

Hartley Lab Newsletter

University of Wisconsin-Madison
Waisman Center

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Thank you for being a part of our study - Family Outcomes in Autism Spectrum Disorder. We have learned so much from you! We would like to provide you with an update as we are nearing the end of our fourth year of data collection. The overall goal of the study is to understand the dynamics of families who have a child on the autism spectrum (AS). Specifically, we are interested in how the experiences and well-being of family members are linked overtime at both a day-to-day level and from one year to the next.

We hope to learn about both the challenges and triumphs experienced by families who have a child on the AS, and to understand the processes that promote optimal development and well-being across family members. This information can help us inform social policies, debunk myths, and identify needed interventions and supports. The purpose of this newsletter is to give you an update on findings from the study. We have also included information on AS local resources.

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Study Update

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What Parents are saying about *Siblings of Children on the Autism Spectrum*

Cindy Gauthier, Paige Bussanich, & Sigan Hartley

Parents were asked: “How has the sibling benefited or been shaped in positive ways as a result of their brother or sister on the AS?” Below, we have highlighted a few themes that emerged across the 300 parents in our study.

- Siblings learn how to be accepting of others.
 - “Learning... that not everyone is the same but do not have to be treated different because of it” - father about 12-year-old daughter
 - “He has an increased tolerance for odd or silly behaviors in other children” - mother of 15-year-old son
- Siblings develop deep empathy.
 - “He is very in touch with his emotions” -father about 7-year-old son
 - “He is a very caring and thoughtful person who really has a special place in his heart for people with special needs” - father about 10-year-old son
- Siblings develop appreciation for giving back and helping others.
 - “...learned how to interact with other children as well with special needs” -father of 12-year-old daughter
 - “...attends ‘lunch bunch’ at school for social games for kids on the AS even though his brother isn’t at school” -father of 11-year-old son
- Siblings gain increased maturity.
 - “She has developed patience with other children who have special needs. She is more mature than peers” -mother about 12-year-old daughter
 - “He seems to like to help her remember and keep track of her things” - mother 16-year-old son



Parental Sleep Quality and Behavior Problems of Children with ASD

Iulia Mihaila & Sigan Hartley

Not getting enough sleep can make it difficult to cope with life stress. Previous studies have found that parents who have a child on the AS report poorer sleep quality than do other parents. In part, poor sleep may be due to the sleep problems of children on the AS (44%-83% of children on the AS have sleep problems) – if children aren't sleeping, this often means that parents are not sleeping. Parents' poor sleep quality may also be due to experiencing elevated parenting stress which can interfere with the body's ability to relax (Meltzer and Mindell, 2008). In a sleep-stress cycle, experiencing a night with poor sleep can then contribute to experiencing more stress the next day, contributing to poor sleep quality the next night, and so on (Basner et al., 2013; Doane and Thurston, 2014; Vandekerckhove and Cluydts, 2010).

Little is known about the impact of sleep on parents' experience of behavior problems by their child on the AS. Following a night with poor sleep, parents may perceive child behavior problems as more frequent and severe and be less able to cope with child-related challenges. The goals of this study were to look at the association between mother's and father's previous-night sleep quality, subjective rating of the frequency and severity of behavior problems by their child on the AS, and their daily positive and negative mood.

The study examined the 176 couples in the study who completed the 14-day daily diary. Parents were between the ages of 25 and 54 years. The child on the AS ranged from 5-12 years. On each day of the daily diary, parents were asked about their previous night's sleep quality, their child's behavior problems, and their mood.

We found that at a day-to-day level, previous night's sleep quality was *not* related to parents' rating of the subjective frequency or severity of their child's behavior problems. But, mothers who had higher quality sleep on average reported that their child had less severe behavior problems than did mothers who had lower quality sleep on average. Overall this means that getting chronically poor sleep (e.g., poor sleep several days per week) is linked to experiencing more child-related challenges for mothers. In contrast, having one poor night of sleep is not likely to impact the experience of child-related challenges the next day for a mother who generally gets good sleep.

In our study, fathers of children on the AS reported a lower quality of sleep overall than mothers. Yet, sleep quality was not associated with subjective ratings of child behavior problems in fathers. It is unclear why similar sleep quality associations were not found in fathers. In our study, on average (although not always the case), fathers spent less time in child-related activities than mothers. This difference may mean that father's sleep is not as closely tied to child-related experiences.

Mothers and fathers who had higher (rather than lower) sleep quality on average reported a more positive daily mood. Additionally, fathers with a higher (rather than lower) sleep quality on average reported a less negative mood. Indeed, previous night's sleep quality had a strong effect on daily mood.

This study was published in the journal *Autism*. <https://www.ncbi.nlm.nih.gov/labs/articles/27899714/>

Family Resources



Parent to Parent
www.p2pwi.org



Waisman Resource Center
www.waisman.wisc.edu/wrc/
800-532-3321



Acceptational Minds
www.acceptational
minds.org



Friends of Autism
www.friendsofautism.org
920-851-5100



www.asew.org
414-988-1260

General Tips for Getting High Quality Sleep

- **GET AT LEAST 7 HOURS**

IT IS RECOMMENDED THAT ADULTS TRY TO GET AT LEAST 7 HOURS OF SLEEP A NIGHT.

- **TRY TO STICK TO A SLEEP SCHEDULE**

ATTEMPT TO KEEP A REGULAR BED TIME AND WAKE UP TIME. AFTER A NIGHT OF LESS SLEEP DO NOT TRY TO "CATCH UP" ON SLEEP; GET BACK ONTO YOUR REGULAR SLEEP SCHEDULE.

- **BE MINDFUL OF WHAT YOU ARE EATING AND DRINKING THROUGHOUT THE DAY**

IT IS BEST TO LIMIT CAFFEINE CONSUMPTION THROUGHOUT THE DAY BUT ESPECIALLY BEFORE BED. FURTHER, TRY NOT TO GO TO BED ON AN EMPTY STOMACH OR UNCOMFORTABLY FULL.

- **INCLUDE PHYSICAL ACTIVITY IN YOUR DAY**

TRY TO GET AT LEAST 30-45 MINUTES OF PHYSICAL ACTIVITY A DAY. IF POSSIBLE, DO NOT BE TOO ACTIVE BEFORE BED.

INFORMATION FROM MAYO CLINIC

Daily Couple Experiences in Families of Children on the Autism Spectrum

Sigan Hartley, Leann Smith DaWalt, & Haley Schultz

The goal of this study was to examine the day-to-day couple experiences of parents who have a child on the AS relative to parents who have children not on the AS. We wanted to know if the experiences associated with having a child on the AS shape couple interactions in both desirable and undesirable ways. The families who had a child on the AS and families who had children not on the AS were included in the analyses. On each day of the 14-day daily diary, parents reported on the time they spent with their partner, the support they received from their partner, and how close they felt to their partner. They also reported the number of positive couple interactions they had with their partner (for example, gave a compliment to him/ her, kissed or hugged him/ her) and the number of negative couple interactions they had with their partner (for example, made a critical comment of him/ her, purposefully avoided or ignored him/ her).

Our findings suggested a pattern of both vulnerability and strength. Couples parenting a child on the AS reported spending an average of 21 fewer minutes per day with their partners compared to couples with a typically developing child. Spending less time together could account for why fathers of children on the AS reported feeling less closeness to their partners than those raising typically developing children. The AS group of parents also reported fewer positive couple interactions, such as sharing jokes, having a meaningful conversation or being intimate. In part, the lower couple time seen in the AS group may result because these parent have more demands on their time. For example, they may have to navigate therapy sessions, provide help with everyday living skills, and manage special education or interventions.

On the other hand, parents of a child on the AS showed no increase in daily number of negative couple interactions, like critical comments or avoiding their partner, when compared to couples with a child not on the AS. Parents who had a child on the AS also felt just as supported by their partner as did parents of children not on the AS. These are important relationship strengths. Implications for this study are discussed on the next page.

Implications from the Study:

- Effort should be given to debunking myths that parents of children on the AS are fated to experience dismal couple relationships. Group differences were limited. Most couples reported positive couple relationships.
- Support services should acknowledge that the difficulty of juggling multiple demands (e.g., child on the AS, siblings, employment, couple relationship, etc.) may mean that parents have limited time to spend with their partner.
- Support services that encourage parents to carve out time to share feelings and thoughts, as opposed to only working through daily life demands, may be beneficial. For example, couples could reserve five minutes in the evening for sharing stories from their day.
- Professionals should consider supporting parents in creating opportunities for positive couple interactions such as doing a fun activity together or taking a moment to text/email a joke to their partner over their lunch hour.
- Public policies are needed to reduce care demands and emotional stressors by increasing respite care, family supports (e.g., paid providers to help with childcare and/or household tasks), and/or financial assistance to parents.
- These do not need to be achieved through increasing couple alone time. Instead, they could be achieved by fostering positive and fun family-wide activities (i.e., involving not only partners, but also the child on the AS and other family members).

This study was published in the *Journal of Autism and Developmental Disorders*. <https://link.springer.com/article/10.1007/s10803-017-3088-2>

A Look into the Future

Please let us know if your contact information changes! In the coming years we will be continuing to learn about families and the autism spectrum.

Future topics that our research will be focused on:

- ✓ Parent – child interactions
- ✓ Sibling experiences
- ✓ Friendships
- ✓ Co-parenting experiences

Interested in these topics or learning more? Please contact our lab!
Do you know a family that might be interested? Please feel free to give them our contact information.

Hartley Lab Contact Info

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Parent quotes about the amazing accomplishments of children on the AS in our study...

- “He always tries his hardest in school and I love seeing him help his younger siblings.” - Mother
- “[Child] got his black belt in taekwondo earlier this year and he was asked to join the academy’s leadership program. He now teaches younger children once a week at taekwondo and it’s been great to watch.” - Mother
- “[Child] was being picked on at school. He walked away and told the teacher instead of getting angry.” -Father
- “He routinely stands up for his morals and is very strong against peer pressure.” - Father
- “[He] tried a new activity (Two! Snowshoeing and ice skating) with no hesitation or fear, just enthusiasm. He is so willing to try anything physical like that.” - Mother
- “He finally put his head under the water this summer and it was very difficult for him but he did it! Sometimes the little things have more impact than the larger ones.” – Father
- “He had a really fantastic report card with good grades and very sweet comments from his teacher.” - Mother

The Hartley Lab is located at the Waisman Center, University of Wisconsin-Madison.

The principal investigator is Sigan Hartley, Associate Professor of Human Development and Family Studies

