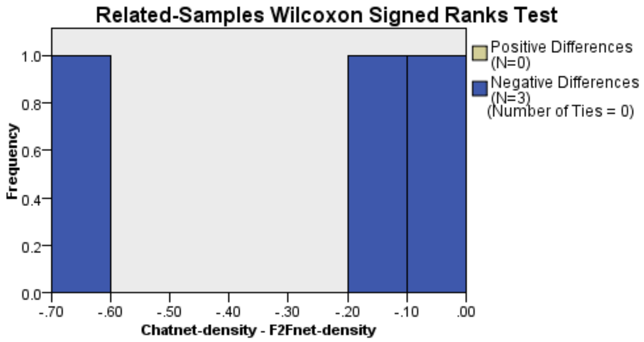
Total N	16
Test Statistic	18.000
Standard Error	9.804
Standardized Test Statistic	-.969
Asymptotic Sig. (2-sided test)	.333



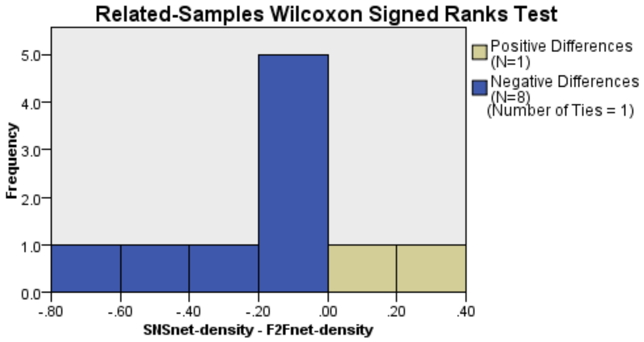
Total N	6
Test Statistic	5.000
Standard Error	4.770
Standardized Test Statistic	-1.153
Asymptotic Sig. (2-sided test)	.249



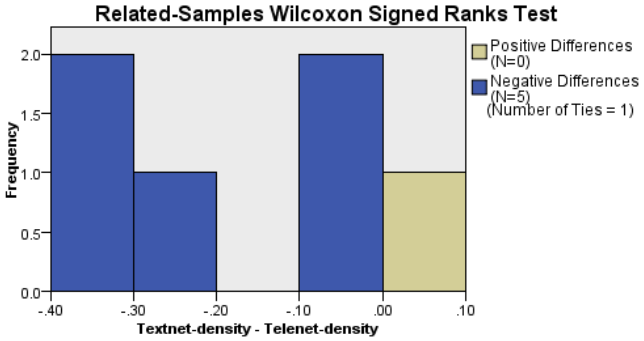
Total N	14
Test Statistic	16.500
Standard Error	12.743
Standardized Test Statistic	-1.766
Asymptotic Sig. (2-sided test)	.077



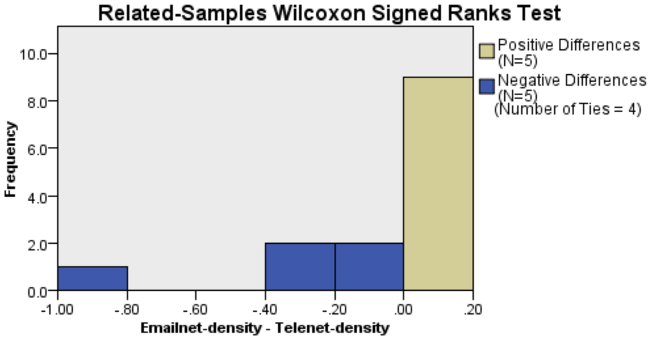
Total N	3
Test Statistic	.000
Standard Error	1.871
Standardized Test Statistic	-1.604
Asymptotic Sig. (2-sided test)	.109



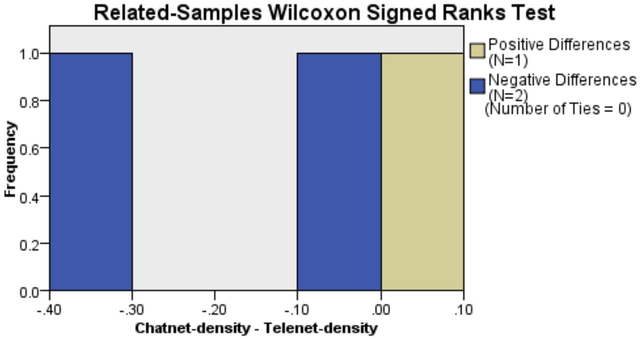
Total N	10
Test Statistic	7.000
Standard Error	8.441
Standardized Test Statistic	-1.836
Asymptotic Sig. (2-sided test)	.066



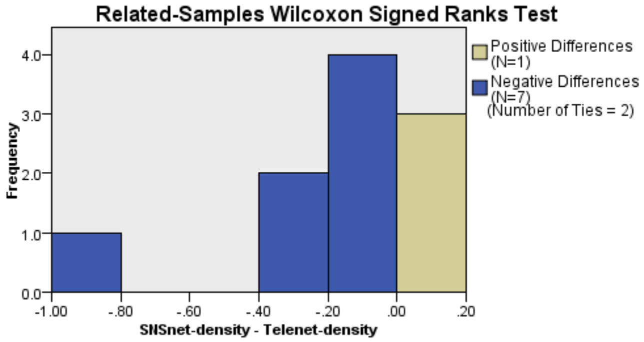
Total N	6
Test Statistic	.000
Standard Error	3.708
Standardized Test Statistic	-2.023
Asymptotic Sig. (2-sided test)	.043



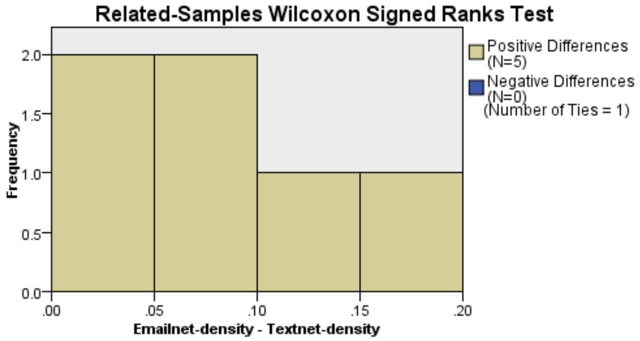
Total N	14
Test Statistic	17.000
Standard Error	9.811
Standardized Test Statistic	-1.070
Asymptotic Sig. (2-sided test)	.285



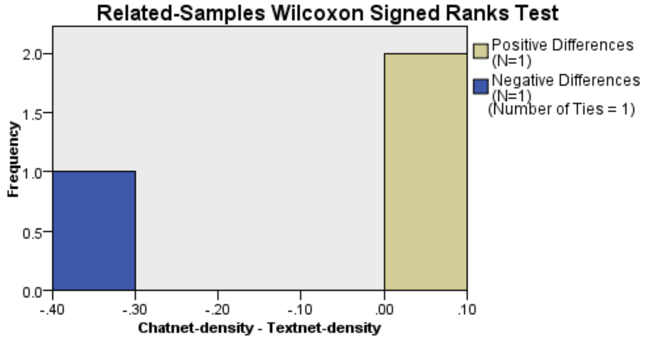
Total N	3
Test Statistic	1.000
Standard Error	1.871
Standardized Test Statistic	-1.069
Asymptotic Sig. (2-sided test)	.285



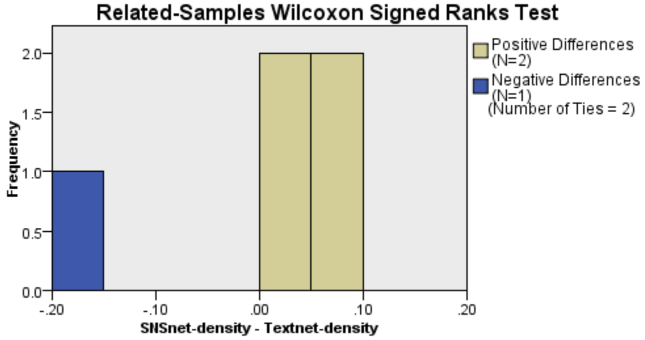
Total N	10
Test Statistic	1.000
Standard Error	7.141
Standardized Test Statistic	-2.380
Asymptotic Sig. (2-sided test)	.017



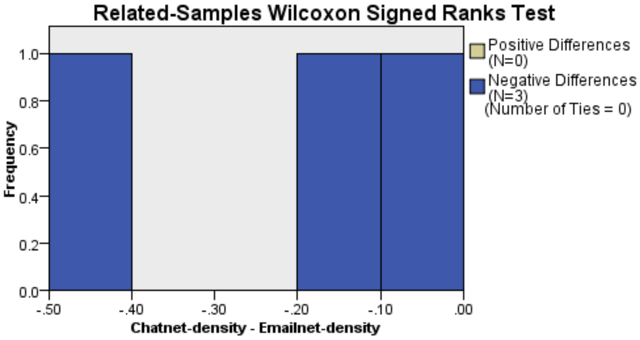
Total N	6
Test Statistic	15.000
Standard Error	3.708
Standardized Test Statistic	2.023
Asymptotic Sig. (2-sided test)	.043

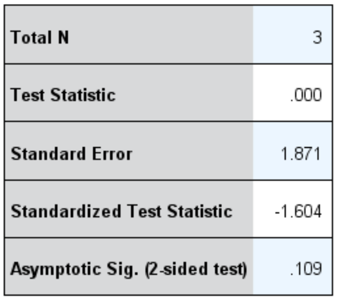


Total N	3
Test Statistic	1.000
Standard Error	1.118
Standardized Test Statistic	-.447
Asymptotic Sig. (2-sided test)	.655

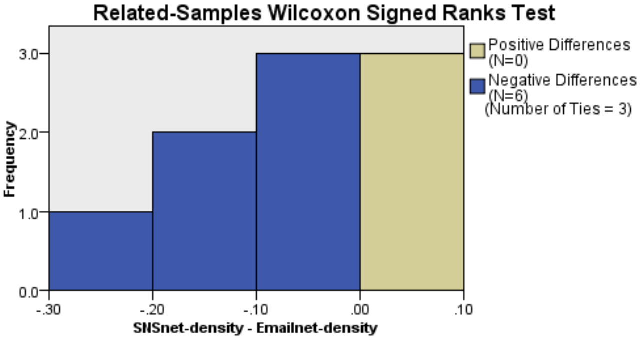


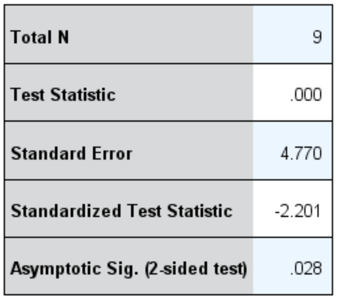
Total N	5
Test Statistic	3.000
Standard Error	1.837
Standardized Test Statistic	.000
Asymptotic Sig. (2-sided test)	1.000





Total N	3
Test Statistic	.000
Standard Error	1.871
Standardized Test Statistic	-1.604
Asymptotic Sig. (2-sided test)	.109





Total N	9
Test Statistic	.000
Standard Error	4.770
Standardized Test Statistic	-2.201
Asymptotic Sig. (2-sided test)	.028

Cronbach’s Alpha for Internal Consistency

Case Processing Summary

		N	%
Cases	Valid	17	30.9
	Excluded[a]	38	69.1
	Total	55	100.0

a. Listwise deletion based on all variables in the procedure.

Reliability Statistics

Cronbach's Alpha	Cronbach's Alpha Based on Standardized Items	N of Items
.789	.795	5

Item Statistics

	Mean	Std. Deviation	N
Get info	2.76471	2.332633	17
Share info	4.94118	2.860738	17
Advice	3.11765	2.735927	17
Emotional support	4.47059	2.981561	17
Assistance	3.64706	2.523420	17

Inter-Item Correlation Matrix

	Get info	Share info	Advice	Emotional support	Assistance
Get info	1.000	.419	.866	.421	.431
Share info	.419	1.000	.360	.568	.499
Advice	.866	.360	1.000	.399	.387
Emotional support	.421	.568	.399	1.000	.023
Assistance	.431	.499	.387	.023	1.000

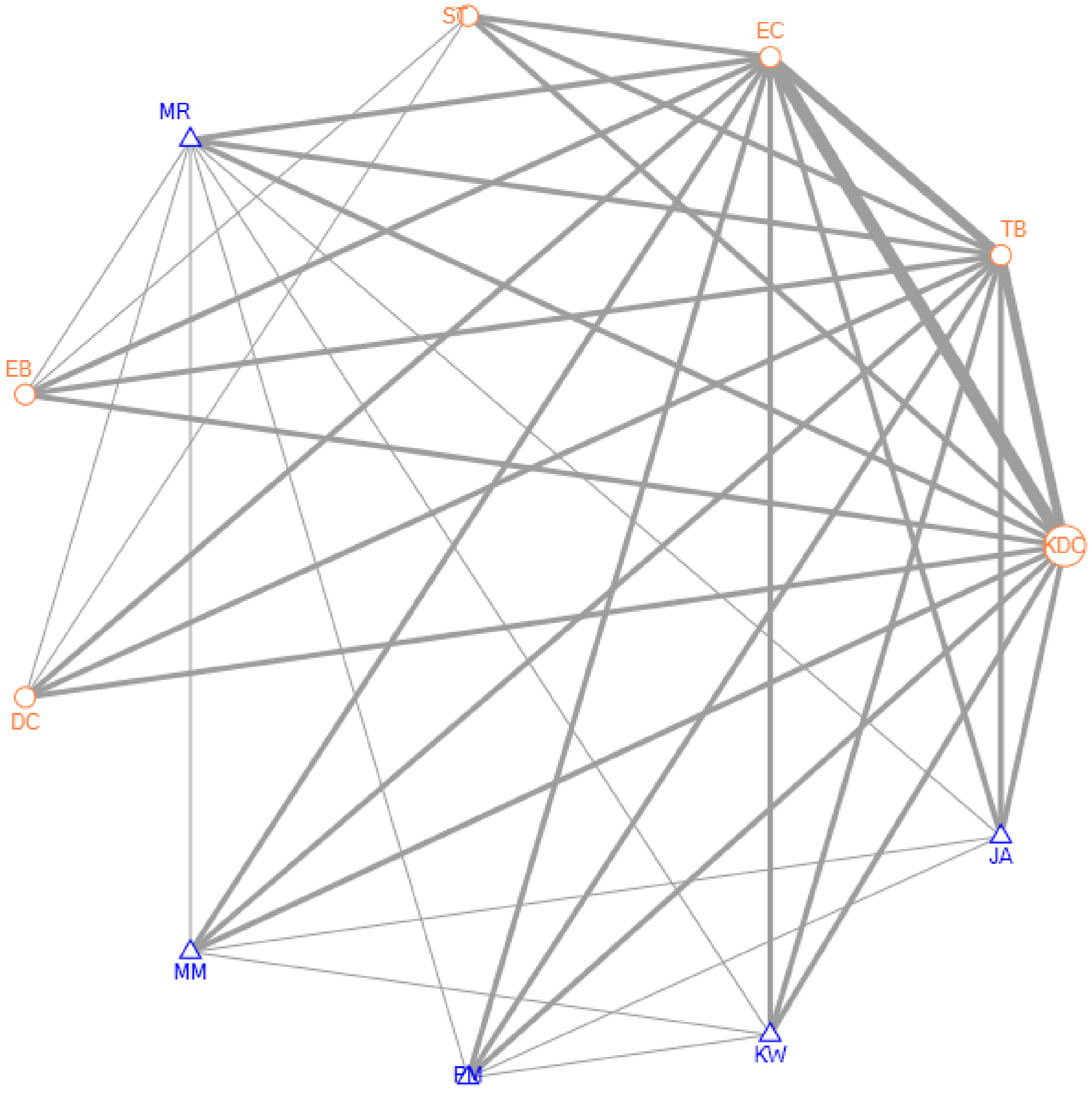
Item-Total Statistics

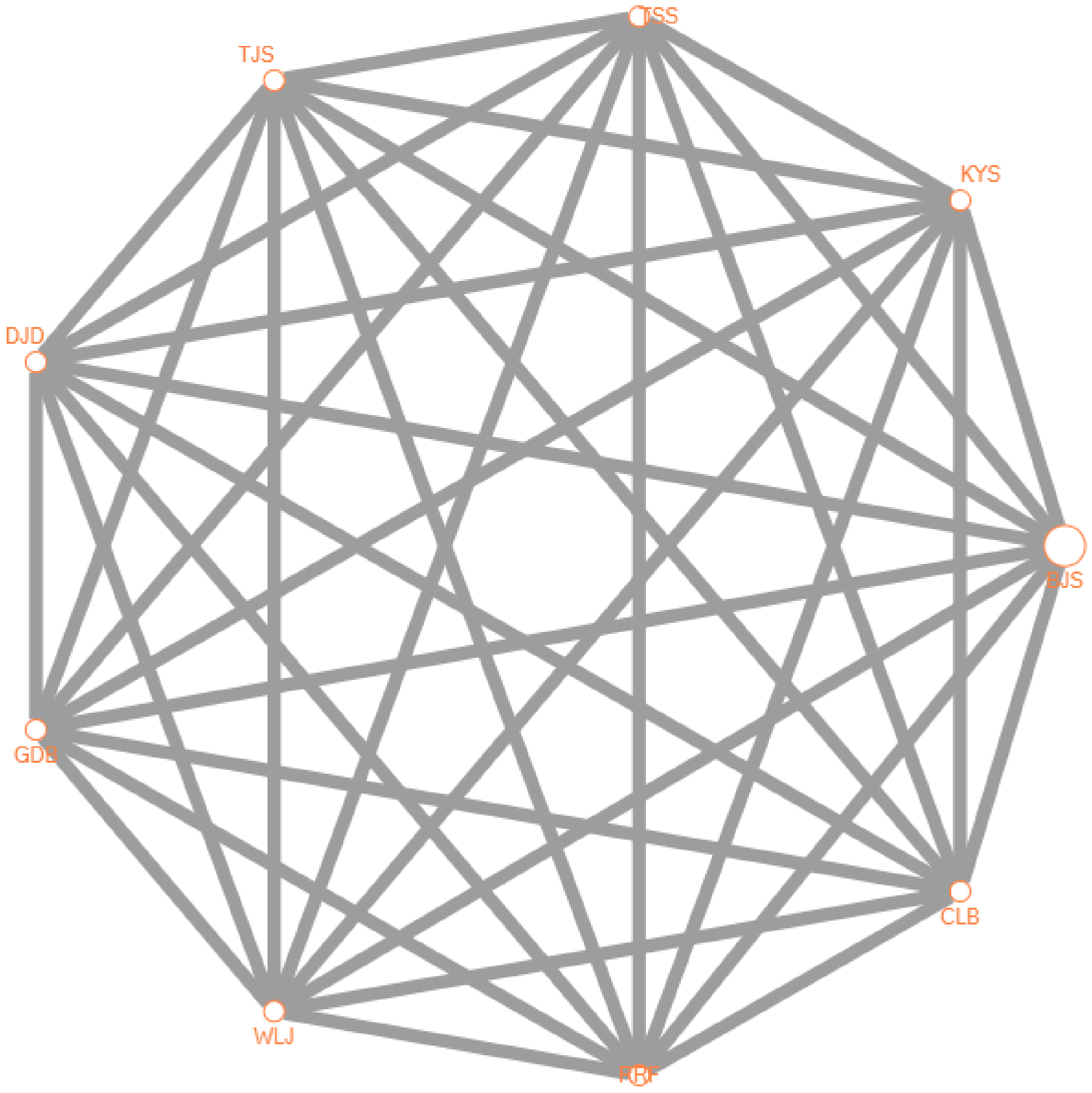
	Scale Mean if Item Deleted	Scale Variance if Item Deleted	Corrected Item-Total Correlation	Squared Multiple Correlation	Cronbach's Alpha if Item Deleted
Get info	16.17647	65.654	.730	.772	.705
Share info	14.00000	62.375	.622	.563	.731
Advice	15.82353	62.654	.659	.754	.719
Emotional support	14.47059	67.390	.458	.508	.790
Assistance	15.29412	74.346	.413	.463	.795

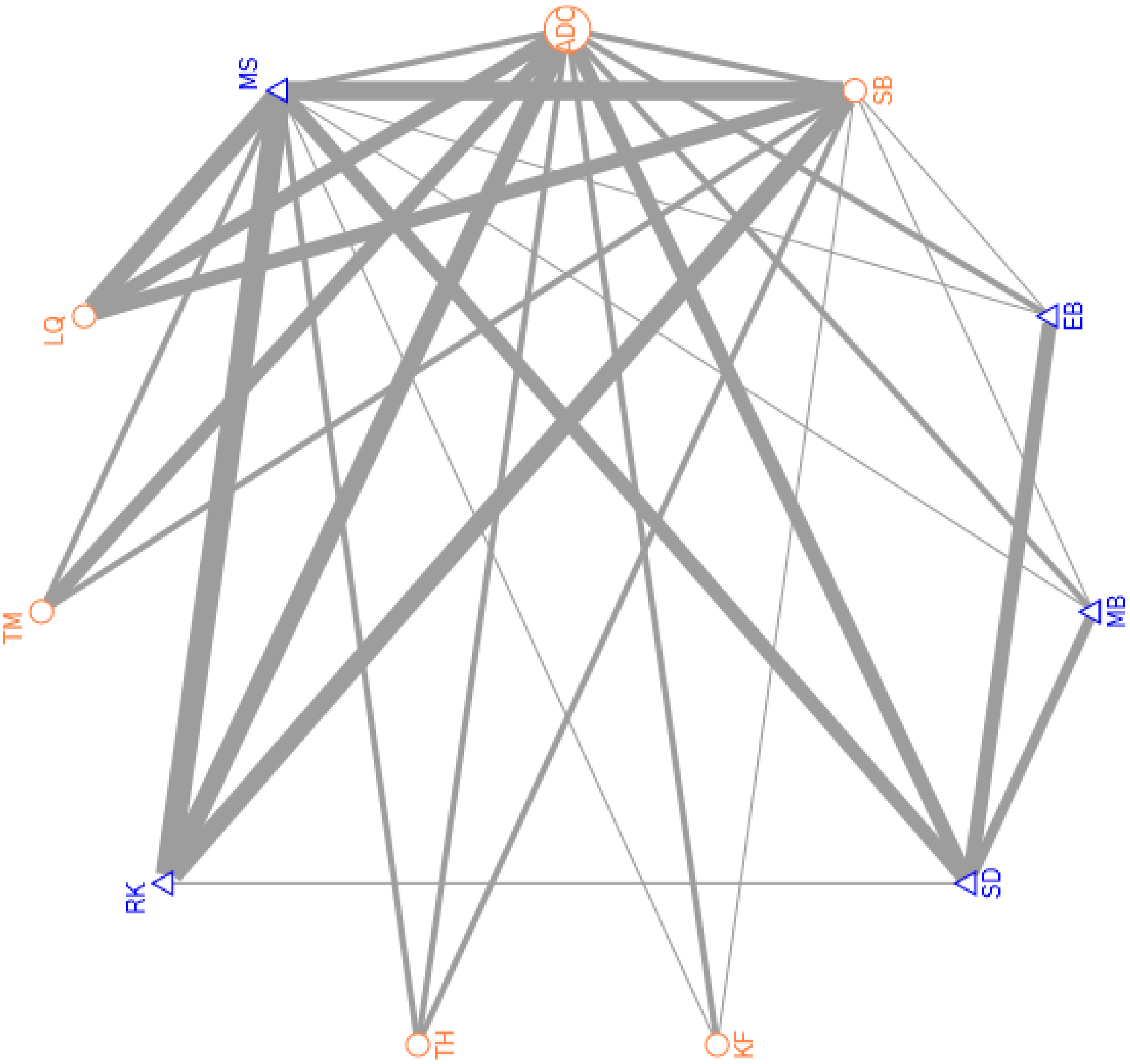
Scale Statistics

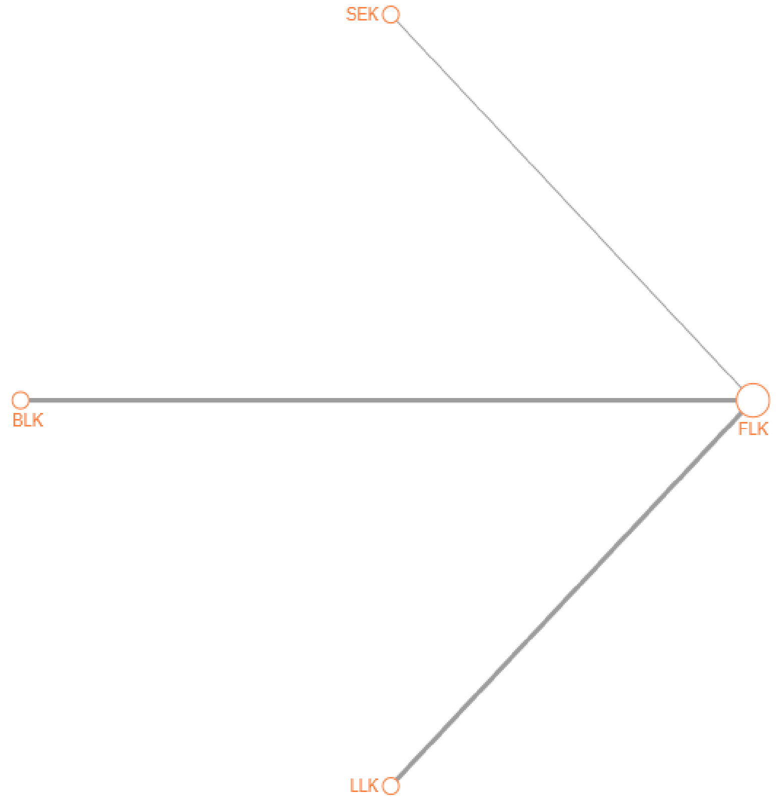
Mean	Variance	Std. Deviation	N of Items
18.94118	98.684	9.933973	5

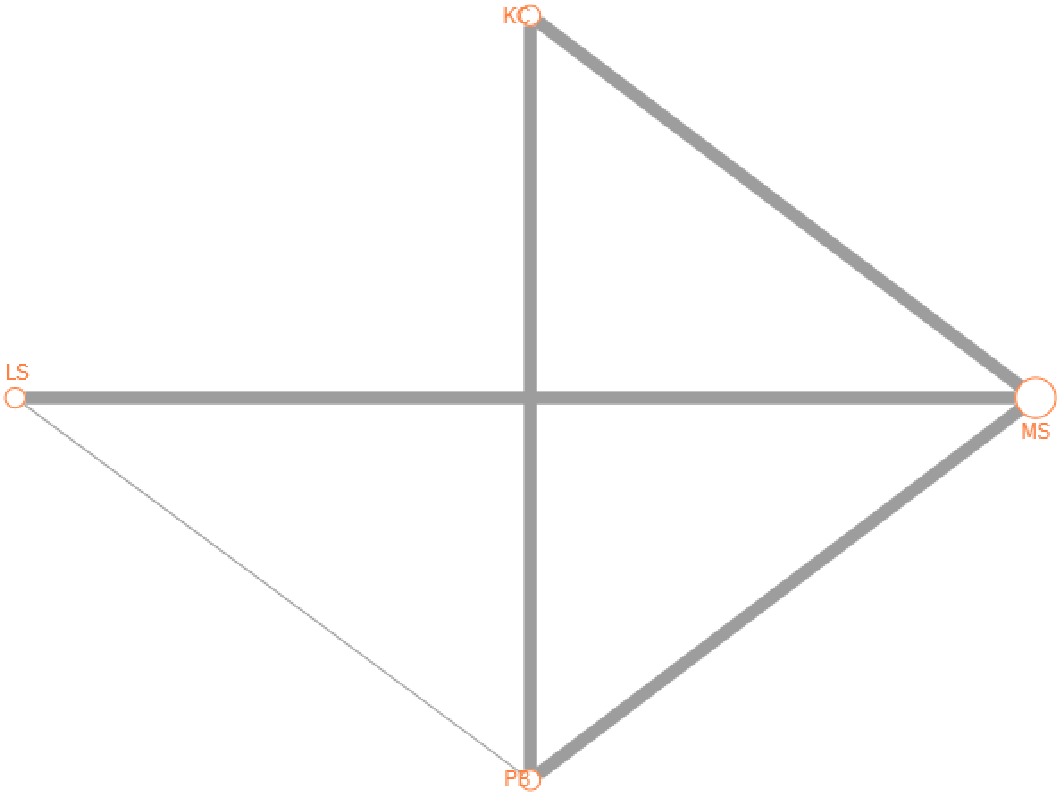
Appendix D: Participant Whole Network Sociograms

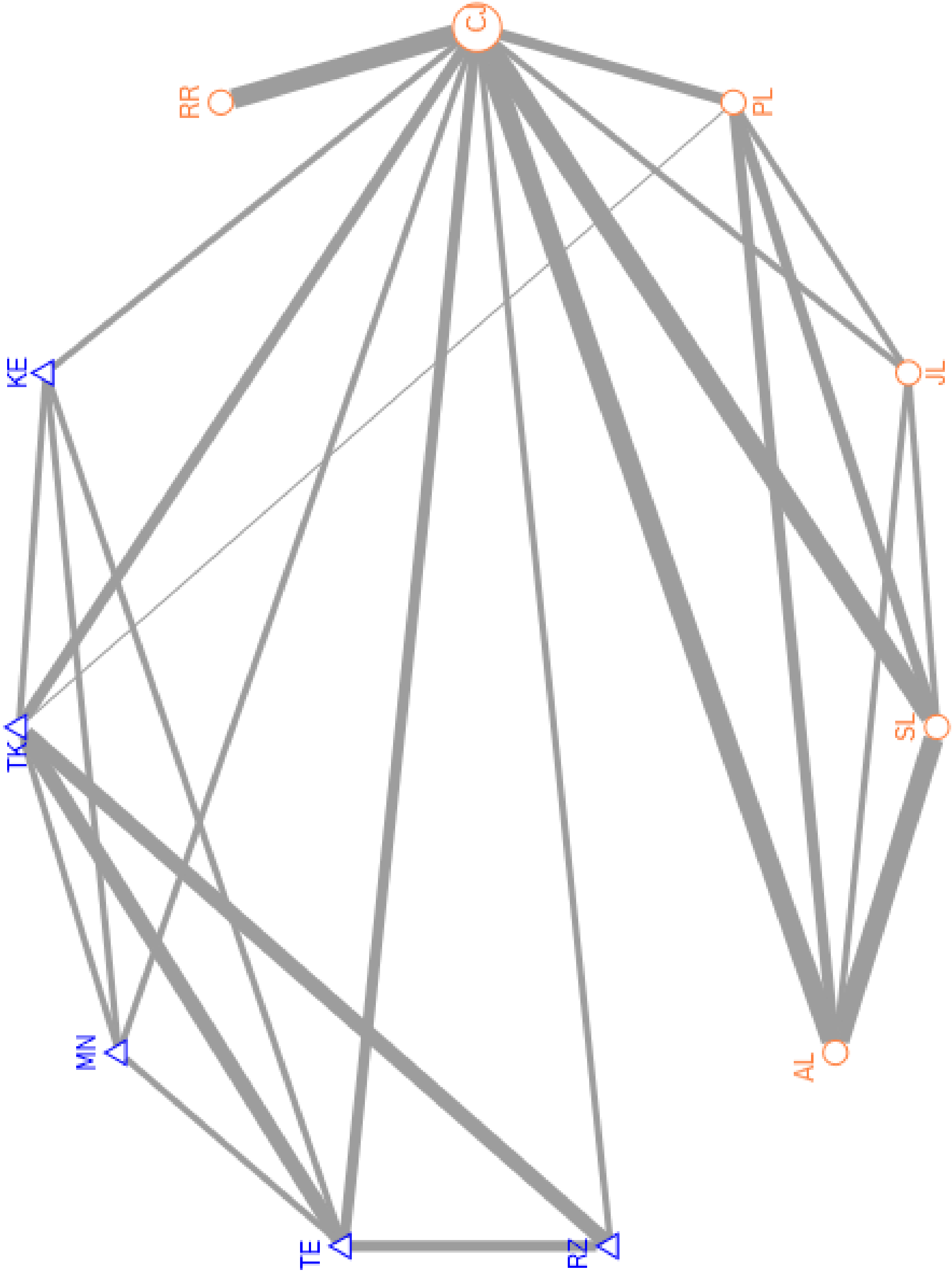

ST
EC
MR
TB
EB
KDC
DC
JA
MM
KW
PM

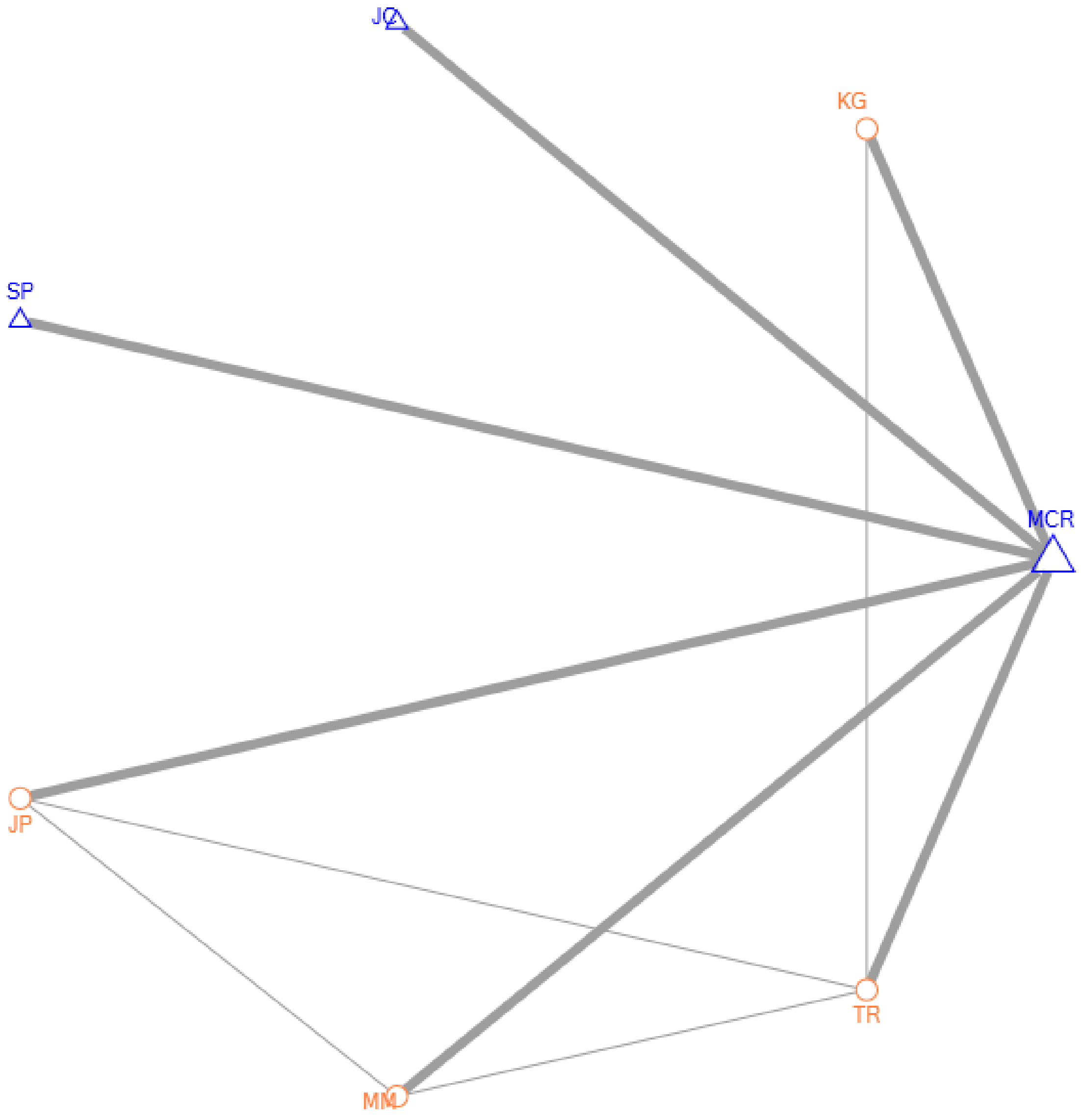

TSS
TJS
KYS
DJD
BJS
GDB
CLB
WLJ
RRF

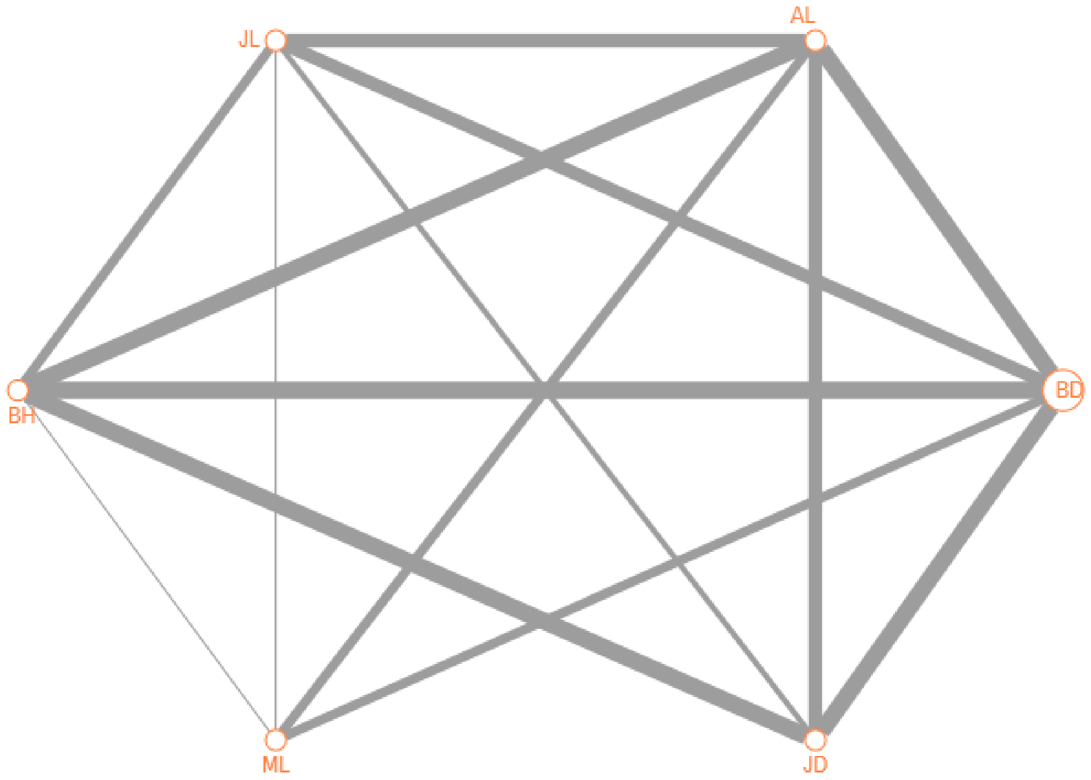

ADC
MS
SB
LQ
EB
TM
MB
RK
SD
TH
KF

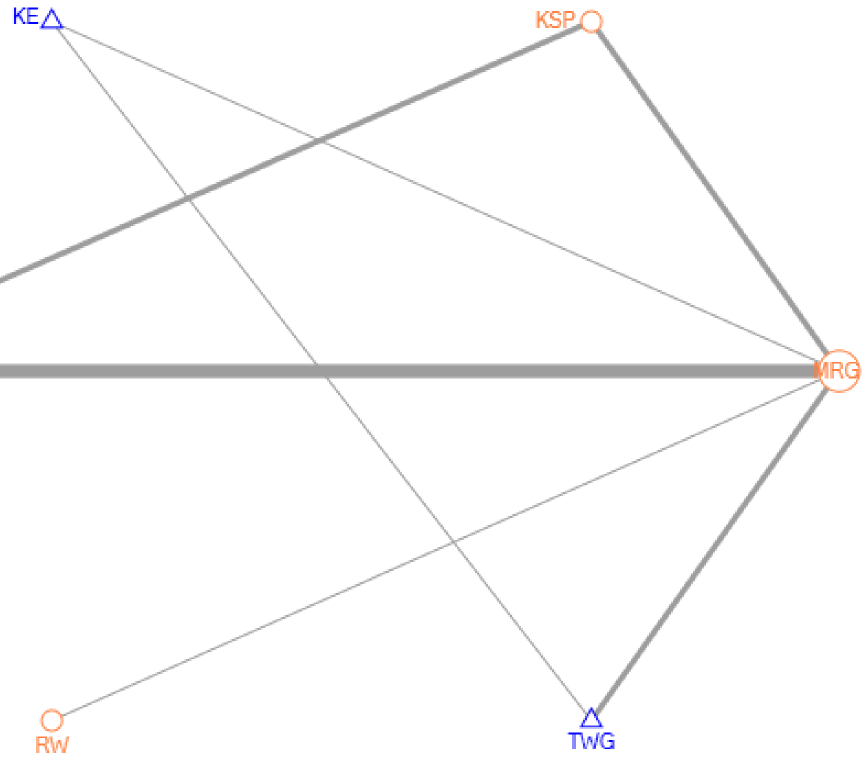

SEK
BLK
FLK
LLK

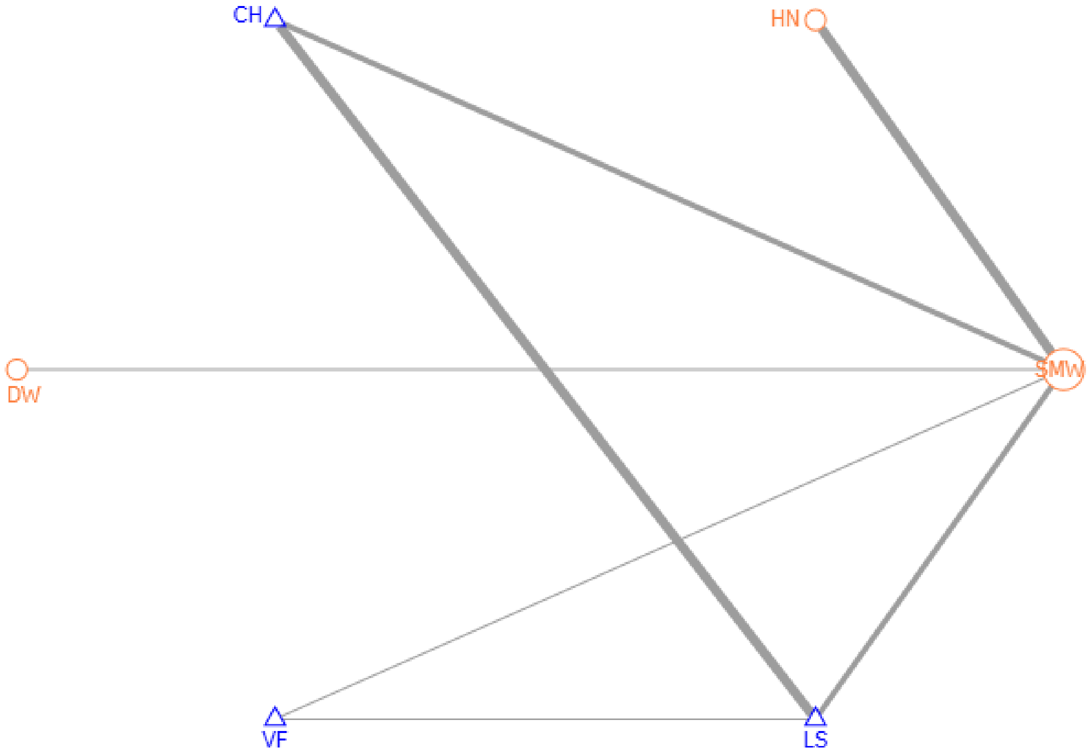

KC
LS
MS
PB

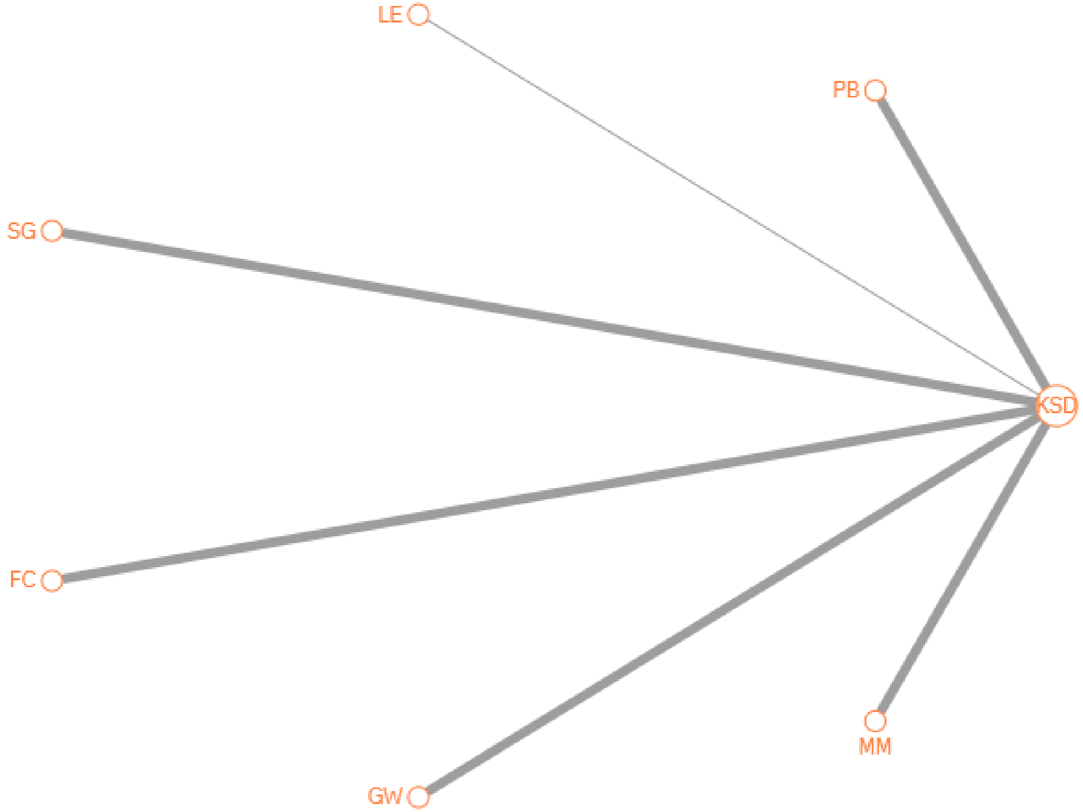

CJ
RR
PL
KE
JL
TK
SL
MN
AL
TE
RZ

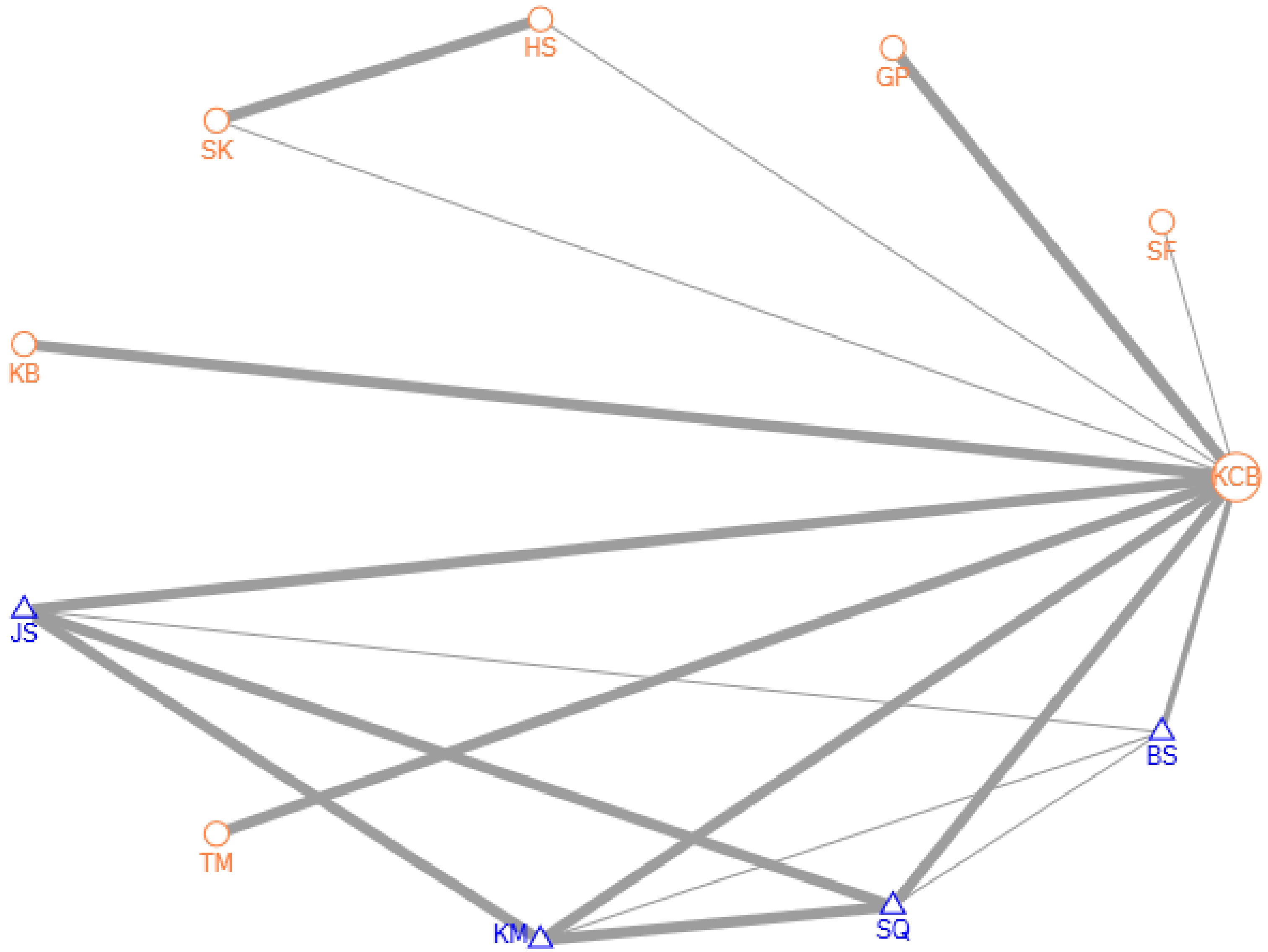

JC
KG
SP
MCR
JP
TR
MM

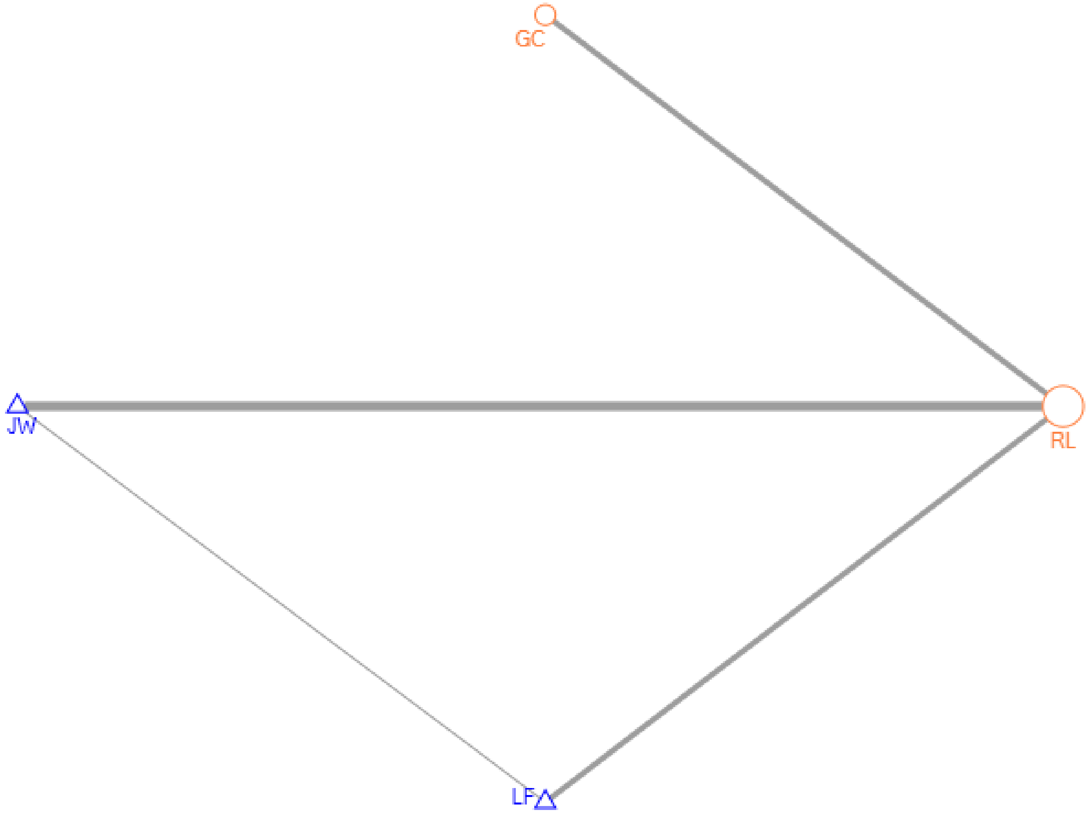

JL
AL
BH
BD
ML
JD

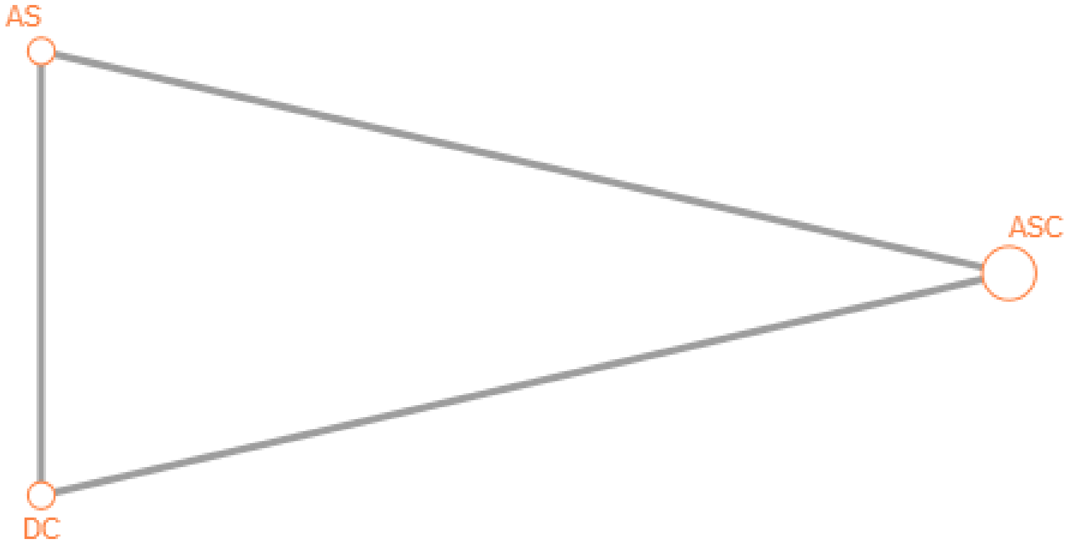

KE
KSP
AP
MRG
RW
TWG


CH
HN
DW
SMW
VF
LS


LE
PB
SG
KSD
FC
MM
GW


HS
GP
SK
SF
KB
KCB
JS
BS
TM
KM
SQ


GC
JW
RL
LF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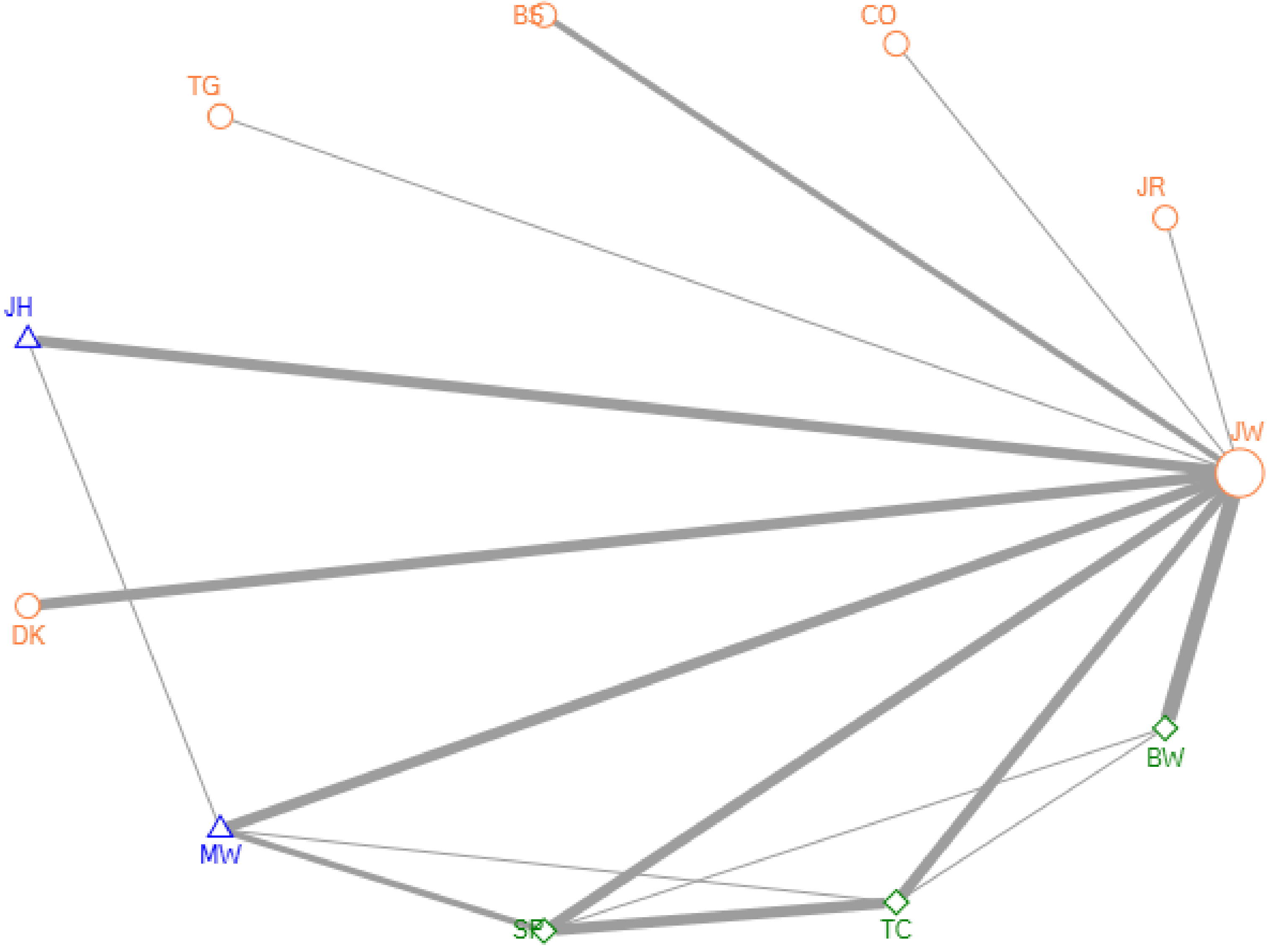
ASC
DC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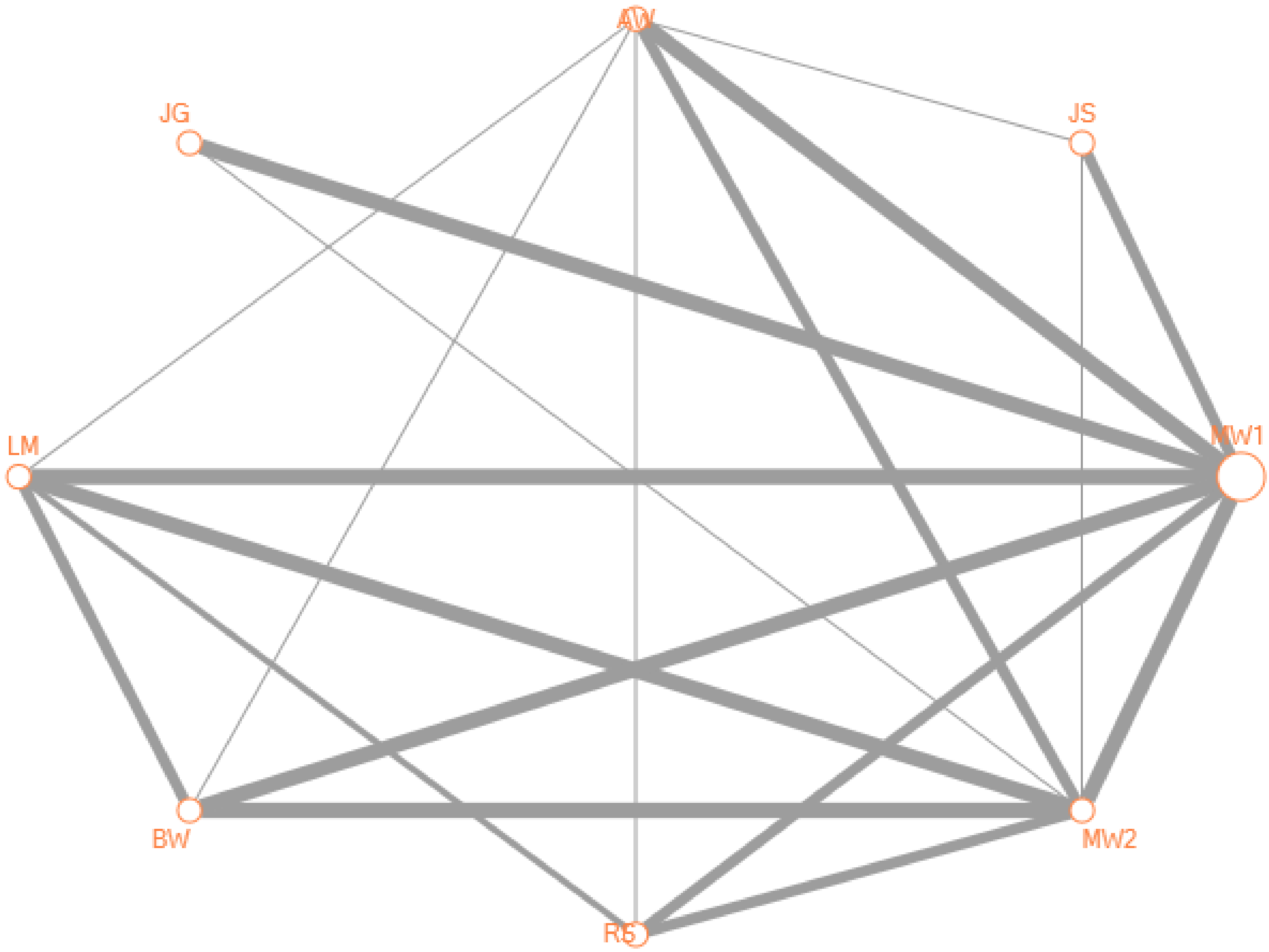
CO
TG
JR
JH
JW
DK
BW
MW
SF
TC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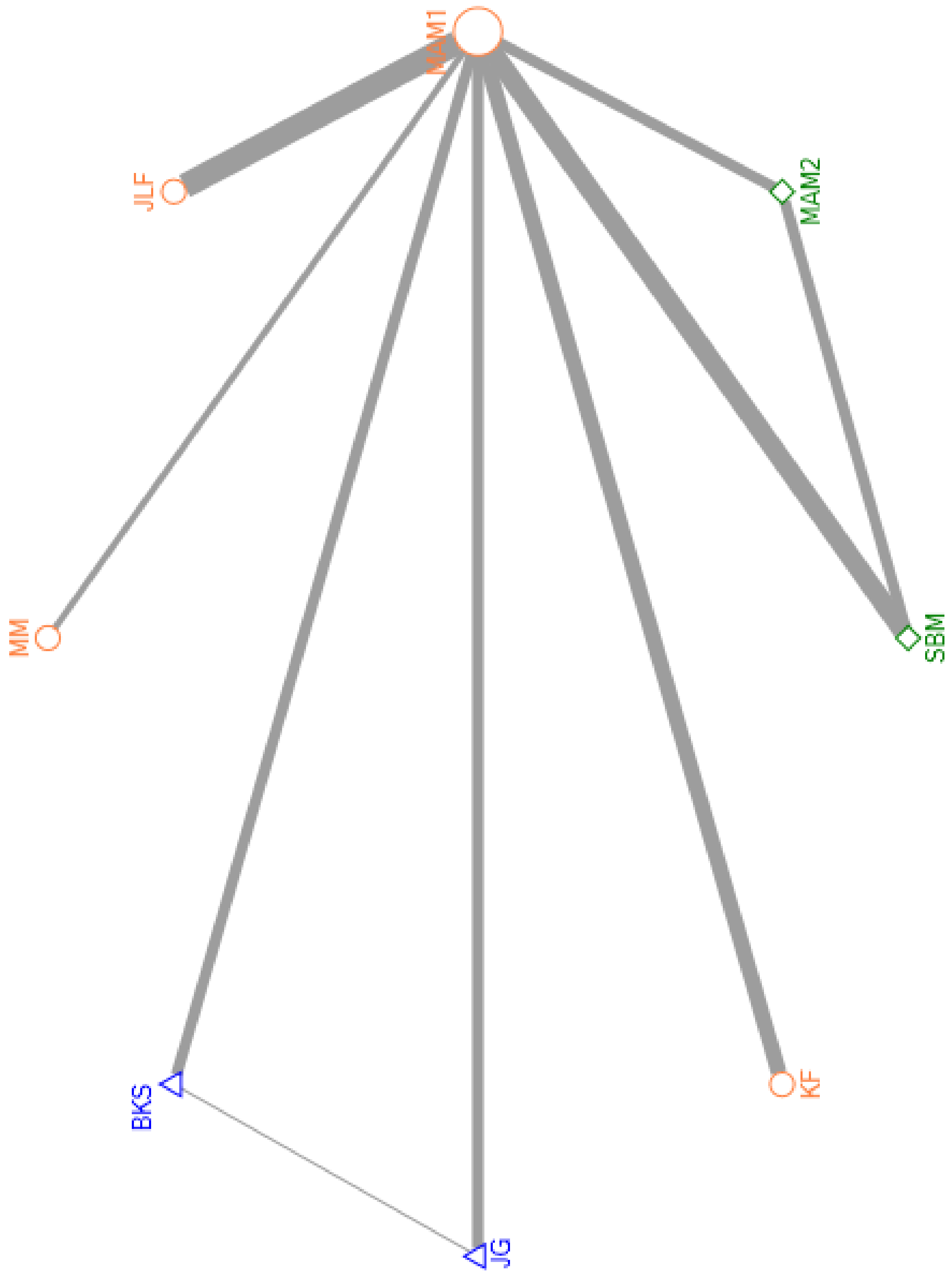
JG
JS
LM
MW1
BW
MW2
RS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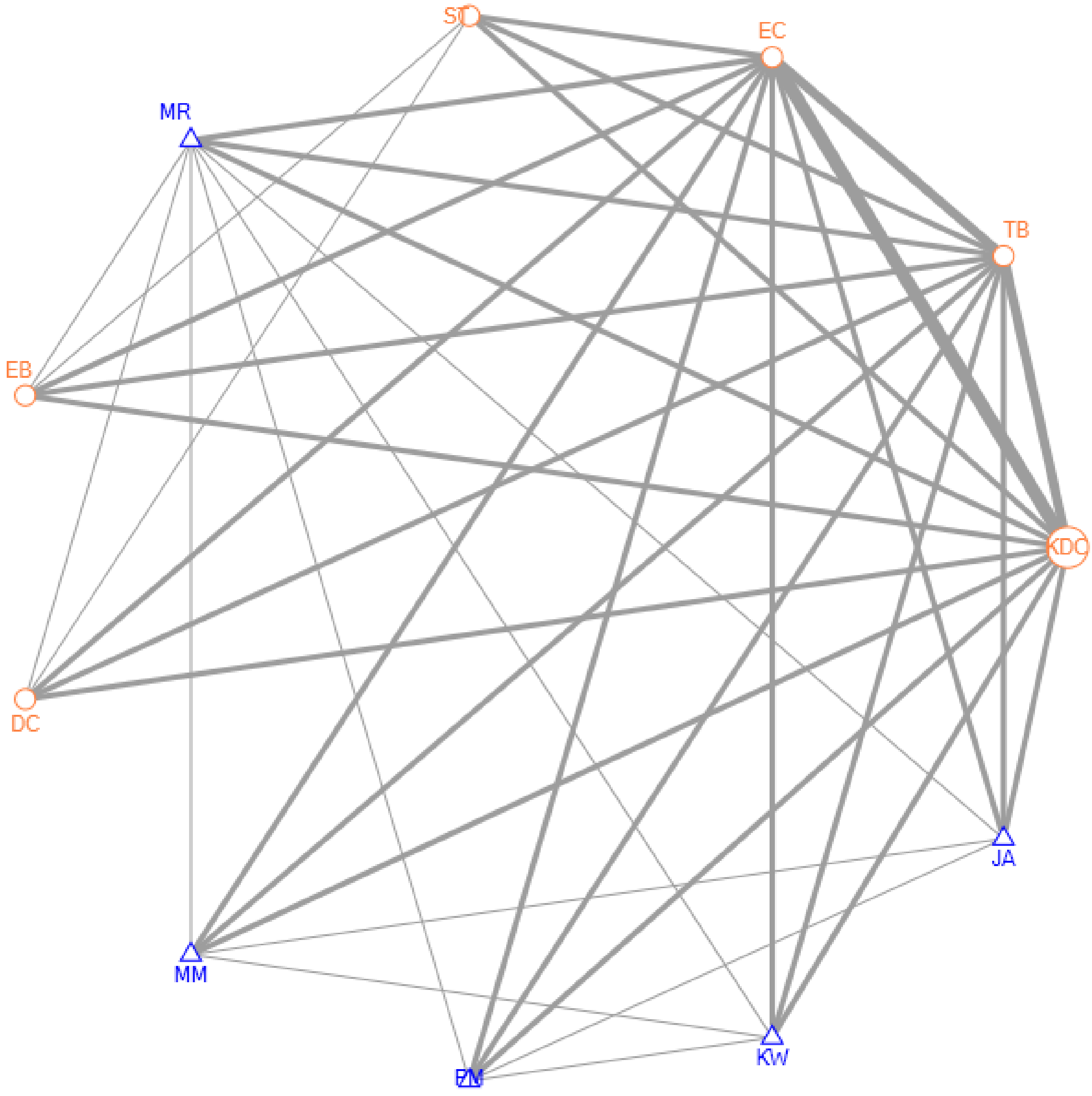
JLF
MAM2
MM
SBM
BKS
KF
JG


ST
EC
MR
TB
EB
KDC
DC
JA
MM
KW
PM

Appendix E: Vita

Heather Coates

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Education

MLS, 2010 (*ALA-accredited program*)
School of Library & Information Science, Indiana University – Indianapolis, IN

MS in Health Informatics, 2010
School of Informatics, Indiana University – Indianapolis, IN

BS, 1995-1999
Neurobiology, School of Science, Purdue University – West Lafayette, IN

1994-1995
Biology, Bard College at Simon's Rock, Great Barrington, MA

Experience

06/2010 – present
Research Assistant, Indiana University Medical Library

- Prepare historical materials for flatbed and open book scanning.
- Optimizing scanned images using Photoshop.
- Processing bulletins for optical character recognition (OCR) using ABBY FineReader.
- Assign authoritative metadata to bulletins and images using multiple vocabularies: PHIN, MeSH, LCSH, TGM, and local.
- Perform background research relating to personal and corporate names, archaic medical and chemical terms, as well as brand names and products.
- Upload optimized files to the content management system.

08/2006 – 02/2010
Behavioral Research Coordinator, Indiana University Department of Psychiatry, CSATC

- Coordination of clinical research studies and training programs involving school personnel and children with autism spectrum disorders.
- Development of a free health literacy workshop titled "Inform Yourself" for parents of children with special needs.
- Design and development of the program website, including two redesigns representing significant growth in content and resulting in increases of more than 300% in pageviews and 200% in visitors.
- Coordination and design of outreach events and materials to promote program missions.
- Implementation of various technologies to provide accessible web-based consumer health information in compliance with ADA and Section 508 guidelines.
- Provision of specialized information services to Center faculty; in-depth searching and monitoring of literature as relevant to program training and research missions.
- Design and creation of multimedia, web-based instructional modules for parents and school personnel using Adobe Flash and Adobe Captivate.
- Ensure and document human subjects compliance for several research projects according to university SOP and federal guidelines.

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05/2008 – 12/2008
Intern (volunteer), Indiana University Medical Library

- Design and build a web portal using CSS and X/HTML to provide public access to the INPub digital collections of text, data, and images.
- Assign authoritative metadata using PHIN and MeSH vocabularies.
- Assist in documenting best practices for digitization of public health bulletins, data, and images.

01/2006 – 08/2006
Executive Assistant, COMMAND Corporation

- Support senior management consultant in developing and conducting management simulations for MBA students.
- Maintain financial records for several equity funds and personal assets.
- Coordinate schedule, travel, and daily office functions for senior management consultant.

08/2002 – 01/2006
Lab Coordinator, Indiana University Department of Psychology

- Support the PI in managing the daily operations of the lab.
- Coordination of technicians and students on various grant-funded research projects.
- Financial management for several federally funded and foundation awards.
- Supervision and basic training of technicians and student research assistants.
- Ensure and document human subjects compliance for several research projects according to university SOP and federal guidelines.

Research Assistant, Indiana University Department of Psychology

- Daily coordination of National Institute of Drug Abuse R01 study activities such as recruitment, scheduling, participant interviews, data entry, and data processing.
- Training and daily supervision of student research assistants.
- Perform study related literature searches.
- Ensure and document human subjects compliance for several research projects according to university SOP and federal guidelines.

06/2000 – 06/2002
Business Office Manager, Rosewalk of Lafayette

- Entering and posting census, resident fund transactions, cash receipts, adjustments and ancillaries on a daily basis, coordinate with MDS Coordinator to submit medical billing claims, assist families with admission and discharge, and account collections by month-end deadlines.
- Support and back up of AP and HR functions and collaboration with management team to serve residents.

Receptionist, Rosewalk of Lafayette

- Greet patients and families, operator telephone system, and direct visitors.
- Support administrator and business office staff in daily operations.
- Develop documentation and communication tools for business office functions.

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Bibliography

Abstracts

Johnson, S. A., Lutgring, J., Burt, R., Murphy, R. R., Theiner-Schumacher, P., Coates, H., Yechiam, E., & Stout, J. C. (2005). *Skin Conductance Responses during the Iowa Gambling Task in Asperger's Disorder.* Presented at the 2005 annual meeting of the Cognitive Neuroscience Society, New York, NY.

Scholarly Publications

Coates, H. (2009). Autism Spectrum Disorders - Wading through the controversies on the web. *Medical Reference Services Quarterly*, 28(3), 259-267. doi:10.1080/02763860903069987

Coates, H. (2007). Social networking sites as a means of access to health information. *Consumer Connections*, 23(**3**). Retrieved from http://caphis.mlanet.org/newsletter/index.html

Posters & Presentations

Coates, H. (2010, September). The exchange of information as a dimension of social support in caregiver networks. *Poster session presented at the Midwest Chapter of the Medical Library Association, Madison, WI.*

Mahoui, M. Jones, J. Zollinger, D. Andersen, K. Coates, H. (2008). Leveraging user search behavior to design personalized browsing interfaces for healthcare Web sites. *American Medical Informatics Annual Symposium Proceedings,* 6, 994.

Korzekwa, P. A., Swiezy, N. B., Stuart, M. L., Pozdol, S., Hume, K. & Coates, H. (2007). *Product rating: An evaluation of IEP, BIP, and permanent product samples as an outcome in professional training.* Paper presented at the Association for Behavior Analysis International annual convention, San Diego, CA.

Online & Instructional Content

Coates, H. C. (2010). *HANDS in Autism Program website*. Retrieved on February 24, 2010 from http://www.handsinautism.org.

Coates, H. C. (2009). *HANDS in Autism Summer Training 2009 Program Orientation and Program Philosophy module*. Retrieved on February 24, 2010 from http://in-psyc-hands.ads.iu.edu/training2009/m1/orientation.swf.

Coates, H. C. (2009). *HANDS in Autism Summer Training 2009 Program What is Autism? module*. Retrieved on February 24, 2010 from http://in-psyc-hands.ads.iu.edu/training2009/m2/whatIsAutism.swf.

Coates, H. C. (2009). *HANDS in Autism Summer Training 2009 Program Best Practices module*. Retrieved on February 24, 2010 from http://in-psyc-hands.ads.iu.edu/training2009/m3/bestPractices.swf.

Coates, H. C. (2008). *Indiana Public Health Digital Library*. Retrieved from http://inpub.medicine.iu.edu.

Professional Service

2009-2011	Chair, Midwest MLA 2011 Continuing Education Committee
2009-2010	Member, IUPUI Staff Council
2008-2009	Secretary/Treasurer, Association of Library and Information Science Students (ALISS), Indiana University – Indianapolis
2005-2006	Curriculum Steering Committee, School of Library and Information Science, Indiana University – Bloomington

Memberships

Indiana Health Sciences Library Association
Medical Library Association & Midwest Chapter
American Society for Information Science and Technology
American Library Association
Society for Clinical Research Associates

Community Service

2009-present	Adult Literacy Tutor, IndyReads Program, Indianapolis, IN

Skills

Operating Systems: Windows, UNIX, Macintosh, Linux
Web Development: XHTML, CSS, Perl/CGI, SQL, XML/XSLT, ActionScript3.0, Flash, Dreamweaver, Fireworks, Flash Media Interactive Server
Instructional Technology: InDesign, Captivate, Premiere Pro, SMART Technologies SmartBoard, Turning Technologies clicker response system, Starbak streaming video server
Reference & Instruction: specialized information services for research faculty, coursework in reference services, adult instruction, health sciences resources, and distance learning
Databases: PubMed, Medline (Ovid), PsychINFO, CINAHL, ERIC, EMBASE, the Cochrane Library, ISI Web of Science

Continuing Education

2009

11/2009	Systematic Review Workshop: The Nuts & Bolts for Librarians (MLA, 20hr)
10/2009	XML: The Basics (IU STEPS)
10/2009	XML: Transforming Content with XSLT and XPath (IU STEPS)
10/2009	Let's Talk Teaching: Web2.0 Storytelling webinar (IUPUI Center for Teaching & Learning)
09/2009	Using Rubrics to Assess & Enhance Learning (IUPUI Center for Teaching & Learning)
01/2009	Blended Librarianship - Design Thinking (ACRL)
01/2009	Can You Hear Me Now: How to Make a Podcast (MLA)
01/2009	Fireworks: Designing an Interactive Website (IU STEPS)

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2008

11/2008	InDesign: The Basics (IU STEPS)
11/2008	InDesign: Refining Your Publication (IU STEPS)
10/2008	Jossey-Bass Online Teaching & Learning Conference
10/2008	ActionScript Basics (IU STEPS)
05/2008	MeSH for Searchers (MLA, 8hr)
05/2008	MLA Annual Conference, Chicago, IL
03/2008	Web2.0 Principles & Best Practices: Discovering the Participatory Web (MLA, 2hr)

2007

11/2007	Flash: The Basics (IU STEPS)
11/2007	Flash: Interactivity Basics (IU STEPS)
10/2007	Web Design & Usability (IU STEPS)
09/2007	Indiana University Research Coordinator Education Training Program
05/2007	MLA Annual Conference, Philadelphia, PA

2006

10/2006	Instructional Design for Distance Learning/Web-based Teaching (MLA, 8hr)
10/2006	Midwest MLA Annual Conference, Louisville, KY