UNIVERSITY OF WISCONSIN-LA CROSSE

Graduate Studies

PHYSICAL ACTIVITY AND STRESS LEVELS AMONG PARENTS OF CHILDREN WITH AUTISM

A Manuscript Style Thesis Submitted in Partial Fulfillment of the Requirements for the Master of Science Degree in Exercise and Sport Science-Physical Education Teaching (Adapted Physical Education Concentration)

Margaret E. Burrows

College of Science and Health
Department of Exercise and Sport Science
Physical Education Teaching: Adapted Physical Education Concentration

August, 2010

PHYSICAL ACTIVITY AND STRESS LEVELS AMONG PARENTS

OF CHILDREN WITH AUTISM

By Margaret E. Burrows

We recommend acceptance of this thesis in partial fulfillment of the candidate's requirements for the Master of Science Degree in Exercise and Sport Science-Physical Education Teaching (Adapted Physical Education Concentration)

The candidate has completed the oral defense of the thesis.

Manny Felix — 8/2/10

Manny Felix, Ph.D. — Date
Thesis Committee Chairperson

Garth Tymeson — 8-2-10

Garth Tymeson, Ph.D. — Date
Thesis Committee Member

8-2-10

Richard Mikat, Ph.D. — Date
Thesis Committee Member

Thesis accepted

Vijendra K. Agarwal — 8/13/10

Vijendra K. Agarwal, Ph.D. — Date
Associate Vice Chancellor for Academic Affairs

ABSTRACT

Burrows, M. Physical Activity and Stress Levels Among Parents of Children with Autism. MS in Exercise and Sport Science-Physical Education Teaching, Adapted Physical Education Concentration, August 2010, 56pp. (M. Felix)

Parents of children with autism may experience high levels of stress due to the nature of raising a child with autism. This stress can impact the quality of life and health among this group. These parents are in need of programs (e.g., respite, wellness, fitness) to help improve their overall well-being and quality of life. Regular participation in physical activity may be one of many strategies used by these parents to effectively manage stress levels. The objective of this study was to determine if a relationship existed between physical activity and stress levels among parents of children with autism. Parents of children with autism (N = 183) completed an online survey that included the Parenting Stress Index-Short Form (PSI-SF) (Abidin, 1995) and questions regarding their physical activity levels. Results showed that parents of children with autism had unusually high levels of stress. A weak inverse relationship was found between the parents current participation in exercise ($r = -.16$) and non-exercise physical activity ($r = -.24$). While these relationships are statistically significant ($p < .05$), the correlation is not great enough to be of any practical significance as indicated by their coefficients of determination. The establishment of causality will require experimentation in future research. Future studies regarding the impact of physical activity, health, and wellness on stress may help these parents find strategies to effectively manage their high stress levels.

ACKNOWLEDGMENTS

I would like to thank Dr. Manny Felix for guiding me through this thesis project. Dr. Felix provided me with insight and support to make this possible. I would also like to thank Dr. Garth Tymeson and Dr. Richard Mikat for serving on my thesis committee.

Thanks is also expressed to Psychological Assessment Resources (PAR) in Lutz, FL for granting permission to use the Parenting Stress Index-Short Form by Richard R. Abidin. In addition, the International Autism Network Community (IAN) was an important resource in assisting with recruiting subjects for this study. I would like to acknowledge Office of University Graduate Studies at the University of Wisconsin-La Crosse for awarding this thesis project a Graduate Student Research, Service, and Educational Leadership Grant. I would like to thank the parents of children with autism who completed the online survey.

Lastly, I would like to thank my family and close friends for their support and encouragement throughout my experience as a graduate student. Mom, Matt, Royce, Cathy, and Matt Shutt, thank you for helping me through this process.

This thesis is dedicated to my late father who inspired me to continue my career in the field of physical education. He impacted the lives of many people as a physical education teacher and coach. He is truly missed and is in my thoughts everyday.

TABLE OF CONTENTS

PAGE

ABSTRACT.....…….iii

ACKNOWLEDGEMENTS……iv

TABLE OF CONTENTS……v

LIST OF TABLES……vii

LIST OF APPENDICES……..viii

INTRODUCTION……...1

Hypotheses……...3

Significance of the Study……4

METHODS……..5

Subjects……5

Research Design……...5

Testing Procedures……...5

Measuring Stress……..6

Measuring Physical Activity……7

Statistical Analysis……...7

RESULTS……8

Parents of Children with Autism……..8

Children with Autism……...8

Stress Among Parents……..9

Figure 1. Physical Activity Levels Among Parents of Children with Autism…...11

DISCUSSION……13

CONCLUSION……..16

REFERENCES……..17

APPENDICES……...19

LIST OF TABLES

TABLE PAGE

1. Demographics of the Participant's Children……8

2. Results (mean ± SD, percentile) of the PSI-SF……..……..10

3. Descriptive Statistics of the Parent's Physical Activity……..10

LIST OF APPENDICES

APPENDIX PAGE

A. Informed Consent Form ….……..19

B. Online Survey……...23

C. Review of Related Literature……..…28

INTRODUCTION

All parents experience different levels of stress that influence their personal well-being. Stress is defined by the American Institute of Stress (2010) as a subjective sensation associated with varied symptoms that differ from person to person. It affects our bodies, emotions, thoughts, and behaviors. The effects of stress can be positive, negative, or a combination of the two.

Some parents experience stress due to having a child with a disability. Recent research suggests raising a child with a disability can be more difficult than raising a similar child without a disability (Singer, Ethridge, & Aldana, 2007)**.** This added difficulty will increase the stress levels in parents. Comparative studies have shown that parents of children with disabilities have significantly higher levels of stress than parents of nondisabled children. Further, parents of children who have developmental disabilities have higher rates of depression than parents of children without these disabilities. Increases of depression are associated with increases in stress (Singer et al, 2007).

Many factors influence how parents manage stress associated with having a child with a disability. Some of these factors include age of the parents, gender of parents, and disability related factors or type of disability. According to Ha, Hong, Seltzer, and Greenberg (2008), older parents are more emotionally prepared to parent a child with a disability than younger parents. Age generally indicates maturity, thus it is expected that older parents are more capable of facing challenging situations.

Gender may even be a strong indicator of stress as mothers of children with disabilities typically have greater stress levels than fathers. This is probably because mothers typically assume a greater burden of responsibility as primary caregivers (Tomanik, Harris, & Hawkins, 2004). Research has also suggested that women assume the role as the primary caregiver for their family. Mothers also tend to experience greater depression, poorer well-being, and worse physical health outcomes than men in care giving roles of children with disabilities (Ha et al, 2008).

The type of a child's disability influences parental stress. It has been reported that mothers of children with autism experience behavioral problems from their child on a daily basis. Mothers of adolescents and adults with autism have similar stress to parents of children with cancer, combat soldiers, Holocaust survivors, and individuals suffering from post traumatic stress syndrome (Seltzer, Greenberg, Hong, Smith, Almeida, Coe, & Stawski, 2009). Thus, parents of children with autism experience a substantial amount of stress which can impact their overall health and well-being.

Autism is a complex developmental disability which is usually detected within the first three years of life. Autism affects a person's ability to communicate and interact with others (Autism Society of America, 2008). Some characteristics of autism include: difficulty in verbal and nonverbal communication, social interaction, and leisure or play activity.

The prevalence of autism is one per 110 births in the U.S. and rising (Autism Society of America, 2008). Many parents of children with autism have significant daily stress and may not routinely practice regular physical activity to sustain personal health

and well-being. Currently, there is a lack of research that focuses on parents of children with autism and their physical well-being.

Everyone has a different way of coping with stress. One way that people cope with stress is through regular exercise. Exercise has been shown to decrease stress (Mayo Clinic, 2008). It is reasonable to argue that exercise can help many parents of children with autism spectrum disorders (ASD) to more effectively manage their stress. Past published investigations reported that individuals with improved levels of fitness are capable of managing stress more effectively than those who are less physically fit. According to Schnohr, Kristensen, Prescott, and Scharling, (2005) men and women who are physically active during their leisure time are less worried and tense, and have higher life satisfaction. There is an inverse relationship between physical activity and stress. The more an individual participates in physical activities; it is likely their stress levels will also decrease.

Although it has been found that parents of children with ASD generally have higher stress levels compared to parents of children with and without other disabilities, there is a lack of research that examines physical activity levels among parents of children with ASD. The purpose of this study was to determine whether or not a relationship existed between stress levels and participation in physical activity of parents of children with ASD.

Hypotheses

The hypotheses tested in this study include:

Null Hypothesis: There is no relationship between stress and physical activity levels of parents of children with ASD.

Alternative Hypothesis: There is a significant relationship between stress and physical activity levels of parents of children with ASD.

Significance of the Study

Many studies have determined that parents of children with ASD have higher levels of stress compared to other parents. Mothers of children with ASD spend significantly more time providing childcare and less time in physical leisure activities than mothers of children without disabilities (Smith, Hong, Seltzer, Greenberg, Almeida, & Bishop, 2009). Fatigue, arguments, avoided arguments, and stressful events were reported to be higher among mothers of children with ASD compared to mothers of children without disabilities (Smith et al, 2009).

This study would help determine if there is a relationship between stress and physical activity levels of these parents. If the results of this study indicate a relationship between stress levels and participation in physical activity, the needs of these parents should be further addressed. Respite programs that include physical activity and wellness could be offered to these parents to enhance their quality of life, as well as those of their families. There is a need to determine how regular participation in physical activity can impact stress in this population of parents. If stress can be effectively managed, then quality of life is more likely to be enhanced not only for these parents but also for the child with ASD. Children with ASD rely primarily on their parents for advocacy and effective intervention.

METHODS

Subjects

Participants (N = 183) in this study were U.S. parents of children (ages 4-21) with a documented diagnosis of any type of autism spectrum disorder. All parent participants were 18 years of age or older. Participants were selected using convenience sampling methods. Various autism agencies and advocacy groups assisted in recruiting subjects (e.g., Interactive Autism Network, Autism Society of Wisconsin, University of Wisconsin-La Crosse, Center on Disability Health and Adapted Physical Activity) by directly emailing a cover letter which provided an online link to a survey.

Research Design

Autism agencies directly emailed the cover letter to prospective participants (Appendix A) along with a link to the online survey: Parenting Stress Index-Short Form (PSI-SF) (Appendix B) and the Physical Activity Questionnaire (Appendix B). The cover letter informed each participant of the purpose and significance of the study, including assurances of anonymity, voluntary participation, and the option to withdraw at any time without penalty. Completion and return of the survey indicated their implied voluntary consent to participate in the study. Data collection was in April and ended in May of 2010.

Testing Procedures

The PSI-SF and the Physical Activity Questionnaire were used in this study to determine the relationship between stress and physical activity levels of parents of children with ASD. An online survey was developed that consisted of the PSI-SF and various items measuring physical activity.

Measuring Stress

Stress levels were measured by the PSI-SF to identify stressful areas in parent-child interactions. The PSI-SF is a self-reported, 36-item questionnaire, designed to measure stress on three different subscales: parental distress (PD), parent-child dysfunctional interaction (P-CDI), and difficult child (DC). The three subscales combine to yield a total stress score (TS). The PD subscale determines the distress a parent is experiencing in his or her role as a parent as a function of personal factors that are directly related to parenting (e.g., stresses associated with the restrictions placed on other life roles, conflict with the child's other parent, lack of social support). The P-CDI subscale focuses on the parent's perception that his or her child does not meet the parent's expectations, and the interactions with his or her child are not reinforcing to him or her as a parent (e.g., the parent may feel the child is a negative element in the parent's life, the parent may see himself or herself as abused or rejected by the child, the parent may feel alienated by the child). The DC subscale focuses on some of the basic behavioral characteristics of children that make them either easy or difficult to manage (e.g., temperament of the child, child behaviors) (Abidin, 1995).

The PSI-SF has been used in many previous studies on stress among parents of children with disabilities and is considered both a valid and reliable assessment instrument. The PSI-SF has been used to study samples of various populations (e.g., parents of children with hearing impairments, visual impairments, developmental disabilities). According to Abidin (1995), the test-retest reliability is .84 and the alpha reliability is .91 for the total stress score from the PSI-SF. The test-retest reliability was

assessed using the first sample over a six month retest interval. The coefficient alpha was calculated based on a normative sample of 800 subjects.

Measuring Physical Activity

Six items in the survey addressed participants' physical activity levels using sliding scales of 0 to 100 (items C5 and C6 of Appendix B). The questions were authored by the researcher. The Physical Activity Questionnaire examined exercise and non-exercise physical activity. Exercise physical activity included planned physical activity (e.g., biking, swimming, jogging, weight lifting). Non-exercise physical activity included activities of daily living (e.g., gardening, household chores). Further, the Physical Activity Questionnaire assessed the parent's physical activity levels in three areas: before the child was diagnosed with ASD, what it was the time the questionnaire was completed, and what the parents desired their participation in physical activity to be.

Statistical Analysis

Statistical analyses were completed using Microsoft Excel 2007 and the Statistical Package for the Social Sciences (SPSS 18.0). Characteristics of the subjects in the study were evaluated using descriptive statistics. Pearson product moment correlation analyses were used to determine the relationships between stress and physical activity levels in parents.

RESULTS

Parents of Children with Autism

A total of 183 parents of children with ASD responded to the survey. Fifteen (8.2%) of the participants were male and 167 (91.8%) were female. The mean age of parent respondents was 43 ± 7 years. The age of parents ranged from 28 to 60 years. It was reported that 159 (86.9%) of the participants were married, three (1.6%) were single, 16 (8.7%) were divorced or separated, and three (1.6%) were in a committed relationship.

Children with Autism

In order to be eligible for the study, all participants must have had at least one child with ASD. Of the 183 subjects, 86 (55%) reported having a child with autism, 30 (19%) reported having a child with Asperger's syndrome, and 41 (26%) reported having a child with a Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS). None of the participants reported having a child with Rett's syndrome or Childhood Disintegrative Disorder. Refer to Table 1 for demographics of the participant's children.

Table 1. Demographics of the Participant's Children

	Age mean ± SD	Autism n (%)	Asperger's n (%)	PDD-NOS n (%)	Total n (%)
Male	10 ± 4	86 (55%)	30 (19%)	41 (26%)	157 (86%)
Female	10 ± 4	4 (15%)	4 (15%)	7 (27%)	26 (14%)
Total	10 ± 4	34 (19%)	34 (19%)	48 (26%)	183 (100%)

Regarding independence of their children, 58 (31.7%) participants indicated their child had mild deficits in functional abilities in daily living (little to no assistance needed throughout a typical day). Ninety one (49.7%) participants reported their child as having

moderate deficits in functional abilities in daily living (some assistance needed throughout most of the day), and 34 (18.6%) participants reported their child as having severe deficits in functional abilities in daily living (continual assistance needed throughout most of the day).

Seventy (38.3%) reported children with a diagnosis of autism who also had a secondary condition (e.g., apraxia, learning disability, obsessive-compulsive disorder (OCD), and attention-deficit hyperactivity disorder (ADHD)) and 113 (61.7%) children were not reported to have a secondary condition. The total number of children living in the household including the child with autism ranged between one child to more than four children. There were 27 (14.8%) families with one child in the household, 111 (60.7%) with two children in the household, 36 (19.7%) with three children in the household, and eight (4.4%) with four or more children in the household. It was also reported that 44 (24%) of families had another child with a disability (e.g., Asperger's syndrome, autism, Down syndrome, and ADHD) and 131 (71.6%) did not have another child with a disability.

Stress Among Parents

The mean total stress score of all parents derived from the PSI-SF was 109 ± 22. The total stress score is the sum of three subscales: Parental Distress (PD); Parent-Child Dysfunctional Interaction (P-CDI); and Difficult Child (DC). Results from the PSI-SF are presented in Table 2. There is a Defensive Responding category that is used to indicate whether an individual is responding in a defensive manner and caution should be used while interpreting results. Scores for Defensive Responding, subscale scores, and the total stress score are considered high when they are at or above the 85th percentile.

Table 2. Results (mean ± SD, percentile) of the PSI-SF

	DefR	PD	P-CDI	DS	TS
Male	22 ± 7, 97	36 ± 12, 90	32 ± 9, 97	40 ± 8, 96	108 ± 25, 97
Female	23 ± 6, 98	37 ± 9, 92	30 ± 8, 95	41 ± 9, 96	109 ± 22, 97
Total	22 ± 6, 97	37 ± 10, 92	31 ± 8, 96	41 ± 9, 96	109 ± 22, 97

Note: DefR = Defensive Responding Score; PD = Parental Distress; P-CDI = Parent-Child Dysfunctional Interaction; DS = Difficult Child; TS = Total Stress

Information about the parent's physical activity was obtained by using sliding scale questions. The type of physical activity was categorized as either: non-exercise physical activity and exercise. For each type, parents indicated their physical activity levels one year prior to their child's diagnosis, their current level of physical activity, and their desired physical activity level. Results of the physical activity questionnaire are presented in Table 3 and Figure 1.

Table 3. Descriptive Statistics of the Parent's Physical Activity

	Non-exercise Activity			Exercise		
	Before	Current	Desired	Before	Current	Desired
Male	57 ± 25	41 ± 22	71 ± 15	46 ± 27	31 ± 26	60 ± 15
Female	65 ± 22	53 ± 26	76 ± 16	55 ± 27	36 ± 28	72 ± 20
Total	64 ± 22	52 ± 26	75 ± 16	55 ± 27	36 ± 28	71 ± 10

Figure 1 shows the average level of parent's participation in physical activity one year prior to their child's diagnosis, their current level of physical activity, and their desired physical activity level. As shown in Figure 1, parents participated in a greater

amount of physical activity before their child's diagnosis. Parent's reported that their desired level of physical activity is higher than what they currently do for both exercise and non-exercise physical activity.

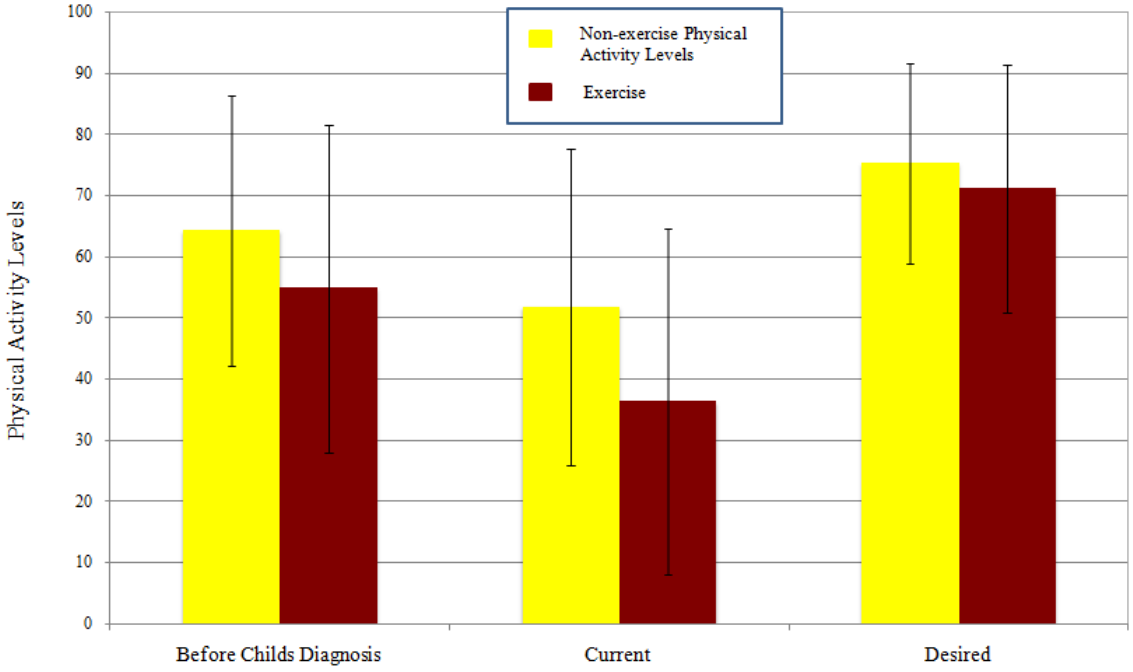


Figure 1. Physical Activity Levels Among Parents of Children with Autism

Pearson product moment correlations were used to determine if there was a correlation between the total stress (TS) scores and each of the questions regarding exercise and non-exercise physical activity levels (questions C5_1 to C6_3, Appendix D). A significant correlation of $r = -.16$ ($p < .05$) was found between TS and the primary caregiver's current level of non-exercise physical activity. While this correlation is statistically significant ($p < .05$) it may not be practically significant as the coefficient of determination is $r^2 = .02$. A significant correlation of $r = -.24$ ($p < .05$) was also found between TS and the primary caregiver's current level of exercise. While this correlation

is also statistically significant ($p < .05$) it may not be practically significant as the coefficient of determination is $r^2 = .06$.

DISCUSSION

There were 183 primary parent caregivers of children with autism who participated in this study, of which 15 (8.2%) were men and 167 (91.8%) were women. This pattern matches previous research regarding the role of gender and the primary caregiver. Past research has suggested that women assume the role as the primary caregiver for their family. Women generally spend more time caring for other family members, but also tend to experience greater depression, poorer well-being, and worse physical health outcomes than men in care giving roles (Ha et al, 2008).

Parents in this study reported 157 (85.8%) male and 26 (14.2%) female children with a diagnosed condition of autism. This outcome supports the significantly higher prevalence of males to females with autism in the U.S. According to the Centers for Disease Control and Prevention (2007) the prevalence of autism has increased to one in every 110 births in the U.S. and almost one in 70 male children.

Parents scored high on all three subscales and the total stress score of the PSI-SF. The average scores were all above the 90th percentile on the PSI-SF (scores above the 85th percentile are considered high) which shows that this population of parents experiences unusually high levels of stress (Abidin, 1995). The mean total stress score of participants in this study was 108.92 out of 112. Another study measured mother's of children with Down syndrome and autism using the PSI-SF. The mean stress score for that population was 99.33 (Beck, Hastings, Daley, & Stevenson, 2004). This suggests that parents of children with autism, along with other disabilities have high levels of stress.

Parental participation in physical activity was higher before their child's diagnosis of autism for both exercise and non-exercise physical activity. This may be due to the

challenges parents of children with autism face on a daily basis. Parents may not have enough time or feel they have enough energy to participate in physical activity due to the circumstances of having a child with autism. Parents also reported they would like to increase their participation in physical activity from what it currently is, and what it was one year prior to their child's diagnosis with autism. These results indicate that parents need an opportunity to find time during the day for health-related physical activity. Physical activity based respite programs may be a positive way to help this population of parents participate regularly in more physical activity.

The purpose of this study was to determine if there was a relationship between stress and participation in physical activity among parents of children with autism. It was anticipated that high stress levels would have an inverse relationship with physical activity would decrease among this population of parents. The results statistically supported the hypothesis. There was a slight inverse relationship between TS and the primary caregiver's current level of non-exercise physical activity and TS and the primary caregiver's current level of exercise.

A significant correlation was not found between TS and exercise and non-exercise physical activity levels one year before the child's diagnosis. This may be because the primary caregiver was not impacted by the stressors of having a child with autism at that time. A significant correlation was also not found between TS and desired exercise and non-exercise physical activity levels. Participation in physical activity may be one way to help manage stress, however, there may be other strategies that would benefit this population of parents as well (e.g., counseling and sleep).

Findings of this study show that physical activity and stress among parents of children with autism do not have a strong correlation**.** However, parent's of children with autism experience unusually high levels of stress and reported they want to increase their participation in physical activity and that their levels decreased since having a child diagnosed with ASD. This population of parents is in need of programs, or opportunities to reduce their current stress levels. The physical activity of parents of children with autism decreased after the diagnosis of their child. Physical activity may be one way to reduce the stressors that these parents face on a daily basis. It may be necessary to further research this population of parents to determine ways to help reduce stress and improve personal well-being.

CONCLUSION

Continuing to study the impact of having a child with autism is important to determine a need for and benefits of physical activity respite services to be provided to parents of children with ASD. The results of this study show that there may be a relationship between high levels of stress and participation in physical activity of parents of children with ASD. The establishment of causality will require experimentation in future research. Continued study of parent's of children with autism is needed to discover ways to support this population. Helping this population to cope with the impact of autism will likely promote family wellness and relieve burdens on the American and international public. Physical activity professionals can assist with promoting health and physical activity in parents of children with autism to enhance their quality of life.

REFERENCES

Abidin, R. (1995). Parenting Stress Index Professional Manual (3rd ed.). Lutz, FL: Psychological Assessment Resources.

American Institute of Stress (2010). Stress reduction, stress relievers. Retrieved from http://www.stress.org/topic-reduction.htm

Autism Society of America. (2008). *About* autism. Retrieved from http://www.autism-society.org/site/PageServer?pagename=about_home

Beck, A., Hastings, R., Daley, R., & Stevenson, J. (2004). Prosocial behavior and problems independently predict maternal stress. *Journal of Intellectual and Developmental Disability, 29 (4)*, 339-349.

Centers for Disease Control and Prevention (2010). Autism spectrum disorders. Retrieved from http://www.cdc.govncbddd/aut/ism/index.html.

Ha, J., Hong, J., Seltzer, M., & Greenberg, J. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior, 49*, 301-316.

IBM SPSS Statistics (Version 18) [Computer software]. Chicago, IL: IBM Company Headquarters

Mayo Clinic (2008). Autism. Retrieved from http://www.mayoclinic.com/health/autism/DS00348.

Schnohr, P., Kristensen, T., Prescott, E., & Scharling, H. (2004). Stress and life dissatisfaction are inversely associated with jogging and other types of physical activity in leisure time: the Copenhagen city heart study. *Scandinavian Journal of Medicine and Science in Sports, 15,* 107-112.

Seltzer, M., Greenberg, J., Hong, J., Smith, L., Almeida, D., Coe, C., & Stawski, R. (2009). Maternal cortisol levels and behavior problems in adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-009-0887-0

Singer, G., Ethridge, B., & Aldana, S. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental

disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities, 13*, 357-369.

Smith, L., Hong, J., Seltzer, M., Greenberg, J., Almeida, D., & Bishop, S. (2009). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders.* Advance online publication. doi:10.1007/s10803-009-0844-y

Tomanik, S., Harris, G., & Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29(1),* 16-26.

APPENDIX A

INFORMED CONSENT FORM

UNIVERSITY of WISCONSIN
LA CROSSE

Physical Activity and Stress Levels Among Parents of Children with Autism

Dear Parent:

You are invited to participate in a study that is investigating stress and physical activity levels among parents of children with autism. This research is being conducted as part of my thesis research project and is sponsored by the UWL Center on Disability Health and Adapted Physical Activity. This letter and the accompanying surveys are being sent to you from the office of Dr. Manny Felix of the UWL Center on Disability Health and Adapted Physical Activity who has identified you as a qualified participant in this study.

Your participation would consist of completing an online survey which would take approximately 10 minutes. You have rights and assurances that aim to minimize any risks, real or perceived, as a result of your participation. Participation in this study is purely voluntary. You do not have to participate in this study if you do not want to. If you do participate, your responses to the survey will be confidential. Only group results will be shared and your individual results will never be associated with your identity.

Different people react differently to survey questions. You may choose to skip questions if you want. You have the right to end your participation at any time without penalty.

I hope that you will participate in this survey. Likely outcomes of this research can justify the necessary supports and services, including wellness programs, respite care, physical activity interventions among others, for parents of children with autism. If you decide to participate, please complete the survey by:

1.) Clicking on the link below (or copy the link and paste into the web address box):

https://uwlacrosse.qualtrics.com/SE?SID=SV_08OK4mpCCo4h0z2&SVID=Prod

2.) Enter the password provided here (all lower case lettering): **autism**

Please complete the survey at a convenient time for you and where distractions are held to a minimum. Completing the online survey implies your consent to participate. If you prefer not to take the survey online and would like a hard copy of the survey, please let me know by emailing me at burrows.marg@students.uwlax.edu.

Any questions regarding this study can be directed to any of these individuals:

Margaret Burrows, Graduate Student, 608.785.8695 .
Manny Felix, Director, CDHAPA, 608.785.8691
Vijendra Agarwal, Associate Vice Chancellor/Academic Affairs, 608.785.8007

Thank you in advance for your participation. It would be greatly appreciated by me, the UWL Center on Disability Health and Adapted Physical Activity, and many others involved in the autism community. If you would like a copy of the results of this study, please email me at burrows.marg@students.uwlax.edu.

Dear IAN Research participant,

You may qualify for the study, below. You should click on the study link or contact the study team directly, using the information provided, if you are interested in joining. You do not have to participate in this study and your non-participation will neither affect the care you receive from any health provider nor your standing as a participant in IAN Research.

Please note that IAN Research is serving as a resource linking the autism community and researchers. This study is not endorsed by or performed under the auspices of the IAN Research project at Kennedy Krieger Institute/Johns Hopkins.

Name of Study: Physical Activity and Stress Levels Among Parents of Children with Autism
Institution: University of Wisconsin-La Crosse Center on Disability Health and Adapted Physical Activity
Location: Online study; no geographic limitation within the United States
Eligibility Criteria: Parents/primary caregivers of children, ages 4-21 years, with a diagnosis on the ASD; one survey per household
Principal Investigator: Dr. Manny Felix
Contact Information: Margaret Burrows, study coordinator - phone: (608) 785-8695; email: burrows.marg@students.uwlax.edu
Study link:
https://uwlacrosse.qualtrics.com/SE?SID=SV_08OK4mpCCo4h0z2&SVID=Prod
Enter this password: "autism" *(all lower case lettering)*

Dear Parent:

You are invited to participate in a study investigating stress and physical activity levels among parents of children with autism. Likely outcomes and benefits of this research may justify necessary supports and services - including wellness programs, respite care, and physical activity interventions - for parents of children with autism.

Your participation would require you to complete an online survey which should take no more than 20 minutes. Please complete the survey at a convenient time for you and where distractions are held to a minimum. Your participation is voluntary and you may skip any questions that you do not feel comfortable answering. You may quit the survey at any time; however, you will not be able to return to your partly-completed survey once you have left it. Completing the online survey implies your consent to participate.

Those who complete the survey will have the option of entering a drawing for one of five $25 gift cards to Amazon.com (odds of winning 1 in 40). To enter the drawing, you will need to enter your email address into the survey; however, your email address will not be associated with your responses. If you do enter the drawing and provide your email address, we will also be able to send you the results of the study.

If you decide to participate, please complete the survey by:

1. Clicking on the link below (or copy the link and paste into the web address box): https://uwlacrosse.qualtrics.com/SE?SID=SV_08OK4mpCCo4h0z2&SVID=Prod

2. Entering this password: "autism" *(all lower case lettering)*

If you prefer not to take the survey online and would like a hard copy of the survey, or if you have any questions regarding this study, please contact Margaret Burrows, study coordinator, by phone (608) 785-8695 or email burrows.marg@students.uwlax.edu.

Thank you in advance for your participation.

Dr. Manny Felix and the Study Team

APPENDIX B

ONLINE SURVEY

Qualtrics Survey Software 6/21/10 1:21 PM

autism

Information about you (the primary caregiver)

T1

Physical Activity and Stress Levels Among Parents of Children with Autism

Thank you for participating in our study about physical activity and stress. Your participation should take about 20 minutes. All of the information you submit will be kept confidential and only group data will be used in publications or presentations. By clicking the "submit" button at the end of the survey, you are giving your informed consent to participate in this study. Again, thank you for your time and valuable information.

Only the ***primary caregiver*** of the child with autism should complete this survey. Please complete all items as thoroughly as possible.

Information about you (the primary caregiver)

C1 **What is your gender?**

- ○ Male
- ○ Female

C2 **What is your age in years?**

C3 **What is your ethnicity/race?**

White/Caucasian

C4 **What is your marital status?**

Married

C7 **In what state do you currently reside?**

Alabama

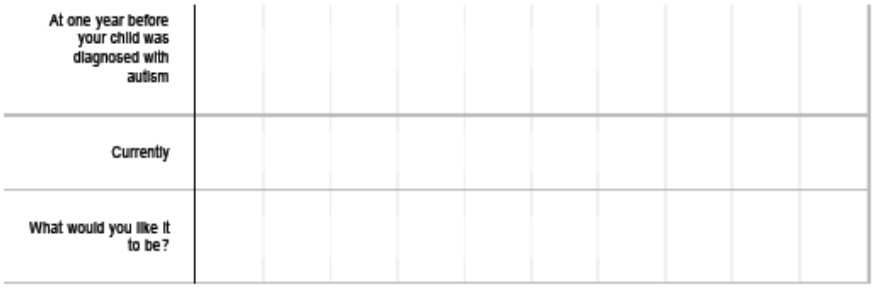
C5 **Information about your physical activity**

Describe your physical activity level by using the sliders below.

Non-exercise Activity - This includes activities like walking, gardening, shopping, household cleaning, manual labor, etc.

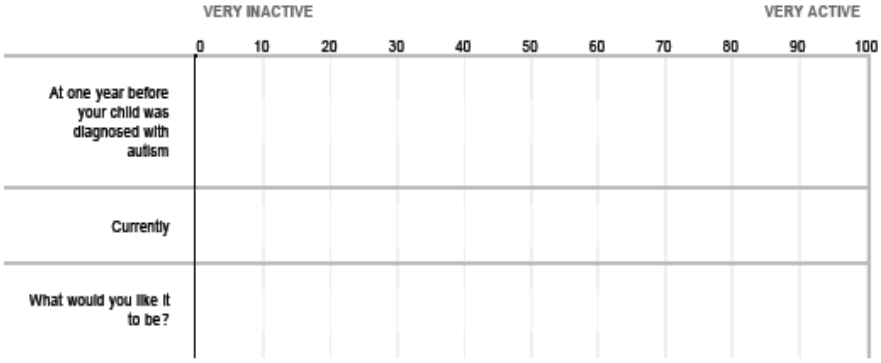
VERY INACTIVE VERY ACTIVE

0 10 20 30 40 50 60 70 80 90 100



C6

Exercise - This includes activities like running, swimming, biking, strength training/ weight lifting, and fitness classes (e.g. yoga, aerobics, etc).



Information about your child with autism

T2

Information about your child with autism

A1

What is your child's gender?

- ○ Male
- ○ Female

A2

What is your child's age in years?

A3

Indicate if your child has been diagnosed with any of the following (check all that apply):

Autism	Asperger's Disorder	Rett's Syndrome	PDD-NOS	Childhood Disintegrative Disorder
☐	☐	☐	☐	☐

A4 **How would you best describe your child's functional abilities in activities of daily living?**

- ○ Mild (little to no assistance required throughout a typical day)
- ○ Moderate (some assistance required throughout most of the day)
- ○ Severe (continual assistance throughout most of the day)

A5 **Does your child have another disability or secondary condition?**

- ○ Yes
- ○ No

Display This Question:
If Does your child have another disability or secondary cond... **Yes** **Is** **Selected**

A6 **Please specify your child's secondary disabilities and/or conditions.**

Information about other children in the household

T3 **Information about other children in the household**

O1 **Total number of children in the household (including your child with autism):**

O2 **Ages of the children (not including the child with autism):**

O3 **Do any of the other children have a disability?**

- ○ Yes
- ○ No

Display This Question:
If Do any of the other children have a disability? **Yes** **Is** **Selected**

O4 **Please specify the disabilities of the other children.**

PARENTING STRESS INDEX-SHORT FORM

SAMPLE QUESTIONS

1.) I often have the feeling I cannot handle things very well. SA A NS D SD

20.) My child is not able to do as much as I expected. SA A NS D SD

30.) My child gets upset easily over the smallest thing. SA A NS D SD

Note: Due to copyright restrictions by Psychological Assessment Resources the entire PSI-SF survey cannot be posted. Three sample questions were taken from the PSI-SF. There is one sample question from each of the subscales: Parental Distress, Parent Child Dysfunction Interaction, and Difficult Child.

APPENDIX C

REVIEW OF RELATED LITERATURE

REVIEW OF RELATED LITERATURE

Introduction

All parents experience different levels of stress that influence their personal well-being. Stress is defined by the American Institute of Stress (2010) as a subjective sensation associated with varied symptoms that differ from person to person. It affects our bodies, emotions, thoughts, and behaviors. The effects of stress can be positive, negative, or a combination of the two.

Some parents experience stress due to having a child with a disability. Research suggests that raising a child with a disability may be very stressful. This may place an undue burden on parents experiencing stress. Comparative studies have shown that parents of children with disabilities have significantly higher levels of stress than parents who have nondisabled children. Researchers have shown that many parents of children who have developmental disabilities experience high levels of stress. It has also been reported that greater rates of depression among parents of children with disabilities are strong indicators of unusually high levels of stress within these families (Singer, Ethridge, & Aldana, 2007).

The type of disability influences parental stress. It has been reported that mothers of children with autism experience behavioral problems elicited by their child on a daily basis. Mothers of adolescents and adults with autism have increased stress that is similar to findings of other groups experiencing chronic stress such as parents of children with

cancer, combat soldiers, Holocaust survivors, and individuals suffering from Post Traumatic Stress Syndrome (Seltzer et al, 2009). Thus, for parents of children with autism, a substantial amount of stress is apparent and can impact the health and wellness of these individuals.

The prevalence of autism has risen to one in every 110 births in the U.S. (Autism Society of America, 2008). The number of families impacted by developmental disabilities is increasing rapidly. It may be that parents of children with autism have significantly increased daily stress and may not routinely practice healthy activities to sustain personal health and well-being. There is a lack of research that focuses on parents of children with autism and their physical well-being. Parents who have children with autism generally have higher stress levels than parents of children with other disabilities and parents of typically developing children (Seltzer, Greenberg, Hong, Smith, Almeida, Coe, & Stawski, 2009). Do parents of children with autism attain adequate levels physical activity and maintain optimum health? The following literature review focuses on research that describes the stress of having children with autism on parents.

Autism

Autism is a complex developmental disability. If a child has autism, it usually appears during the first three years of life. Autism affects a person's ability to communicate and interact with others (Autism Society of America, 2008). Some characteristics of autism include: difficulty in verbal and nonverbal communication, social interaction, and leisure or play activity.

Autism is considered one of five pervasive developmental disorders (PDD). PDD is a category of neurological disorders that have severe and pervasive impairment in

several areas of development. According to the Centers for Disease Control and Prevention (2010) the prevalence of autism has increased to one in every 110 births in the U.S. resulting in 1.5 million American's living with the effects of autism.

The actual cause of autism is unknown. A person with autism shows differences in the shape and structure of the brain compared to persons without autism. There may be a link between heredity, genetics, and medical problems as a cause of autism. There also may be genetic vulnerability and environmental factors such as environmental toxins (e.g., heavy metals and mercury) that cause autism (Autism Society of America, 2008). There is currently a large research community investigating different possible causes and treatments for autism.

Observation of the person's communication, behavior, and developmental levels are used to identify signs of autism. There are no medical tests used to diagnose autism, however, several screening instruments are used by pediatricians and others to diagnose autism. Pediatricians are often the professionals who diagnose autism. It is important to detect autism early. According to the Autism Society of America (2008), there is a dramatically better outcome for individuals on the autism spectrum if they are detected at an early age. Early detection of autism allows individuals with autism opportunities to have intervention and therapy during a critical period of development for the child.

Stress Levels of Parents of Children with Disabilities

There are many factors that may affect stress associated with having a child with a disability. These factors include age and gender of the parents, disability related factors such as the type or severity of the disability, and financial burden. Four areas of theory and evidence were looked at using data from the Study of Midlife in the U.S. (MIDUS).

The purpose of the study was to examine: the effect of having children with developmental or mental health problems on parent's mental and physical health, the extent to which this effect varies by parental age and gender, and the effects of disability-related factors on the well-being of parents of children with disabilities (Ha, Hong, Seltzer, & Greenberg, 2008). The areas include: stress of parenting a disabled child, the impact of the age of the child, and disability-related factors affecting the well-being of parents of children with developmental disorders and mental health problems (Ha et al, 2008). Parenting a disabled child includes many challenges in working with child care programs, especially financially. This article also indicated that parents take on additional financial burdens due to the specific type of disability and that insurance is not always able to cover all necessary medical protocols. The data for the analysis of this study were drawn from the MIDUS (Study on Midlife in the United States). The study was conducted nationally by computer-assisted telephone interviews and mail-back questionnaires

The dependent variables researched included: negative affect (alpha = .85), psychological well-being (alpha = .94) and somatic symptoms (alpha = .69). The parent's age at the onset of the child's disability and the duration of the disability were significantly related to the dependent variables. The independent variables researched included: parental age, parental gender, and whether the parent had a child with a disability. Parenting a child with a developmental problem and parenting a child with a mental health problem were two dichotomous variables in this study. Socioeconomic and disability-related variables were also included in this study to receive data.

Parental age is an important factor that may influence how well parents adjust to parental stress. Research between the caregiver's (parent's) age and the caregiver's distress has been inconclusive. However, age was related to lower levels of distress in previous studies. According to Ha et al. (2008) research has shown that older parents experience lower levels of distress in response to their child's behavior problems compared to younger parents; however, they may experience an increase in emotional and cognitive strain. Parents who were older when their child was diagnosed with a developmental problem and mental health problems reported lower levels of negative effect and marginally better psychological well-being than those who were younger at the age of their child's diagnosis (Ha et al, 2008). Also, parents who had more than one child with a disability had significantly higher levels of negative affect and marginally greater somatic symptoms for parents of children with both developmental and mental health problems.

Results from the study showed that parents of children with developmental or mental health problems experienced significantly higher levels of negative affect, marginally poorer well-being and more somatic symptoms than parents of nondisabled children. According to Ha et al. (2008) older parents were better prepared to parent a child with a disability than younger, adolescent parents. Age generally indicates maturity, thus it is expected that older parents are able to sustain more challenging situations. Contrary to previous research, it was shown that having a disabled child did not have more of an impact on the mother compared to the father. It was stressful for both. However, mothers are usually the primary caregiver of the household. According to Ha et al. (2008), it may be that mothers reap greater emotional gratification and satisfaction

from care giving than men, which may reduce psychological distress and enhance well-being.

Different disabilities have characteristics that make them unique. For example, persons with autism have difficulty interacting and communicating with others. Both the general disability type and unique characteristics of the child pose challenges for family members, teachers, and other persons who interact with that person who has a disability. Certain disabilities may be perceived as more challenging to work with than others. Also, the severity of disabilities varies from person to person which can influence the degree of stress experienced by parents.

A study compared parenting stress levels in accordance to specific disabilities (Baker & McCal, 1995). The purpose of the study was to compare reports of parenting stress and child behavior problems among mothers of children with attention-deficit hyperactivity disorder (ADHD), mothers of children with learning disabilities, and mothers of nondisabled children. The subjects who qualified for the study completed the Child Behavior Checklist and the Parenting Stress Index. The study included 16 subjects (mothers) who had children with ADHD, 16 mothers of children with a diagnosed learning disability, and 16 mothers who had nondisabled children. This study compared stress levels of mothers of ADHD, mothers of children with learning disabilities, and mothers of nondisabled children. The results were used to compare the three groups using one-way multivariate analysis of variance and one-way analyses of variance with post-hoc analyses.

According to Baker and McCal (1995) mothers of children with ADHD were found to have significantly more parenting stress compared to mothers with nondisabled

children. It was also found that children with ADHD were described as displaying characteristics of being moody and less adaptable to environments compared to children in other groups; thus, parents with children who have ADHD are reported to have significantly higher stress levels due to their child's behavioral characteristics. The study infers that parents who have children with disabilities have higher stress levels than parents who have children without disabilities. Furthermore, parents who have children with specific disabilities may have increased stress levels due to the specific disability and characteristics elicited by the child.

Stress Levels of Parents of Children with Autism Spectrum Disorders

Previous research has determined that the amount of stress parents of children with disabilities experience is related to the type of disability and the severity of the child with the specific disability (Baker & McCal, 1995). Autism spectrum disorder (ASD) is a disability characterized by disruptive, external, unusual behaviors (e.g., difficulty with verbal and nonverbal communication, difficulty with social interaction, repetitive behaviors). Current literature and autism advocacy organizations recognize the high parent stress associated with raising a child who is on the autism spectrum. Osborne and Reed (2009) indicated that past studies have found higher levels of parenting stress in parents of children with ASD than in parents of children with any other type of disability and/or health problem. Two studies were conducted by Osborne and Reed (2009) to determine stress levels in parents of children with ASD. The first study focused on whether parenting stress is influenced by child behavior problems, and the severity of the child's ASD. The second study focused on whether child behavior problems or parenting

stress precede one another. Children with ASD demonstrate many unusual behaviors that may be difficult to handle for their parents and caregivers.

Study 1 determined the relationships between the behavior problems of the child with ASD and parental stress. The study was conducted over a 9-10 month period and measures were taken at two different times (Time 1 and Time 2). Time 1 was the first measure. Time 2 was the second measure after a 9 to 10 month period. Time 1 looked at the relationship between child behavior problems and parenting stress and Time 2 looked at possible evidence of temporal directionality effect.

The sample included 65 children with ASD, including 59 males and 6 females. The children's age ranged between 2 to 4 years. It was required that the children had an independent diagnosis of ASD by their pediatrician. Parental stress was measured using the Questionnaire on Resources and Stress (QRS-F). The QRS-F has been used in many studies to measure parental stress. High scores on the QRS-F indicate high stress levels. Results revealed a relationship between parenting stress and child behavior problems. It was also noted that as a child with autism becomes older the parenting stress decreases.

In study 2 the sample included 83 children (75 male and 8 female) between 5 to 16 years of age who had an independent diagnosis of ASD by their pediatrician. The Parenting Stress Inventory (PSI) was used to determine parental stress. According to Osborne and Reed (2009) the PSI is a 120-item self-report survey that measures stress in the parent in two major domains: child characteristics and parent characteristics. The PSI has a high internal reliability and the total stress score of the test is the overall indicator of the parent-child relationship stress (Abidin, 1995).

The findings of the study show a strong relationship between child behavior problems and parenting stress in both younger children as well as older children. Disruptive types of child behaviors and problems were said to increase stress levels of parents of children with ASD. In general discussion, the findings also indicate that parenting stress is highly associated with an older child's behavior problems and not as much with the severity of the child's ASD. However, this is the opposite in younger children with ASD.

Osborne and Reed (2009) stated that a possibility may be that parents with children with ASD tend to be more reactive instead of proactive in dealing with their children's behaviors. Another possibility is that the stress the parents experience triggers changes in the parents' ability to accommodate and respond to specific behaviors patiently and rationally.

The gender of the parent is an influential factor in raising children with ASD. The purpose of a study by Sharpley, Bitsika, & Efremidis (2005) was to determine whether parental stress, anxiety and depression from parenting a child with autism was related to gender or alleviated by social support. A survey was sent out to families of children with autism. The surveys included the Zung Rating Anxiety Scale and the Zung Self-Rating Depression Scale which are instruments used to look at anxiety and depression.

The responses to the surveys provided information about the nature of the child's disorder, parental well-being, parents' daily level of stress from parenting, confidence in handling their child, and the frequency of being stretched beyond their limits (Sharpley et al, 2005). The dependent variables in this study were gender of parents, age of parents,

age of child and age of onset, parental health, and access to other family members and level of understanding of those family members of the child (Sharpley et al, 2005).

Sharpley et al. (2005) stated that parenting a child with ASD was very demanding due to the poor understanding of autism by the general public when compared with other disabilities and the socially inappropriate and aggressive nature of much autistic behavior. Having a child with ASD also has been shown to have negative effects on marital relations. It was also noted that parents sometimes need to devote extra time to a child with ASD which can make other children feel neglected, or cause conflict among siblings (Sharpley et al, 2005). The authors describe three of the most stressful factors of having a child with ASD as the permanency of the condition, the lack of acceptance of autistic behavior by society, and low levels of social support. Other factors that increase the level of stress experienced by parents of children with autism are the age of the child. As children with ASD get older parental stress tends to increase (Sharpley et al, 2005).

The study by Sharpley et al. (2005) was designed to determine whether parental stress, anxiety, and depression arising from parenting a child with ASD could be related to gender or alleviated by social support. Questionnaires were sent to 1,076 families with children with autism in Victoria, Australia. Only 213 questionnaires were completed and returned (Sharpley et al, 2005).

The children of the parents sampled ranged between the ages of 3 to 33 years. Seventy-five percent of the children were less than nine years of age. There were 64.4% female respondents to the survey. When dealing with their child's behavior, 81.9% of the parents reported they were sometimes stretched beyond their limits. It was noted that parents with children with ASD felt unable to cope, anxious or stressed, depressed,

isolated and lonely, blamed themselves or just felt awful. There were 11.5% parents who felt stretched beyond their limits between 6 to 10 times each month.

This study also looked at gender as a factor contributing to parental stress. Findings show that females were more anxious and more depressed than males. Females reported they felt stretched beyond their limits each month significantly more than males. Females also reported they had greater levels of confidence in handing their children. Parental health was an important section of this study. Parents who had an illness or disability had significantly higher stress levels from parenting than those without an illness or disability.

Results of the study show the levels of anxiety and depression were higher in parents of children with ASD compared to parents with nondisabled children. The findings of the study show females reported higher levels than males of outcomes of parental stress, but higher levels of confidence in taking care of their child with ASD than males. This was an expected outcome of the study.

One implication from this study is to provide training to other family members in order to support the parents. Family support and knowledge helps alleviate parental stress. Parental illness or disability needs to be considered while developing training for parents of children with ASD. Parents with a significant disability or illness may need assistance as their condition may prevent them from caring for their child properly.

Behaviors exhibited by a child with ASD may negatively impact the parents in many ways, especially in the family and public settings. Support systems are necessary for parents of children with ASD. Montes and Halterman (2007) stated that past research has shown parents of children with autism had much higher levels of family strain and

low social support. It was also indicated that having a child with ASD was the primary contributor to maternal stress as well as having other mental health problems. There may be a strain on marital and family functioning with families that have a child with ASD. Parents of children with ASD may use poor coping strategies that may negatively impact the marital relationship.

Mothers are generally the primary caregivers in households. Research has implied that the primary caregivers are usually the parents who experience the most stress. A survey program was conducted by the National Center for Health Statistics. The survey interviewed 102,353 parents of children between the ages of 0 to 17 years. The telephone survey determined whether the parent had a child with ASD and the physical and mental health of the parent of the child. The telephone survey requested to speak to the parent who was most knowledgeable about their child who was usually the mother.

The results of the telephone survey indicate that mothers of a child with ASD rated their overall health as poor or fair. Mothers of a child with ASD were more likely to report poor or fair mental and emotional health which was lower compared to mothers with a nondisabled child.

According to Montes and Halterman (2007) parents reported that their child with ASD was significantly harder to care for than most children of the same age compared to mothers without a child with ASD. The results also show that mothers of children with ASD dedicate more of their life to their child than expected. Mothers of a child with ASD reported they were less likely to be able to talk to their child about things they wanted to. It was implied that the communication barrier of persons with ASD plays a role in this

finding because parents struggle to have a normal relationship with their child compared to a parent raising a typically developing child.

Mothers of children with autism experience high levels of stress and mental health problems. However, parents of children with ASD also demonstrate significant strength in coping, parent-child relationship, and psychological functioning. The implication of this study suggests that families use compensatory strategies to maintain family stability (Montes & Halterman, 2007).

Another study looked at the relationship between behaviors of children with ASD and maternal stress. According to Tomanik, Harris, & Hawkins, (2004), stress seems to be the greatest for mothers of children with ASD since they generally are the primary caregiver and assume more responsibilities. Children with autism tend to display inappropriate behavior, aggression, and repetitive actions. There are also language and communication barriers (Tomanik et al. 2004). Such behaviors and characteristics of ASD are factors that may increase stress in mothers. Tomanik et al. (2004) indicate that age, gender, cognitive functioning, family size, income, and social support are other variables that may impact maternal stress.

The study included 60 mothers between the ages of 26 and 46 who had a child diagnosed with a pervasive developmental disorder (Tomanik et al, 2004). The Parenting Stress Index-Short Form (PSI-SF) was used to measure stress levels of mothers in the study. The PSI-SF is a shorter but valid version of the PSI that has been used in other studies to measure stress. The subscales of this short form were parental distress, parent-child dysfunctional interaction, and difficult child (Tominik et al, 2004). The scores for this test were used in the regression analysis of this study.

Results of this study showed the average total stress scores on the PS-SF was high with a mean score of 97. Total stress scores of 90 or above indicate clinically significant levels of stress. Mothers of children with ASD reported they had significant amounts of stress when their child would display inappropriate behaviors or is unable to take care of themselves. The implications of this study suggest that importance of teaching mothers strategies to manage the child's behaviors more effectively to reduce stress.

Mental health is one aspect of personal well-being that is sometimes affected by having a child with ASD. According to Benson (2006) a mental health outcome linked to the demands of parenting a child with ASD is depression. Benson states that dealing with inappropriate and socially deviant behaviors on a daily basis increases the stress levels endured by parents. The objective of this study was to determine whether there is a relationship between children with ASD's symptoms and severity to depression in parents.

The parent sample consisted of 60 mothers and 8 fathers between the ages of 28 to 61 (Benson, 2006). Parents received a mean score of 16.4 on the CES-D, which implies a probable case of depression. Also, 45% of parents surveyed reported depressive symptoms severe enough to have a clinical diagnosis of depression. The severity of the child's symptoms was both significantly and positively correlated to stress and parent depression.

The findings of this study have important implications. For example, the high level of depression of parents suggests that parents of children with ASD are at an increased risk for poor mental health outcomes. The child's behavior and demands of care giving may be stressful. Clinical interventions may be needed for much of this

population. Mental health programs are can provide respite and other supportive services to parents such as counseling. This study concluded that parental well-being can be directly and indirectly affected by their child's ASD, but stressors can form that impact other aspects of the parent's life not related to ASD.

Mother-child interaction in children with autism and nondisabled children may differ. During the onset of ASD parents are the first to experience the psychological effects of their child's disorder. Many adaptations have to be made for mothers to interact with their child in social development.

Twenty-four children with autism and their mothers participated in a research study by Doussard-Roosevelt, Joe, Bashenova, & Porges (2003). The purpose of the study was to compare mother-child interaction between mothers of children with autism and mother's of nondisabled children using a coding observation system. Typically developing children were used as a comparison group (Doussard-Roosevelt et al, 2003). During the study children with autism were videotaped during free play with their parent for ten minutes. According to Doussard-Roosevelt et al. (2003), maternal approaches toward their child were coded into three types of approach behavior: social approach, physical approach, and object approach. A social approach uses social cues to engage the child, a physical approach use physical movement and object approach is using concrete objects to interact with the child (Doussard-Roosevelt et al, 2003).

The results of the study are useful in helping parents or clinicians work on ways to stimulate social development in children with ASD (Doussard-Roosevelt et al, 2003). Results of the study show that mother-child interactions with children with ASD are different compared to typically developing children. It was also noted that parents who

were consistent and firm while interacting with their child with ASD had more success with responses from their child compared to parents who were flexible with their child with ASD.

Benefits of Physical Activity in Stress Reduction

Many people cope with stress and maintain a healthy lifestyle through participation in physical activity. Physical activity can be defined as simply meaning movement of the body that uses energy. Walking, gardening, briskly pushing a baby stroller, climbing the stairs, playing soccer, or dancing the night away are all examples of being active (United States Department of Agriculture, 2009). Participation in physical activity may be a component of wellness that helps in reducing stress, especially in parents of children with autism.

Each person has a different way of coping with stress. One way that people cope with stress is through regular exercise. Exercise has been shown to decrease stress (Schnohr, Kristensen, Prescott, & Scharling, 2004). It may be reasonable to believe that exercise can help many parents of children with ASD to more effectively manage their stress. Many studies that look at physical activity and stress are correlation studies. Past published investigations conclude that individuals with improved levels of fitness are capable of managing stress more effectively than those who are less fit (Schnohr et al, 2004). According to Schnohr et al. (2004) men and women who are physically active during their leisure time are less worried and tense, and have higher life satisfaction. There is an inverse relationship between an increase in physical activity and stress. The more an individual participates in physical activity; it is likely the stress levels within that individual will also decrease.

There is a lack of research that focuses on the benefit of physical activity and stress reduction in parents. It is commonly believed that physical activity will help reduce stress in individuals; however, continued research on the benefits of physical activity and stress reduction is necessary to determine this.

Summary

Many studies have determined that parents of children with ASD have higher levels of stress compared to other parents. Mothers of children with ASD spend significantly more time providing childcare and completing chores and less time in leisure physical activities than mothers of children without disabilities. Fatigue, arguments, avoided arguments, and stressful events were reported to be higher among mothers of children with ASD compared to mothers of children without disabilities (Smith et al, 2009). It would be beneficial to this population to determine if there is a relationship between stress and physical activity levels. If the results of this study indicate there is a relationship between stress levels and participation in physical activity, the needs of these parents should be further addressed. Respite, physical activity, and wellness programs may be offered to these parents to enhance their quality of life as well as their families. There may be a significant need to determine how regular participation in physical activity can impact stress in this population of parents. If stress can be effectively managed, then quality of life is more likely to be enhanced not only for these parents but also for the child with ASD. Children with ASD rely primarily on their parents for advocacy and effective intervention.

Numerous studies have determined that parents with children with ASD have increased stress levels compared to the general population. However, research is lacking

that looks at the relationship between stress levels and participation in physical activity in parents of children with ASD.

REFERENCES

American Institute of Stress (2010). Stress reduction, stress relievers. Retrieved from http://www.stress.org/topic-reduction.htm

Autism Society of America. (2008). *About autism.* Retrieved from http://www.autism-society.org/site/PageServer?pagename=about_home

Baker, D.B., & McCal, K. (1995). Parenting stress in parents of children with attention-deficit hyperactivity disorder and parents of children with learning disabilities. *Journal of Child and Family Studies, 4(1),* 57-68.

Benson, P. (2006). The impact of child symptom severity on depressed mood among parents of children with ASD: The mediating role of stress proliferation. *Journal of Autism Developmental Disorders, 36,* 685-695.

Centers for Disease Control and Prevention (2010). Autism spectrum disorders. Retrieved from http://www.cdc.govncbddd/aut/ism/index.html.

Doussard-Roosevelt, J., Joe, C., Bashenova, O., & Porges, S. (2003). Mother-child interaction in autistic and nonautistic children: Characteristics of maternal approach behaviors and child social responses. *Development and Psychopathology, 15,* 277-295.

Ha, J., Hong, J., Seltzer, M., & Greenberg, J. (2008). Age and gender differences in the well-being of midlife and aging parents with children with mental health or developmental problems: Report of a national study. *Journal of Health and Social Behavior, 49*, 301-316.

Montes, G., & Halterman, J. (2007). Psychological functioning and coping among mothers of children with autism: A population-based study. *Official Journal of the American Academy of Pediatrics, 119,* 1040-1046.

Osborne, L., & Reed, P. (2009). The relationship between parenting stress and behavior problems of children with autistic spectrum disorders. *Exceptional Children, 76(1),* 54-73.

Schnohr, P., Kristensen, T., Prescott, E., & Scharling, H. (2004). Stress and life dissatisfaction are inversely associated with jogging and other types of physical activity in leisure time: The Copenhagen city heart study. *Scandinavian Journal of Medicine and Science in Sports, 15,* 107-112.

Seltzer, M., Greenberg, J., Hong, J., Smith, L., Almeida, D., Coe, C., & Stawski, R. (2009). Maternal cortisol levels and behavior problems in adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*. Advance online publication. doi:10.1007/s10803-009-0887-0

Sharpley, C., Bitsika, V., & Efremidis, B. (2005). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability, 22(1),* 19-28.

Singer, G., Ethridge, B., & Aldana, S. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities, 13*, 357-369.

Smith, L., Hong, J., Seltzer, M., Greenberg, J., Almeida, D., & Bishop, S. (2009). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders.* Advance online publication. doi:10.1007/s10803-009-0844-y

Tomanik, S., Harris, G., & Hawkins, J. (2004). The relationship between behaviors exhibited by children with autism and maternal stress. *Journal of Intellectual and Developmental Disability, 29(1),* 16-26.

United States Department of Agriculture. (2008). *Inside the pyramid: What is physical activity?* Retrieved from http://www.mypyramid.gov/pyramid/physical_activity_print.html.