

# Meeting the Unmet Respite Care Needs of Families of Children with Special Healthcare Needs



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# Background & Significance

- ❖ 1 in 5 households in the United States cares for a child with special healthcare needs (CSHCN)
- ❖ Defined as “those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally”

(The Child & Adolescent Health Measurement Initiative, 2012)



# Caregiver Risks

- ❖ Increased Stress (Estes, 2009)
- ❖ Increased Fatigue (Whitmore, *review in development*)
- ❖ Poorer Quality of Life (Vasilopoulou & Nisbet, 2016)
- ❖ Marital Stress → Divorce (Saini et al., 2015)
- ❖ Financial Stress and Job Loss (Lindley, Chavez & Zuckerman, 2016)
- ❖ Parenting Difficulty → Child Outcomes (McGrath, 2013)
- ❖ Abuse/Neglect (Cowen & Reed, 2002)



# Respite Care

- ❖ Respite care is defined as temporary relief from the responsibilities of caregiving (Whitmore, 2016a)
- ❖ Respite care may decrease stress and other negative outcomes (Harper et al., 2013; Whitmore, 2016b; Whitmore & Snethen, In Press)
- ❖ Respite care needs are largely unmet (Farmer et al., 2014; Nageswaran, 2009; Whitmore & Snethen, 2018)





# Caregivers of children with ASD may be at greater risk

- ❖ Increasing prevalence of Autism Spectrum Disorder (ASD) → 1 in 59 US children (CDC, 2018)
- ❖ Defined as a group of developmental disabilities that can cause significant social, communication and behavioral challenges (CDC, 2015).
- ❖ Parents experience stress comparable to combat soldiers (Smith et al., 2010)
- ❖ Unique aspects of caring for a child with ASD



# Research Questions

1. What are the differences in the **prevalence of unmet respite care needs** between families of children with ASD and families of CSHCN without ASD?
2. What are the differences in the **prevalence of respite care use** between families of children with ASD and families of CSHCN without ASD?
3. What is the **relationship** between context factors and unmet respite care needs?

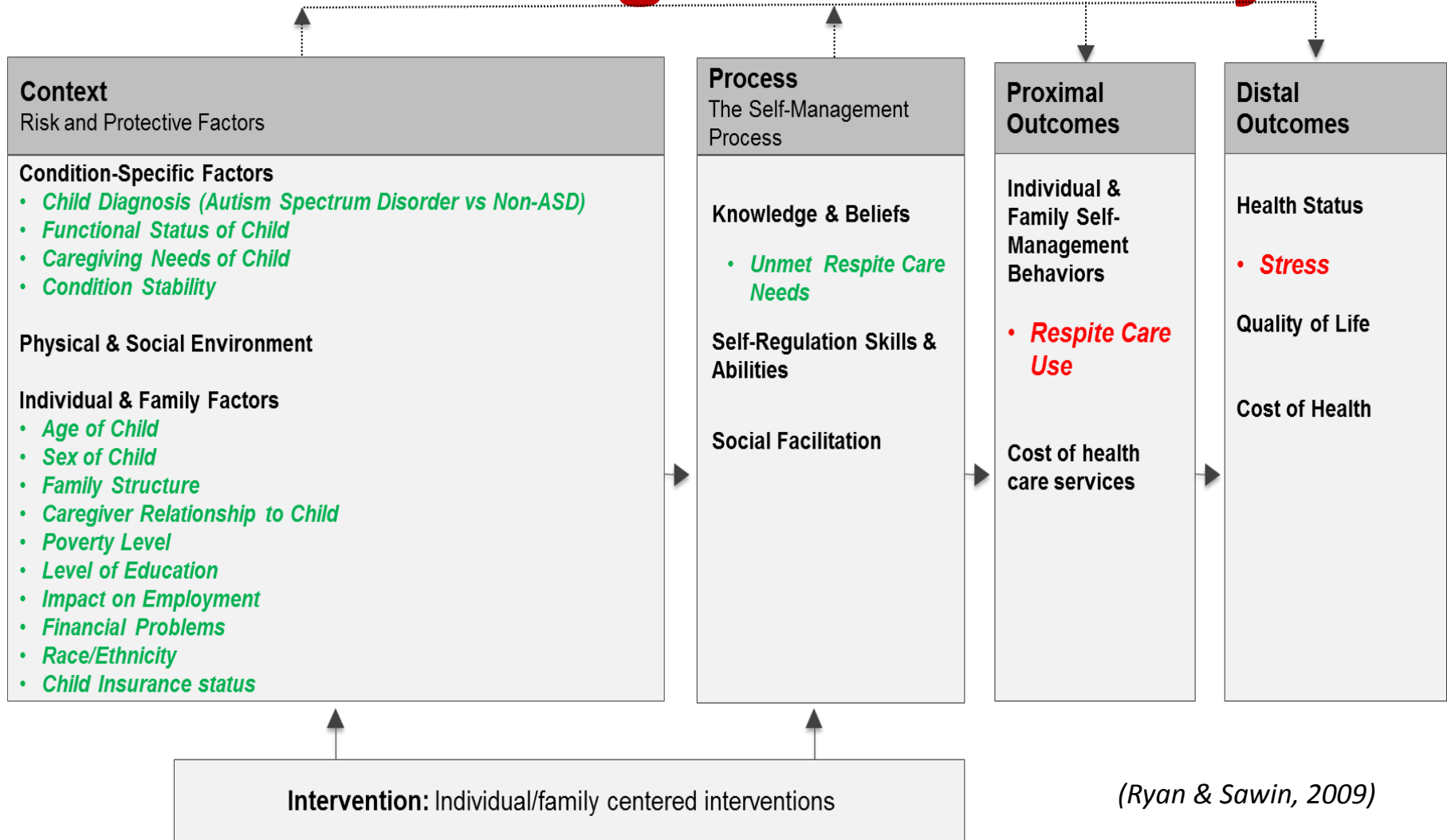


# Methods

- ❖ Exploratory secondary analysis of the 2009-2010 National Survey of Children with Special Healthcare Needs (NS-CSHCN) (Bramlett et al., 2014)
  - Telephone survey of 40,242 parents or guardians (over 18 years of age)
  - Assesses overall health and health status of CSHCN (under 18 years of age)
- ❖ Design
  - Non-experimental, descriptive, correlational
- ❖ Granted exempt status by UWM IRB



# Individual and Family Self-Management Theory





# CONTEXT

## Condition-Specific Factors

- ❖ Child Condition (ASD vs Non-ASD)
- ❖ Functional Status of the Child
- ❖ Caregiving Needs of the Child
- ❖ Hours per Week Providing Care
- ❖ Condition Stability



# CONTEXT

## Individual & Family Factors

- ❖ Sex of Child
- ❖ Child Age Groups
- ❖ Relationship to Child
- ❖ Family Structure
- ❖ Race
- ❖ Poverty Level
- ❖ Highest Level of Parent Education
- ❖ Insurance Status
- ❖ Condition Caused Financial Problems
- ❖ Family Financial Burden
- ❖ Family Member Stopped Working
- ❖ Cut Down Hours Working
- ❖ Impact on Family Work Life



# PROCESS

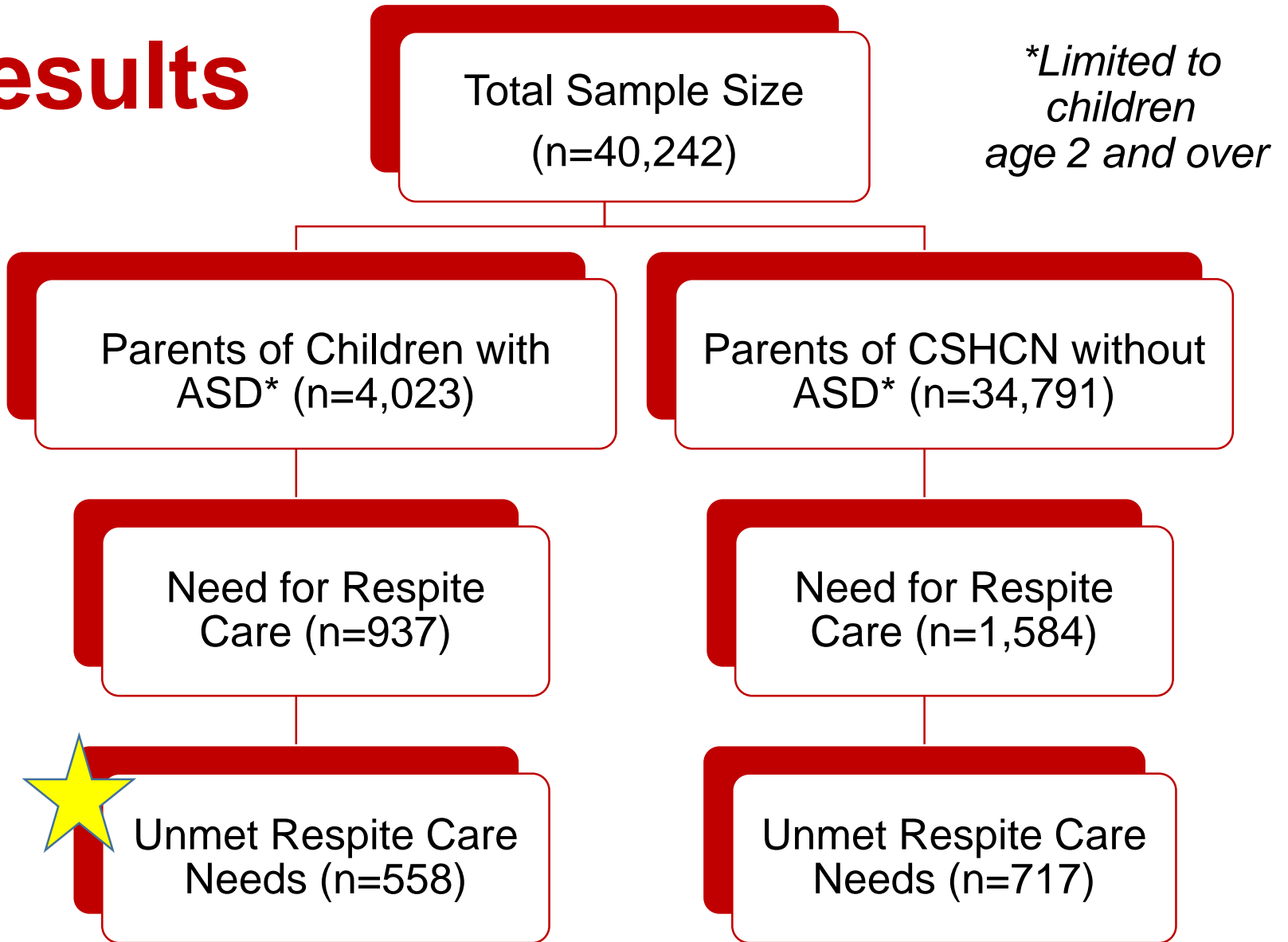
## Knowledge & Beliefs

### Unmet Respite Care Needs

- ❖ Defined as an individual's perception of the degree to which their respite care needs are met.
- ❖ This builds off the survey questions in the NS-CSHCN, which defines unmet respite care needs as having a need for respite care, and not receiving all the respite care, that was needed (Bramlett, et al., 2014).



# Results



# Parents of children with ASD with unmet respite care needs (n=558) were mostly:

- ❖ White (71%)
- ❖ Well-educated (91% >HS)
- ❖ Affluent (60% >200% FPL)
- ❖ Mothers (82%)
- ❖ Male children (79%)
- ❖ Between 12 and 17 years old (44%)
- ❖ Two parent household (62%)
- ❖ Limited functional status (71%)
- ❖ Provided health care at home (68%)



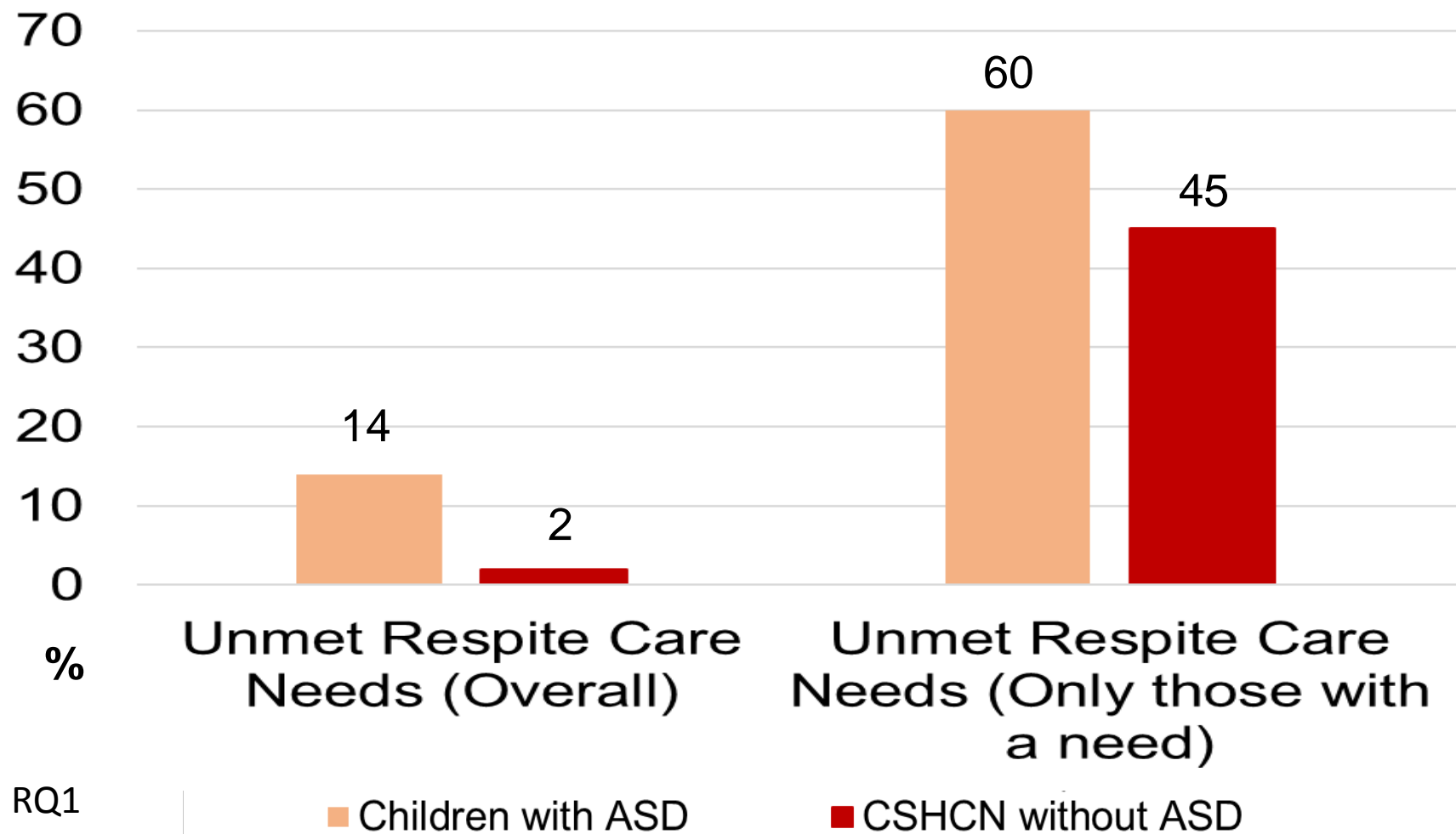
# Caring for a CSHCN had an impact on the family

- Spent 11 or more hours per week providing care (45%)
- Child's condition caused financial problems (66%)
- A total of 77% indicated that their child's health condition had an impact on family work life
  - 51% cut down hours
  - 54% stopped working





# RQ1: Unmet respite care needs are greater for children with ASD



RQ1



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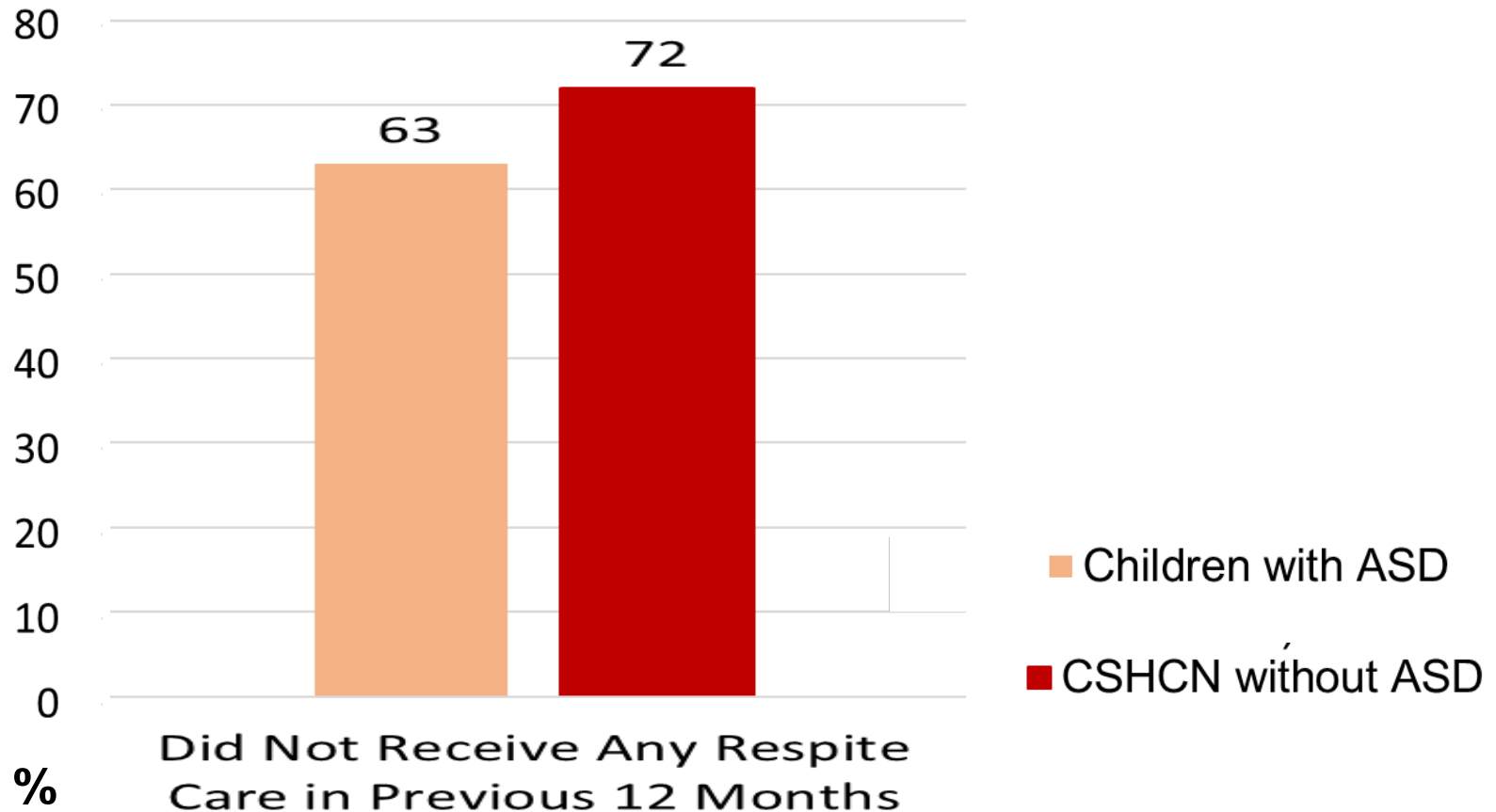
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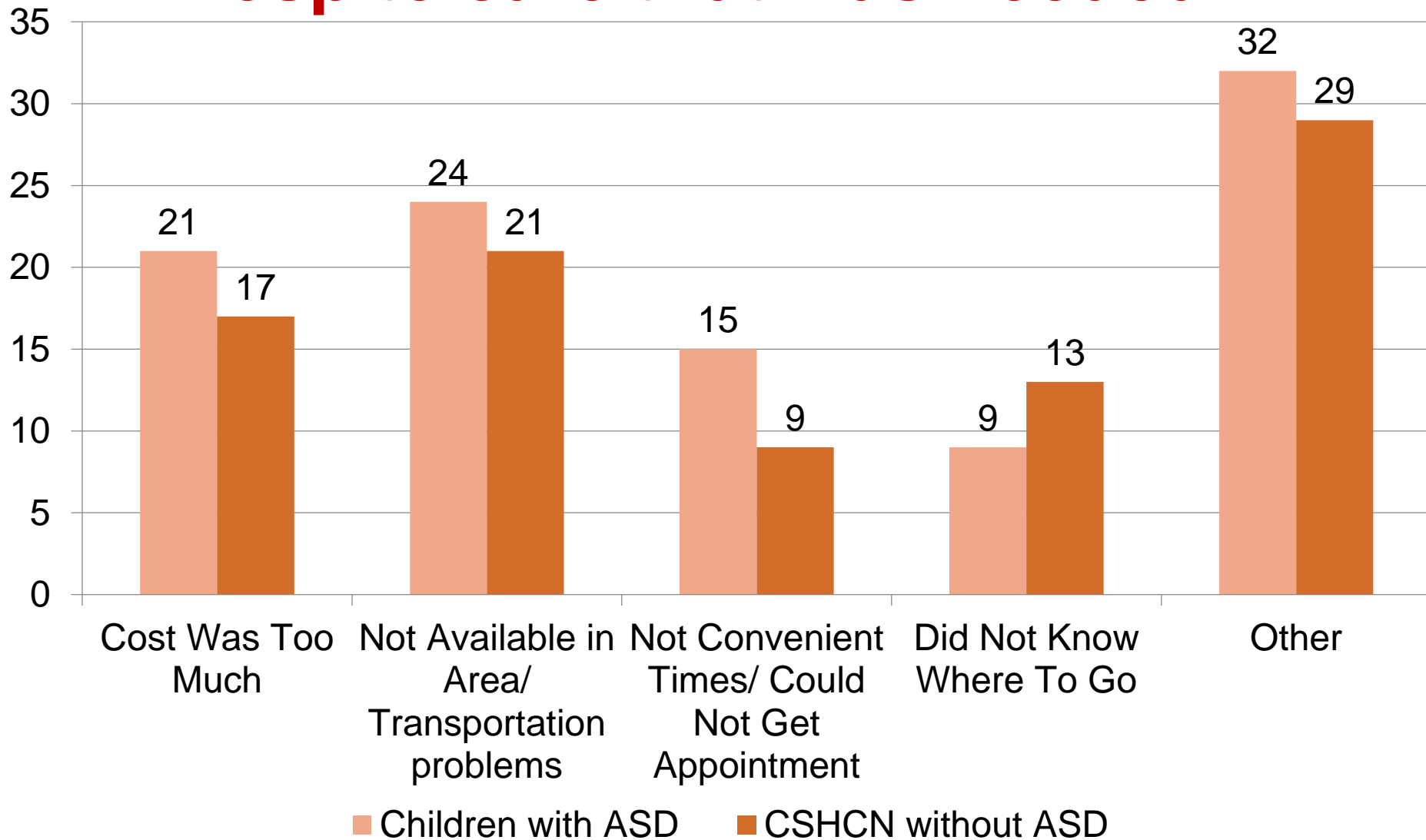


# RQ2: Most with an unmet need did not receive any respite care





# Why did your family not get all the respite care that was needed?



# RQ3: Multivariate Logistic Regression Results

## *Multivariable Models*

Sample	Block 1 Control Variables	Block 2 Predictor Variables
CSHCN with ASD subgroup	<b>Relationship to child†</b> <b>Highest level of parent education†</b> <b>Insurance status†</b>	<b>Functional status of the child †</b> <b>Hours per week providing care †</b> <b>Family financial burden †</b> Impact on family work life
CSHCN without ASD subgroup	<b>Age groups†</b> <b>Highest level of parent education†</b>	<b>Functional status of the child †</b> Hours per week providing care Condition stability <b>Family financial burden †</b> <b>Impact on family work life †</b>
Total sample	<b>Age groups†</b> <b>Relationship to child†</b> <b>Highest level of parent education†</b> <b>Insurance status†</b>	<b>Child condition †</b> <b>Functional status of the child †</b> <b>Hours per week providing care †</b> Condition stability <b>Family financial burden †</b> <b>Impact on family work life †</b>

*Note.* Dependent Variable = Unmet Respite Care Needs. †p<0.05



# Predictors of higher unmet needs varied by subgroup

## Both Groups (analyzed separately)

- ❖ Parent education (more than high school)
- ❖ Child functional status
- ❖ Financial burden

## CSHCN with ASD

- ❖ Parent gender (mothers)
- ❖ Insurance status (private)
- ❖ Hours providing care

## CSHCN without ASD

- ❖ Older children
- ❖ Impact on family work



# Parents of CSHCN with ASD

	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Relationship to child		
Mother	<b>1.655 (1.137-2.407) †</b>	<b>1.732 (1.141-2.631) †</b>
Father	1 (reference)	1 (reference)
Highest level of parent education		
Less than high school	1 (reference)	1 (reference)
High school graduate	0.881 (0.397-1.954)	0.884 (0.332-2.351)
More than high school	<b>2.438 (1.213-4.900) †</b>	<b>1.819 (0.756-4.380) †</b>
Insurance status		
Public only	1 (reference)	1 (reference)
Private only	<b>2.103 (1.516-2.916) †</b>	<b>1.956 (1.314-2.910) †</b>
Both private and public	0.742 (0.536-1.026)	<b>0.592 (0.406-0.863) †</b>
Functional status of child		
Never	2.638 (0.656-10.598)	2.841 (0.608-13.285)
Sometimes	1 (reference)	1 (reference)
Usually	1.363 (0.870-2.134)	1.205 (0.714-2.032)
Always	<b>2.010 (1.398-2.891) †</b>	<b>1.893 (1.224-2.930) †</b>
Hours per week providing care		
< 1 hour per week	1 (reference)	1 (reference)
1 – 4 hours per week	1.277 (0.756-2.156)	1.675 (0.913-3.073)
5 – 10 hours per week	<b>2.226 (1.266-3.915) †</b>	<b>2.595 (1.340-5.024) †</b>
≥ 11 hours per week	1.497 (0.906-2.474)	1.843 (0.990-3.431)
Family financial burden		
No	1 (reference)	1 (reference)
Yes	<b>2.330 (1.780-3.049) †</b>	<b>1.975 (1.422-2.742) †</b>
Impact on family work life		
No	1 (reference)	1 (reference)
Yes	<b>1.730 (1.293-2.315) †</b>	1.187 (0.821-1.715)

Note. Acceptable multivariate model fit (Hosmer-Lemeshow  $\chi^2$  (8) = 6.207,  $p$  = .624). † $p$  < 0.05



# Parents of CSHCN without ASD

	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Age groups		
0 – 5 years	1 (reference)	1 (reference)
6 – 11 years	<b>1.410 (1.048-1.896) †</b>	1.379 (0.999-1.903)
12 – 17 years	<b>1.607 (1.196-2.158) †</b>	<b>1.596 (1.157-2.202) †</b>
Highest level of parent education		
Less than high school	1 (reference)	1 (reference)
High school graduate	1.322 (0.811-2.155)	1.258 (0.734-2.156)
More than high school	<b>1.840 (1.195-2.833) †</b>	<b>1.686 (1.044-2.724) †</b>
Functional status of child		
Never	1 (reference)	1 (reference)
Sometimes	<b>2.026 (1.45-2.862) †</b>	<b>1.594 (1.094-2.323) †</b>
Usually	<b>3.295 (2.216-4.899) †</b>	<b>2.429 (1.576-3.745) †</b>
Always	<b>3.142 (2.227-4.433) †</b>	<b>2.078 (1.397-3.091) †</b>
Hours per week providing care		
< 1 hour per week	1 (reference)	1 (reference)
1 – 4 hours per week	<b>1.955 (1.434-2.665) †</b>	1.420 (1.021-1.974)
5 – 10 hours per week	<b>2.101 (1.453-3.037) †</b>	1.250 (0.835-1.872)
≥ 11 hours per week	<b>2.204 (1.605-3.027) †</b>	1.015 (0.697-1.479)
Condition stability		
Needs change all the time	<b>1.590 (1.182-2.139) †</b>	0.984 (0.703-1.377)
Needs change only once in awhile	<b>1.280 (1.030-1.591) †</b>	1.020 (0.803-1.295)
Needs are usually stable	1 (reference)	1 (reference)
Family financial burden		
No	1 (reference)	1 (reference)
Yes	<b>2.619 (2.127-3.226) †</b>	<b>2.119 (1.670-2.688) †</b>
Impact on family work life		
No	1 (reference)	1 (reference)
Yes	<b>2.090 (1.707-2.558) †</b>	<b>1.533 (1.204-1.953) †</b>

Note. Acceptable multivariate model fit (Hosmer-Lemeshow  $\chi^2$  (8) = 11.132,  $p$  = .194). † $p$  < 0.05



# Discussion

- ❖ Overall, the prevalence of unmet respite care needs in parents of children with ASD (14%) was **7 times** the prevalence in parents of CSHCN without ASD (2%)
- ❖ Prevalence of unmet respite care in CSHCN without ASD (48%) (of those with a need) was almost **double** the prevalence (24%) found by Nageswaran (2009)



# Disparities in unmet respite care needs exist by condition

- ❖ Compared to parents of CSHCN without ASD, parents of CSHCN with ASD were nearly **twice** as likely to have unmet respite care needs
  - OR = 1.788; 95% CI [1.517-2.106]
  - AOR = 1.271; 95% CI [1.037-1.556]



# Parents of CSHCN with ASD were significantly more likely to have unmet respite care needs when:

- ❖ the family experienced financial problems (AOR = 1.975; 95% CI [1.422-2.742])
- ❖ their child's condition "always" affects their ability to do things other children their age can do (AOR = 1.893; 95% CI [1.224-2.930])
- ❖ they spent 5-10 hours per week providing care for their child (AOR = 2.595; 95% CI [1.340-5.024])







# Limitations

- ❖ Secondary analysis
- ❖ Non-experimental design
- ❖ Convenience sample
- ❖ Many single-item, categorical variables
- ❖ Does not account for other potential context, process or outcome factors, such as informal respite care and stress
- ❖ Limitations of study methods



# Implications for Theory, Practice, and Education

## Theory

- ❖ Respite care use conceptualized as self-management behavior
- ❖ Cyclical relationships may exist in the model (cost and family finances)

## Practice

- ❖ Screening
- ❖ Referral to those at high risk

## Education

- ❖ Resources for providers and families
- ❖ Informal respite care



# Implications for Research and Policy

## Research

- ❖ Explore reasons for unmet needs
- ❖ Long-term benefits to families, communities and the health care system
- ❖ NS-CSHCN is an excellent large dataset
- ❖ Compare results to more recent data

## Policy

- ❖ Increased funding for research
- ❖ Reimbursement for respite care
- ❖ Cost-shifting to fund preventative respite care services



# Acknowledgements

## Dissertation Committee

- ❖ Dr. Jennifer Doering
- ❖ Dr. Kathy Sawin
- ❖ Dr. Kris Barnekow
- ❖ Dr. Dora Clayton-Jones

## Co-authors

- ❖ Dr. Kathy Sawin
- ❖ Dr. Kris Barnekow



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- ❖ NS-CSHCN  
Participants
- ❖ Families of CSHCN
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- ❖ My Family





# Thank You!

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# Supplemental Slides



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# Predictors of higher unmet respite care needs (Total Sample)

- ❖ Parent gender (mothers)
- ❖ Parent education (more than high school)
- ❖ Insurance status (private)
- ❖ Financial burden
- ❖ Impact on family work
- ❖ Older child
- ❖ Child with ASD
- ❖ Child functional status
- ❖ Hours providing care



# TOTAL SAMPLE

Context Factors	Unadjusted Odds Ratio (95% CI)	Adjusted Odds Ratio (95% CI)
Age groups		
0 – 5 years	1 (reference)	1 (reference)
6 – 11 years	<b>1.313 (1.037-1.664) †</b>	1.245 (0.941-1.646)
12 – 17 years	<b>1.459 (1.152-1.849) †</b>	<b>1.540 (1.164-2.038) †</b>
Relationship to child		
Mother	<b>1.373 (1.086-1.735) †</b>	<b>1.484 (1.143-1.926) †</b>
Father	1 (reference)	1 (reference)
Highest level of parent education		
Less than high school	1 (reference)	1 (reference)
High school graduate	1.187 (0.783-1.799)	1.052 (0.613-1.807)
More than high school	<b>2.143 (1.487-3.089) †</b>	<b>1.650 (1.013-2.687) †</b>
Insurance status		
Private only	<b>1.524 (1.267-1.833) †</b>	<b>1.382 (1.103-1.733) †</b>
Public only	1 (reference)	1 (reference)
Both private and public	0.918 (0.747-1.127)	<b>0.636 (0.498-0.812) †</b>
Child condition		
Child with ASD	<b>1.788 (1.517-2.106) †</b>	<b>1.271 (1.037-1.556) †</b>
CSHCN without ASD	1 (reference)	1 (reference)
Functional status of child		
Never	1 (reference)	1 (reference)
Sometimes	<b>1.920 (1.388-2.657) †</b>	1.405 (0.950-2.078)
Usually	<b>3.030 (2.135-4.300) †</b>	<b>2.010 (1.310-3.083) †</b>
Always	<b>3.623 (2.654-4.946) †</b>	<b>2.285 (1.529-3.416) †</b>
Hours per week providing care		
< 1 hour per week	1 (reference)	1 (reference)
1 – 4 hours per week	<b>1.826 (1.403-2.376) †</b>	<b>1.684 (1.229-2.308) †</b>
5 – 10 hours per week	<b>2.480 (1.838-3.347) †</b>	<b>1.765 (1.228-2.537) †</b>
≥ 11 hours per week	<b>2.208 (1.702-2.865) †</b>	1.372 (0.971-1.937)
Condition stability		
Needs change all the time	<b>1.544 (1.232-1.936) †</b>	1.015 (0.767-1.345)
Needs change only once in awhile	1.163 (0.978-1.382)	0.848 (0.689-1.044)
Needs are usually stable	1 (reference)	1 (reference)
Family financial burden		
No	1 (reference)	1 (reference)
Yes	<b>2.683 (2.281-3.155) †</b>	<b>2.054 (1.674-2.520) †</b>
Impact on family work life		
No	1 (reference)	1 (reference)
Yes	<b>2.150 (1.829-2.528) †</b>	<b>1.437 (1.160-1.781) †</b>

Note. Acceptable multivariate model fit (Hosmer-Lemeshow  $\chi^2$  (8) = 7.798,  $p = .453$ ). † $p < 0.05$

