

Insights from Families of Children on the Autism Spectrum

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Autism Spectrum (AS)

- ▶ Includes a wide range (“spectrum”) of conditions which share the following characteristics (with varying degrees):
 - ▶ Difficulty in communicating and interacting with others
 - ▶ Repetitive behaviors or limited interests and activities
 - ▶ Sensory sensitivities
 - ▶ Interfere with functioning in social, work/school, or other areas of life
- ▶ 1 in 68 children estimated to have AS in the United States

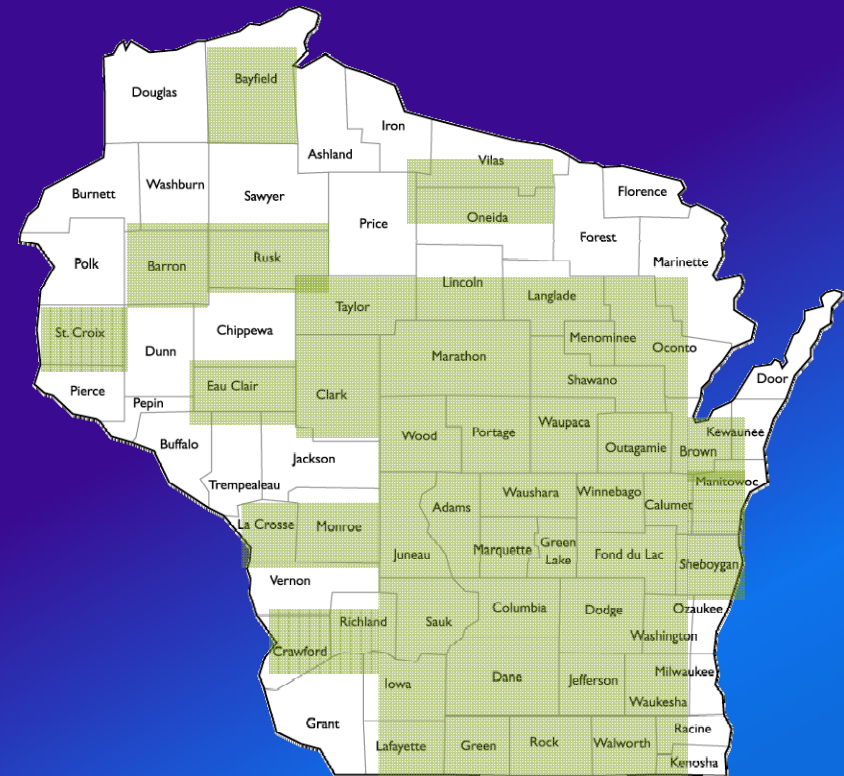
Family Outcomes in AS

Time 1	Time 2 (1 yr later)	Time 3 (1 yr later)	Time 4 (1 yr later)
Questionnaire Packets	Questionnaire Packet	Questionnaire Packet	Questionnaire Packet
Interview	Interview	Interview	Interview
Observations	Observations	Observations	Observations
Teacher Report	Teacher Report	Teacher Report	Teacher Report
	Physiological arousal	Physiological arousal	Physiological arousal
14-Day Daily Diary			

Families in the Study

189 Families who had a child with AS

Mothers	
Age (M [SD])	38.71 (5.59)
Education (%)	
No High School degree	2%
HS degree	6%
Some college	17%
Associate/ Bachelor degree	54%
Graduate degree	21%
Father	
Age (M [SD])	40.44 (6.24)
Education (%)	
No High School degree	6%
HS degree	12%
Some college	14%
Associate/ Bachelor degree	49%
Graduate degree	19%
Child with AS	
Age (M [SD])	7.88 (2.24)
Male (%)	86%



Joys of Parenting



- ▶ "... I don't think I could be any prouder [of child].. every time he accomplishes and does something and goes above and beyond. When people say he is limited and can't do, and then he achieves..."
- ▶ "He's just a great kid, probably one of the better things that have ever happened to me.... "
- ▶ "He makes me laugh quite a bit. He makes me smile."
- ▶ "...I do know that I'm a better person. I'm more patient, I'm much more compassionate for other people's situations ... a positive impact on my life."
- ▶ "... he's just a real joy to have in our house and I think he's really blessing humanity by being here with his loving, loving personality."
- ▶ "I don't know that I would change anything about him.... so even though there's been some things that have been kind of challenging, I think overall it's those things that make him who he is and so it's been a good experience."

Trials of Parenting



- ▶ "We struggle quite a lot over sleep - when she needs to go to bed, when she needs to get up..."
- ▶ "...it's frustrating because with certain behaviors, it does not matter what we do, we have tried everything that we can think of, everything that has been recommended to us from friends and professionals and parents..."
- ▶ "...one of the major issues is the meltdowns in public....go to the store, he assumes that he gets something right away and if he doesn't get it then that's when he throws a fit..."
- ▶ "I worry sometimes about the way other kids treat him because he doesn't follow the social conventions that are typical of his age and kids his age."
- ▶ "The difference with autism, that I see, is paperwork and appointments. So much paperwork and appointments."
- ▶ "There's a lot of things that we would love to be able to do, that we really can't do. Um, like vacations and just you know going out more, socializing more. ... we don't have people over a lot because again it is hard with [child]."

Daily Couple Experiences

Methodology

- ▶ Sample:
 - ▶ 174 families in AS group; 179 families in comparison group
 - ▶ Comparison group = no identified or suspected neurodevelopmental condition
- ▶ Daily Diary:
 - ▶ 94% completed via online surveys, 6% iPod Touch
 - ▶ 90.1% AS group and 89.2% comparison group completed 14 days
- ▶ Measures:
 - ▶ Time spent with Partner: Hours and minutes spent with partner each day
 - ▶ Parent support: 6 questions about extent partner gave advice, gave view on problem, did something to help solve problem, expressed care and concern, listened to feelings, and overall support
 - ▶ Parent Mood: Positive and Negative Affect Scale (PANAS: Watson, Clark, & Tellegen, 1988)
 - ▶ Positive and Negative Couple Interactions (8 positive; 8 negative interactions; Quittner et al. 1998)
 - ▶ Partner Closeness: 6 items about extent to which parent disclosed or told facts, information, thoughts, and feelings. 4 questions about extent felt understood, validated, accepted, and cared for by partner
- ▶ Data Analyses:
 - ▶ One-way Multivariate analysis of covariance to compare means (i.e., average across 14-days)
 - ▶ Dyadic multilevel models using Hierarchical Linear Modeling

Daily Diary



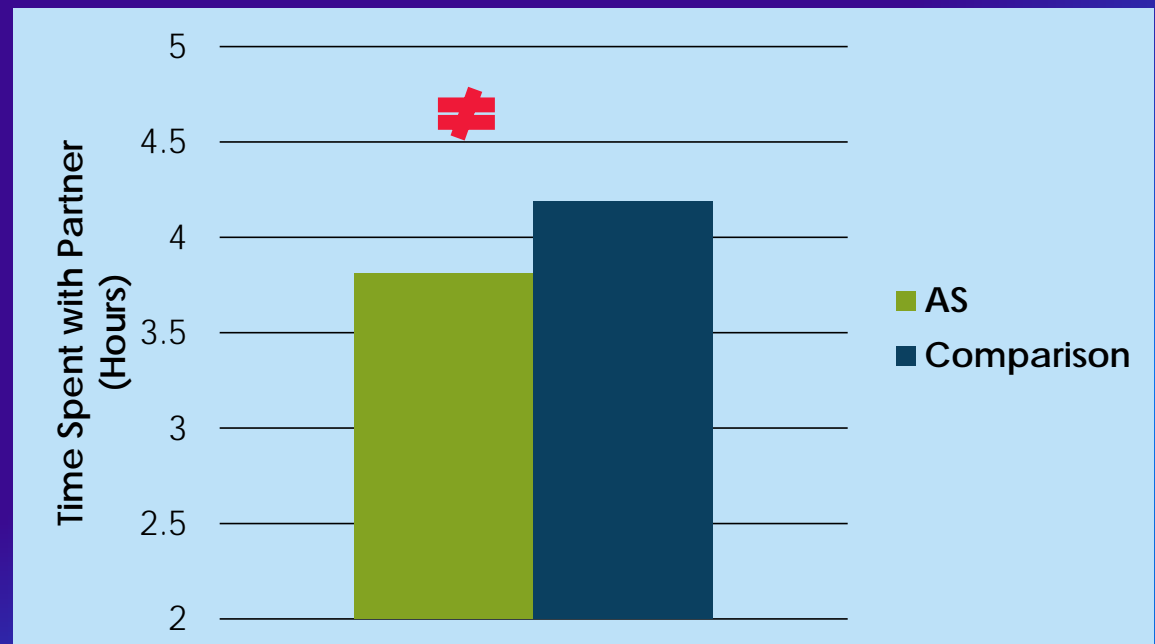
- ▶ 14-day Daily Diary
- ▶ Online or via iPod Touch
- ▶ Parents individually completed
- ▶ Same set of questions each day

In the last 24 hours, to what extent did you feel the following:

	Not At all						A Lot
Excited	1	2	3	4	5	6	7
Nervous	1	2	3	4	5	6	7
Disappointed	1	2	3	4	5	6	7
Energetic	1	2	3	4	5	6	7

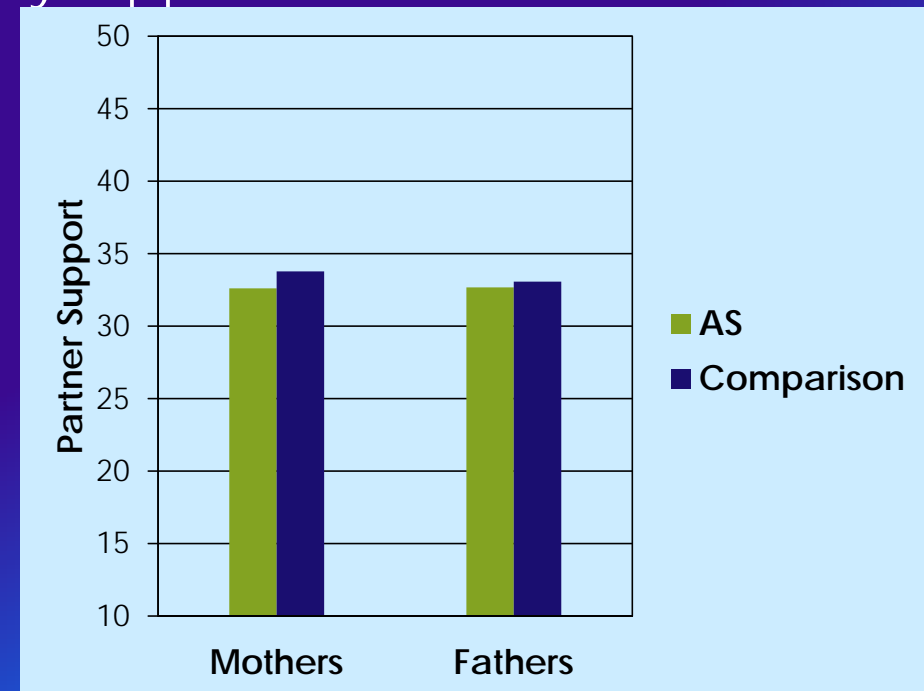
Time with Partner

- ▶ Recorded hours and minutes with partner each day
- ▶ Parents of children with AS less time with partner (ON AVERAGE) than comparison group
- ▶ Average difference:
21 mins/day



Partner Support

- ▶ Does your partner support you in managing daily life demands?
 - ▶ Parents of children with AS felt equally supported (ON AVERAGE) as comparison group

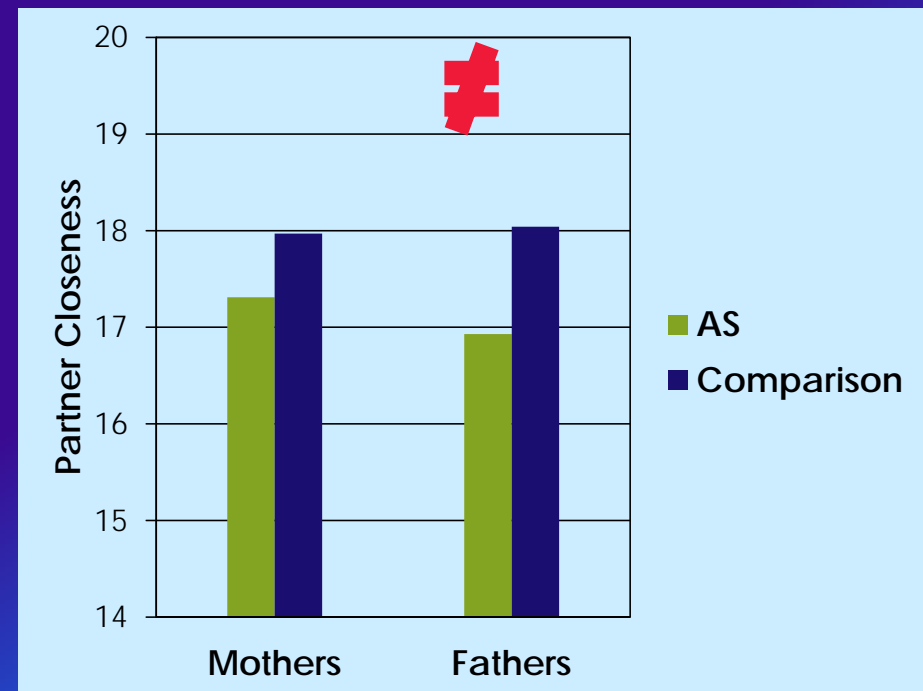


Partner Support

- ▶ "...he is always there for me. We make a great team."
- ▶ "When I get overwhelmed, [partner] talks me through it. Together we somehow get it done."
- ▶ "...she gets the groceries and then I watch the kids. So we kind of piggyback it, so that it is like a team work thing."
- ▶ "When I am frustrated, he will step in. I am always impressed at how he can stay calm."
- ▶ "He doesn't ever question; family comes first."
- ▶ "She's always willing to do anything to help me out...takes care of most things around the house."

Partner Closeness

- ▶ Do you and your partner share thoughts, feelings, and facts? Do you feel close to your partner?
 - ▶ Fathers of children with AS felt less close (ON AVERAGE) than comparison group
 - ▶ Average difference: 8% lower
 - ▶ No group difference in mothers



Partner Closeness

- ▶ "...we cannot do the things that a lot of people take for granted. It's been a year since we went on outing without the kids..."
- ▶ " I just wish I had more time and energy left for [partner] once I get finished with my work responsibilities and parenting [child]... I feel like there is not much left for [partner]. "
- ▶ "Um, we rarely do anything fun, I think just because of time constraints. My parents are the only babysitters that we have because you can't just get a babysitter for someone who doesn't know autism or your child, that's really hard."
- ▶ "I wish we had more time together. But I understand what we have to do to keep [child] supported and keep our house and family and everything afloat requires a lot of separate activities..."
- ▶ "We're kind of just two roommates with kids in the house...but I mean when we do get a chance [to have alone time]... We get along and it kind of nice to reconnect."

Positive and Negative Interactions

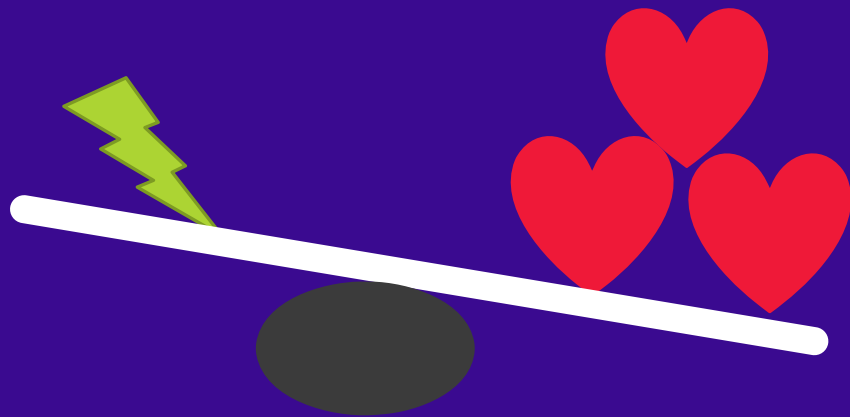
▶ Negative couple interactions

- ▶ Expressed anger or frustration, avoided/ignored, etc.
- ▶ Groups had similar level (ON AVERAGE)

▶ Positive couple interactions

- ▶ Shared a joke, fun activity, enjoyed a conversation, hugged/kissed, etc.
- ▶ Parents of children with AS fewer than comparison group (ON AVERAGE)

Negative: Positive Ratio

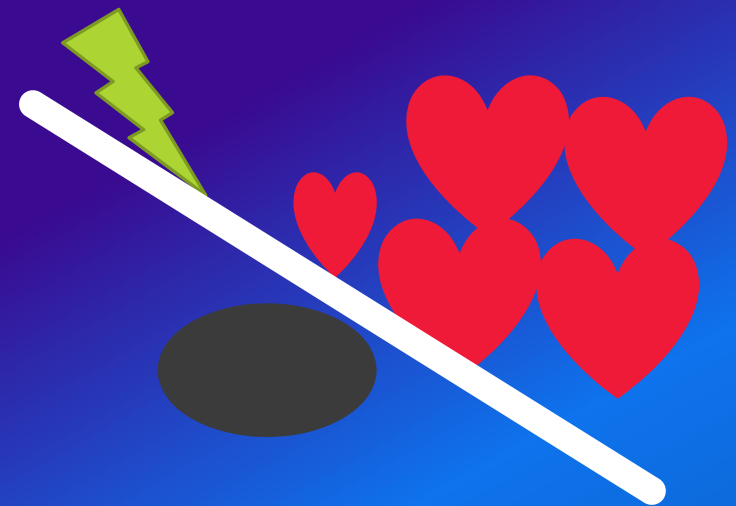


Parents of children with AS

1: 3 negative to positive

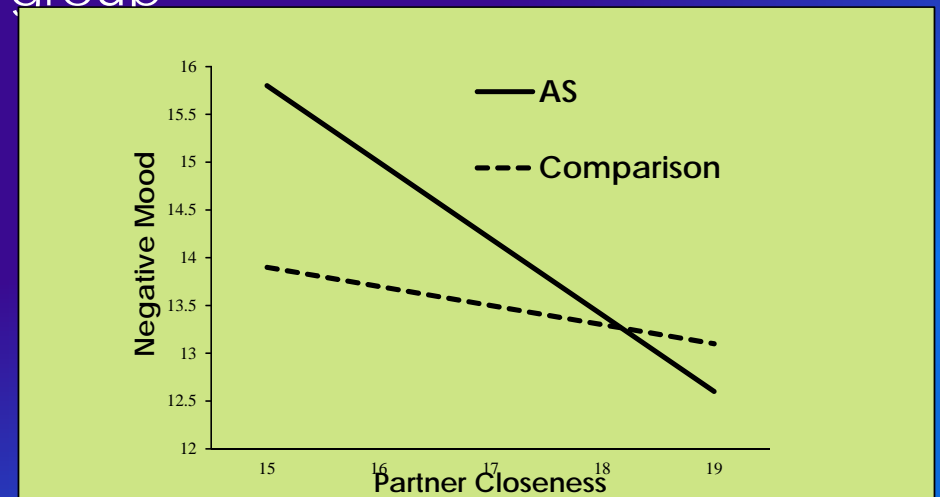
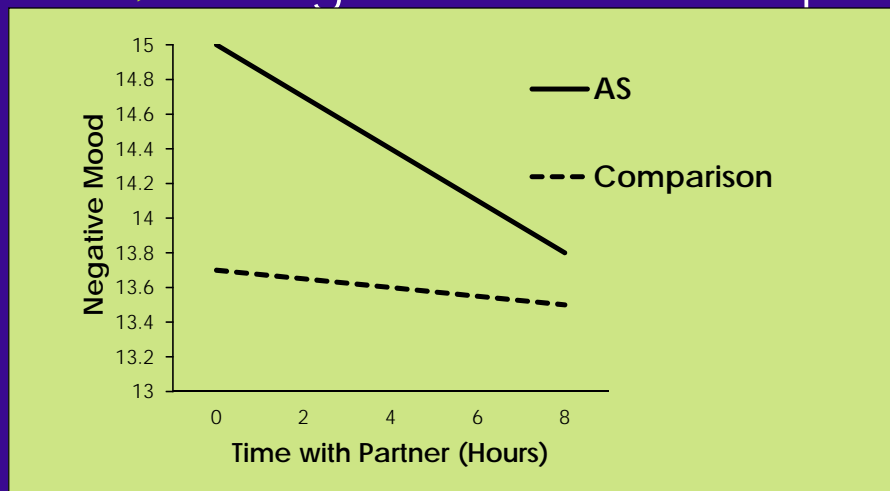
Comparison group

1: 4.4 negative to positive



Daily Couple Experiences and Mood

- ▶ How closely linked are daily couple experiences and parent mood?
 - ▶ Daily negative couple interactions and partner closeness strongest link to mood
 - ▶ Stronger in AS than comparison group



IMPLICATIONS

- ▶ Vulnerability and strength
- ▶ Obstacles to spending time with partner
 - ▶ Greatest toll on partner closeness and positive couple interactions
- ▶ Couple relationship resource for positive experiences in parents

Applications

- ▶ Debunking myths
- ▶ Acknowledging multiple demands
- ▶ When feasible, building in partner closeness and positive couple interactions
- ▶ Couple therapy directions –Acceptance and change-based therapies
- ▶ Learning from couples who are thriving

References

- ▶ Hartley, S.L., DeWalt, L.S., & Schultz, H.M. (in press). Daily couple experiences and parent affect in families of children with versus without autism. *Journal of Autism and Developmental Disorders*.
- ▶ Hartley, S.L., Papp, L.M., & Bolt, D. (2016). Spillover of marital interactions and parenting stress in families of children with autism spectrum disorder.. *Journal of Clinical Child and Adolescent Psychology*. Epub ahead of print.
- ▶ **Hartley Lab website:**
<http://www.waisman.wisc.edu/hartleylab/index.htm>

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WE ARE SO VERY GRATEFUL TO THE FAMILIES WHO ARE WILLING TO SHARE THEIR EXPERIENCES!

Hartley Lab

