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Examining the Relationship Between Parental Hassle and Family Resources after the Clinical Support Withdraws for Low-Resourced Families and Their Children with Autism

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**Author** Chiang, Lauren Minyu

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# UNIVERSITY OF CALIFORNIA

Los Angeles

Examining the Relationship Between Parental Hassle and Family Resources after the Clinical Support Withdraws for Low-Resourced Families and Their Children with Autism

A dissertation submitted in partial satisfaction of the requirements for the degree Doctor of Philosophy

in Special Education

by

Lauren Minyu Chiang

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### ABSTRACT OF THE DISSERTATION

Examining the Relationship Between Parental Hassle and Family Resources after the Clinical Support Withdraws for Low-Resourced Families

and Their Children with Autism

by

Lauren Minyu Chiang Doctor of Philosophy in Special Education University of California, Los Angeles, 2023 Professor Connie L. Kasari, Chair

The present study aimed to examine the parenting hassle experienced by a group of lowresourced families with children diagnosed with autism spectrum disorder (ASD). The study was a follow-up to a randomized controlled trial (Kasari et al., 2014), which investigated the efficacy of two treatment interventions. The focus of the current study was to examine changes in parenting hassle over the course of the interventions (entry to exit) and after the clinical support was withdrawn (exit to follow-up). The study also explored potential predictors of parenting hassle, including ethnicity, location, and family resources. The results of the study showed that family resources were the only significant predictor of parenting hassle, such that low family resources were associated with high parenting hassle. The findings also indicated that time and treatment did not have an effect on parenting hassle, and there were no interactions among the predictor variables (time, treatment, ethnicity, location, and resources). These findings have important implications for the support of families with children with ASD. Understanding the predictors of parenting hassle can help practitioners better support low-resourced families, who may experience greater levels of stress and burden. The study also highlights the need for continued support for families, even after the immediate post-treatment period. By examining the differences in parenting hassle between two treatment groups, researchers and practitioners may better understand the sustainability of benefits from different parent training methods, and ensure that support is provided to families in a manner that is effective and tailored to their individual needs. This study adds to the growing body of research examining the experiences of families with children with ASD. By focusing on low-resourced families and exploring the predictors of parenting hassle, the study provides insights into the needs of these families, and the support that can be provided to mitigate the challenges they face.

The dissertation of Lauren Minyu Chiang is approved.

Lois A. Weinberg

Jennifer Symon

Sandra H. Graham

Catherine Lord Morrison

Connie L. Kasari, Committee Chair

University of California, Los Angeles

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### **Curriculum Vitae**

### **Education**

2016 M.A. in Human Development & Psychology - University of California, Los Angeles
2011 B.A. in Cognitive Science - University of California, Irvine

### **Research Experience**

- 2015- Graduate Researcher Semel Institute; University of California, Los Angeles
- 2023 Supervisor: Dr. Connie Kasari
- 2022 Graduate Researcher Disability Studies; University of California, Los Angeles Supervisor: Dr. Caitlin Solone
- 2011 Research Assistant Family Lab; University of California, Irvine Supervisor: Dr. Agnes Ly

### **Teaching Experience**

- 2017- Adjunct Faculty California State University, Los Angeles
- 2019 Division of Special Education and Counseling Courses: Behavior Supports, Social Skills, and Classroom Management Educating Students with Autism Spectrum Disorders
- 2019 Teaching Assistant University of California, Los Angeles Department of Psychology Course: Research Methods in Psychology
- 2017 Guest Lecturer California State University, Northridge Instructor: Dr. Christina Kang Toolan Course: Early Childhood Development

### Honors & Awards

- 2021 Passed with Honors (Doctoral Qualifying Exam) University of California, Los Angeles
- 2019 Autistic Researcher Travel Award, International Society for Autism Research
- 2018- University Fellowships, University of California, Los Angeles 2021
- 2011 Tau Sigma Honor Society, University of California, Irvine
- 2010 Dean's Honor List, University of California, Irvine

### **Select Conference Presentations**

- Chiang, L. M., Shih, W. I., & Kasari, C. (2022, May). Time Is Not Money— Examining the Relationships between Parental Stress and Family Resources after the Clinical Support Withdraws for Lower Resourced Families and Their Children with Autism. Study presented at the annual meeting of the International Society for Autism Research, Austin, TX.
- **Chiang, L. M.,** Shih, W. I., Gulsrud, A., & Kasari, C. (2021, May). What Happens after the Coach Leaves? Examining the Changes in Parenting Stress in Caregivers of Toddlers with ASD before and after the Withdrawal of Clinical Support. Study presented at the annual meeting of the International Society for Autism Research (Virtual).
- Chiang, L. M., Pizzano, M., Cohenour, T. L., Pak, E., Gulsrud, A., & Kasari, C. (2019, May). Parent Well-Being over 6 Months in a Randomized, Controlled Caregiver Mediated Intervention Study for Toddlers with Autism. Study presented at the annual meeting of the International Society for Autism Research, Montréal, QC.
- **Chiang, L. M.,** Shih, W. I., Gulsrud, A., & Kasari, C. (2017, May). *Differences in Parenting Stress Between Monolingual and Multilingual Parents of Children with Autism Spectrum Disorder (ASD) Participating in an Early Intervention Study.* Study presented at the annual meeting of the International Society for Autism Research, San Francisco, CA.

### Introduction

Parenting stress in caregivers of children with ASD has been well documented (e.g., Benson & Kersh, 2011; Dabrowska & Pisula, 2010; Hayes & Watson, 2013; Robinson & Weiss, 2020; Zaidman-Zait et al., 2017). Social deficits and challenging behaviors that are commonly associated with ASD were found to significantly predict maternal depression (Benson & Kersh, 2011; Davis & Carter, 2008). An autistic child's maladaptive behaviors such as noncompliance, ritualism, and irritability, may be interfering when parents engage in daily routines. These behaviors could further hinder the parents' social engagement, such that parents of a child with behavioral challenges may reduce time spent running errands or socializing with their friends and family, feeling particularly isolated from their peers and community (Harper et al., 2013). As parenting stress potentially counteracts the effectiveness of early interventions (Osborne et al., 2008) and negatively impacts both parental and child outcomes (Neece et al., 2010), understanding the daily stressors that caregivers experience as well as the supporting resources available within their ecological systems may inform targets for more effective interventions.

### Service Needs of Families of Children with ASD

Supporting the service needs of children with ASD often requires multi-disciplinary expertise including speech therapy and behavior intervention. Because children with ASD encounter challenges in various forms across multiple domains of functioning, each child likely requires a unique combination of services across different disciplines. Prevailing views of autism indicate that these children require more services when compared to their peers without ASD or with other disabilities. Such service needs are likely to persist as the individuals with ASD age even though the expenses related to services and accommodations are the highest in early

childhood in the United States (e.g., Buescher et al., 2014; Turcotte et al., 2016). Thus, there is a pressing need for services that are sustainable and more cost-efficient.

Surveys of parent satisfaction with services note that caregivers of children with ASD are often dissatisfied with the quality of the services received (Kogan et al., 2008). Similarly, Bitterman et al. (2008) found that parents of preschoolers with ASD, in comparison to the parents of children with other disabilities, tended to report dissatisfaction with the special education services their children received. Specifically, the parents felt that more services should be provided in terms of dosage as well as variety (Bitterman et al., 2008). Even when children are doing well with the current level of intervention services, parents of autistic children still want more services despite no indication of need (Kasari et al, 2021). Therefore, parent education or intervention strategies that caregivers can implement at home may help relieve some of the unsatisfied service needs (Pickard & Ingersoll, 2016).

### **Importance of Parent Involvement**

The Individuals with Disabilities Education Act (IDEA, 2004) mandates service providers to actively include the parents of children with disabilities from birth to early adulthood. For example, the Early Intervention Program for Infants and Toddlers with Disabilities (i.e., Part C of IDEA, 2004) requires services to be provided in natural environments (e.g., home setting) to support young children at risk of disabilities as well as to enhance individual family's capacity to meet the needs of their child. By stressing the provision of early intervention in natural settings, parent involvement is assumed to be a prominent fixture in terms of childhood development, especially for those children at risk of developmental delay or disorders. Additionally, Part B of IDEA (2004), focusing on school-age children with disabilities, underscores the parent's role as a vital participant, working alongside general and

special educators in the decision-making processes. Specifically, Part B includes related services that assist parents in understanding the special needs of their child in the form of parent counseling and training. Such services provide parents with information about their child's development, and equip parents with necessary skills to support the implementations of their child's IEP or IFSP (IDEA, 2004).

The National Research Council (2001) specifically suggested that parents of children with ASD need to be closely involved, for example, by learning techniques to support their children. As the main social partners of their children with ASD, the parents could consistently create learning opportunities across different contexts to teach their children adaptive skills (McConachie & Diggle, 2007; National Research Council [NRC], 2001).

One promising approach is to involve and train the caregivers of children with ASD to deliver intervention independently. According to Bronfenbrenner and Morris (2006), for an activity (e.g., early intervention) to be effective and its developmental consequences to be realized, it must take place regularly over an extended period. Training caregivers to implement intervention strategies could increase the dosage of interventions a child receives and create consistency in behavior expectations across different settings. The primary caregivers often serve as the main social partners of their child, and therefore could substantially influence their child's development across the lifespan by providing daily learning opportunities (Shire et al., 2015).

### **Parent Training**

Extant literature has examined programs of training parents as interventionists and the efficacy or effectiveness of these parent-mediated approaches in terms of yielding positive child outcomes (e.g., Kasari et al., 2015; McConachie & Diggle, 2007; Patterson et al., 2012; Ratliff-Black & Therrien 2021; Shire et al., 2015; Shalev et al., 2020). In addition to positive child

outcomes, participation in parent training has been associated with increased parental selfefficacy (e.g., Weiss et al., 2013) and decreased parenting stress (e.g., Kasari et al., 2015; Keen et al., 2010). These positive findings have supported NRC's suggestion that parents can be trained to provide quality intervention to their children with ASD (2001). A potential implication of successful parent-mediated interventions is that caregivers could continue to implement the strategies taught by clinicians or researchers outside of intervention sessions. Thus, children may continue to benefit from the interventions without extra cost or constant professional support if their parents consistently implement the intervention strategies. Therefore, we may be able to better address the challenges related to service cost and sustainability by training parents as interventionists, which is less resource-intensive and has greater potential for maintenance of treatment effects (Matson et al., 2009).

However, different types of parent training could have varying effects on the child and the parent. For example, Kasari et al. (2015) found that parent education helped alleviate parenting stress, whereas the participants who received 1:1 coaching on a parent-mediated intervention did not experience significant stress reduction. On the other hand, only parents receiving 1:1 coaching had positive effects on child outcomes. It is also noteworthy that different delivery methods of parent training also require a disparate amount of clinical and human resources. The relationship between having received differentially resourced interventions and experiencing resource-related stress is still largely unexplored.

### **Parenting Stress**

Extant literature on intervention studies tends to focus on stress related to child characteristics since child outcomes are often the focal point in intervention studies. However, stressors that are not directly related to child characteristics can also affect parents' overall

mental health. The study of stress related to raising a child with ASD as well as general parenting challenges can give a holistic picture of parenting stress and caregivers' mental health, which could have a substantial influence on a child's well-being. Belsky's Process of Parenting Model (1984) suggested that parenting is influenced by multiple determinants, which include child characteristics, personal-psychological resources for parents, and contextual sources of stress and support.

### Child Characteristics as Stress Factor

Parenting stress in caregivers rearing a child with ASD has been studied extensively (e.g., Benson & Kersh, 2011; Dabrowska & Pisula, 2010; Hayes & Watson, 2013; Zaidman-Zait et al., 2017). A meta-analysis (Hayes & Watson, 2013) found that caregivers of children with ASD experienced substantially more stress when compared to the caregivers whose children were typically developing or with other disabilities. Namely, social deficits as well as challenging behaviors that are commonly associated with ASD, such as noncompliance and inflexibility, were found to significantly predict depressive mood in mothers (Benson & Kersh, 2011; Davis & Carter, 2008). Such challenging behaviors may be interfering when parents engage in daily routines with their children with ASD. For example, dressing for school or getting ready for bed could be particularly frustrating and time-consuming for the caregivers, if the child has low adaptive skills, difficulty transitioning, or certain rigid routines. Children with ASD could also be noncompliant or easily irritable, resulting in temper tantrums during community outings at a grocery store or in a park, restraining their caregivers from running errands and meeting household needs. Additionally, the child's maladaptive behaviors may hinder the parents' social engagement, such that the parents may reduce time spent socializing with their friends and family to interact with and support their children with ASD, and become withdrawn from their

peers and community (Harper et al., 2013). Neece and colleagues (2012) argued that parent training programs could simultaneously alleviate a child's challenging behaviors and parenting stress because these two variables have a transactional effect, in the sense that a child's challenging behaviors serve as both the antecedent and consequence of parenting stress. Therefore, parental psychological stressors could potentially be mitigated by equipping parents with appropriate strategies.

### Parent's Personal Stress Factors

In addition to the child-related factors, it is essential to investigate stress related to parenting more generally. Parenting stress could be attributed to other aspects that are not directly related to children's characteristics, for example, like personal health and psychological well-being. Some of the established stressors for parenting include the sense of competence, which equates to feeling comfortable and capable in the parenting role, and restrictions of the role, which is limited freedom or constrained personal identity as a result of the parenting role (Abidin, 1990). Daily hassles like constantly having to clean up, having to change personal plans to run extra errands, and difficulties getting privacy (Crnic & Greenberg, 1990) could all contribute to parenting stress that is outside of child characteristics.

#### **Environmental and Resource-related Factors**

According to Derguy et al. (2016), parental stress was most associated with parents' environmental factors, such as marital relationships, social networks, and services received. Such findings underscored the need to take environmental resources into account, especially those of family relations and communication while assessing parental stress (Derguy et al, 2016). As the effects of parenting stress and a child's challenging behaviors could have an impact on the family unit, researchers and practitioners assess the social context and ecological system with which

families interact, while considering intervention and implementation. For instance, social context could include the parent's socioeconomic status, location of residence, an ongoing national financial crisis, or a global pandemic. Such social context may interact with the individual's characteristics (e.g., race, ethnicity, gender, and disability) and potentially affect stress and resources.

For instance, difficulty in navigating the service systems and accessing care contributes to the immediate caregiving burden on the families (Kogan et al., 2008; Pickard & Ingersoll, 2016), and negatively impacts their psychological well-being. Moreover, families of children with ASD seem to experience distressed marital relationships which can also negatively impact the child (Meadan et al., 2010). Parents may also feel isolated from their peers and the community if the parenting burden is overwhelming and no social support is available (Harper et al., 2013). Surveying stressors from different aspects of life could help researchers and practitioners better assess parents' needs and provide targeted support.

The adequacy of resources is intertwined with a family's psychological well-being. Dunst's meta-analysis (2022a) found that the adequacy of family resources is highly related to psychological health, such that higher levels of family resources were related to positive psychological well-being as adequate family resources serve as a buffer for negative life events or other stress triggers. Bronfenbrenner (1979) noted that the adequacy of family resources is a factor that affects parents' practices and beliefs. Family resources are more than just income and education.

Dunst (2021) defined three types of family resources using factor analysis: basic resources, financial resources, and time availability. Amongst the three types of family resources,

the effect size is the largest for the relationship between time availability and participants' health and well-being. For example, having adequate time to engage in personal activities is related to positive psychological health (Dunst, 2021b).

### **Differentially Resourced Interventions for Differentially Resourced Families**

While considering which interventions could be suitable for the parents and their children with autism, one should assess different variables including family resources, socioeconomic status, education level, and ethnic/racial/cultural background. For example, Lopez et al. (2019) found that Latinx families and their children with autism experienced disparities in terms of the number of services received. Distrust in healthcare professionals and knowledge gaps in autism symptoms and care could also contribute to disparities in receiving and accessing appropriate and timely care for some Black families (Burkett et al., 2015). Researchers argued that cultural norms may affect how information is shared within Black communities, which could hinder Black families from receiving autism-related knowledge (Donohue et al., 2019). Black parents reported fewer autism-specific concerns, such as social deficits and repetitive behaviors, in comparison to their white counterparts, even when their child presents more severe autism symptoms (Donohue et al., 2019). Additionally, Non-white parents reported higher stress and could have greater difficulties accessing resources; interventions that are free of charge and are widely available are needed to reduce such disparities in resource accessibility (Krakovich et al., 2016).

Families with different socioeconomic statuses (SES) may be suitable for different interventions (Pickard & Ingersoll, 2016) as those with lower socioeconomic status often have higher unmet needs (Hodgetts et al., 2015) and lack information about available services or how to access these supports (Pickard & Ingersoll, 2016). For example, parents with higher SES

reported more unmet needs regarding the quality of the services received and access to social skills groups. Conversely, their counterparts with lower SES experienced more quantity-related issues, such as fewer hours received or fewer options of services available, and they tended to request respite care, in-home services, and parent training (Pickard & Ingersoll, 2016). Families with lower SES also reported that transportation and not being able to take time off work prevented them from accessing services (Pickard & Ingersoll, 2016). Similarly, Strazdins et al. (2011) suggested that physical location could further exacerbate the income-time tradeoffs as families who live in affordable locations may need to commute further to jobs, therefore having less time to spare for traveling to therapy sessions that are far from home. Carr et al. (2016) found that parents with higher socioeconomic status were more likely to have good treatment attendance, suggesting that lower SES might have a burdensome impact such that families could not get to a therapy session or sustain participation in intervention studies even when conducted in their homes or neighborhoods.

Short-term interventions (e.g., JASPER) may require overall less treatment time, and could promptly target the main deficit that is associated with autism (i.e., social communication) and improve child outcomes like joint engagement and symbolic play (Kasari et al., 2014, 2015). However, it is unclear whether such an influx of resources (i.e., training time and clinical support) could be disrupting or overwhelming for low-resourced families, especially if a research team withdraws without providing booster sessions or buffer time to transition out of the highly resourced active-treatment phase. As Desmarais et al (2018) suggested, parents may have difficulties participating in therapies that are time intensive with their daily responsibilities required to maintain a household. Specifically, parents who have an active role in parent-mediated intervention may need more time and other resources (i.e., clinical support) to

implement interventions consistently and at fidelity. As parenting stress could be exacerbated during transitional periods, waning the treatment slowly while providing support could relieve some parental stress (Desmarais et al., 2018) that may be related to disconnections of services or changes in supporting staff during the transition. Additionally, equipping parents with active coping strategies and social support could lower parenting stress (Zaidman-Zait et al., 2017).

### **Gaps in the Literature**

While parent-mediated interventions appear to help families in improving child outcomes, and sometimes in reducing parental stress, there is little information on what happens after the study personnel cease their support. Do improvements in children, and reductions in parenting stress maintain over a follow-up period? An area of focus that has often been overlooked includes parental well-being in resource-limited families.

First, parental well-being is often overlooked in parent-mediated interventions, as the interventions tend to focus on child outcomes and the parental outcomes that are directly related to the intervention (e.g., fidelity, attendance). However, based on the existing literature, worsened parental well-being could harm both the child and the intervention outcomes (e.g., Neece et al., 2010; Osborne et al., 2008). While child outcomes are the obvious primary focus of intervention studies, parents' psychological well-being should be emphasized as well, especially in parent-mediated interventions. As there are personal and environmental factors that may affect parental well-being besides child characteristics, such as the quality of marital relationships or resources for social support, researchers and practitioners should assess potential predictors of parents' psychological health.

Second, low-resourced families are often underrepresented in research studies, as they may not be aware of opportunities to participate in clinical trials, or simply cannot afford to take

time off work and travel to a research facility consistently. Significant treatment effects may be partially attributed to how well-off the families are to begin with. Few studies conducted in the United States have actively sought out lower-resourced families who usually encounter barriers to accessing services or research opportunities.

Lastly, the impact of the withdrawal of clinical support is not emphasized in the research. Some intervention studies collect short-term follow-up data to examine whether the treatment effect sustains. However, whether the participants struggle psychologically after they exit the study and lose clinical support is not a phenomenon that generally attracts research interest. One exception is a study where parents who experienced higher stress at the beginning of the intervention were more likely to continue reporting high stress levels at the two-year follow-up (Zaidman-Zait et al., 2017).

### **Research Aim**

The main objective of this study was to investigate how parenting stress changed, between the two treatment groups that received either an individual coaching version of a manualized intervention (i.e., JASPER; Kasari et al., 2010) or a group-based training that covered similar materials (i.e., EDUCATION). Specifically, the author examined how the two groups compare over the active treatment course (i.e., entry to exit) and after the clinical support had been withdrawn (i.e., exit to follow-up). Potential predictors of parenting stress change were explored. Particularly, family resources, race and ethnicity, treatment status, and location of residency were the hypothesized predictors for parenting stress.

### **Theoretical Framework**

Belsky's Process of Parenting Model (1984) will be the guiding framework for the proposed study. Based on Belsky's model (1984), parenting functioning is influenced by three

main determinants: the psychological well-being of the parent, the characteristics of the child, and the contextual sources of stress and support. Belsky argued that parents' psychological wellbeing is influenced by marital relations, social networks, and work conditions (1984). Specifically, social networks and the support they provide are considered beneficial for the parent's mental health, which is related to the parenting function (1984). The model presumes that the psychological well-being of the parent and the contextual sources of support are more effective in buffering the parent-child relation from stress than the characteristics of the child (1984). In other words, parental functioning is the least protected when only the child characteristics, but not the other two determinants, promote parental involvement; whereas the parenting function is more protected when the personal resources or the parental psychological well-being subsystem remains intact. Therefore, it may not be sufficient to only address the child's characteristics (i.e., autism core deficits and other challenging behaviors) with early interventions. Researchers and practitioners may need to emphasize parents' psychological wellbeing and the family's social context and resources, which also affect parenting behaviors, to optimize parental competency in parent-mediated interventions for children with autism.

### **Research Questions:**

- How did the two treatment groups (i.e., JASPER vs EDUCATION) compare in terms of parenting stress <u>before</u> and <u>after</u> the clinical support had been withdrawn (i.e., entry vs exit, exit vs follow-up)?
- 2. Are treatment status, race and ethnicity, family resources, and residency location the predictors for parenting stress at entry, exit, and follow-up?

#### Methods

This secondary analysis included 112 families and their children with autism who participated in a multi-site RCT (Kasari et al., 2014). The main outcome measure was the Parenting Daily Hassles (PDH; Crnic & Greenberg, 1990), which was administered at entry, exit, and 3-month follow-up to assess parenting stress.

### **Original Study**

The multi-site study conducted by Kasari et al. (2014) aimed to test the efficacy of a caregiver-mediated intervention of low-intensity and short-term, targeting the core deficits of autism (i.e., JASPER), specifically for lower-resourced families. The families were randomized into two treatment groups, receiving either the caregiver-mediated intervention which was athome with 1:1 active coaching (i.e., JASPER) or the group-based intervention which covered similar materials to JASPER but without the child's presence (i.e., EDUCATION), held at local locations such as schools or community centers. The two treatment groups received the same amount of clinical attention (i.e., same intervention hours per week).

### Interventions JASPER

JASPER stands for Joint Attention, Symbolic Play, Engagement, and Regulation; it is a manualized intervention that targets the core deficits of autism (Kasari et. al., 2006; Kasari et al., 2008; Kasari et al., 2010; Kasari et al., 2012; Kasari et al., 2014; Lawton & Kasari; 2012). It involves active coaching of caregivers to implement strategies for their child with autism, including setting up a learning environment, modeling joint attention gestures, expanding play acts, and using language that aligns with the child's developmental level.

JASPER sessions were held at the participants' homes with 2 1-hour sessions per week for 12 weeks. Every week a new strategy was introduced to the participants, with written

materials provided. Caregivers received 1:1 active coaching with their child present during the intervention sessions. Those whose primary language is not English received the intervention in their preferred language. The fidelity of the trained interventionists who provided the active coaching averaged 76%. The intervention ended when the participants exited the study; no intervention was provided from exit to follow-up.

### **EDUCATION**

The parent education group followed a manualized intervention with written materials like their counterparts received in the JASPER group. Similar to the JASPER group, the parent education focused on teaching communication to their child, behavior management, and building routines. However, unlike the JASPER group, the children of the caregivers were not present during the training, and the training sessions were small group-based. The group sessions were held in neighborhood locations like schools and community centers, with 1 2-hour session each week for 12 weeks. The fidelity of the interventionists averaged 97%. The intervention ended when the participants exited the study; no intervention was provided from exit to follow-up.

### **Participants**

A total of 112 families and their children with autism were included in the analyses. The children were between the ages of 2-5 years, and the families were considered "low-resourced" as they met the criteria for being one of the following: 1) low-income as indicated by the U.S. Department of Housing and Urban Development, 2) mother holding a high school diploma or lower, 3) primary caregiver being unemployed, or 4) receiving government assistance (e.g., Medicaid). The participants are from diverse backgrounds with 66% identifying as racial/ethnic minority and 15% whose primary language is non-English. See Table 1 and 2 for participants' (i.e., child and caregiver) characteristics at baseline.

## Measures Parenting Daily Hassles

Parenting stress, the main outcome variable, was measured by the Parenting Daily Hassles (PDH; Crnic & Greenberg, 1990), which is a 20-item Likert scale administered at entry, exit, and 3-month follow-up. Parents were asked to rate different parenting events in terms of the frequency of occurrence and the intensity of perceived hassle. For the frequency subscale, which is on a 5-point Likert scale, a 0 indicates "never" and a 4 means "constantly." For the intensity subscale, which is also a 5-point Likert scale, the answer ranges from 1 "no hassle" to 5 "big hassle." The PDH yields two scores, a frequency score and an intensity score, which would be the sum of the frequency subscale and the intensity subscale, respectively. The two subscales are highly correlated (r=.78). As suggested by Crnic and Greenberg (1990), only the intensity score was used in the statistical analysis as it was of greater theoretical interest and produced more meaningful findings. Additionally, both PDH subscales have two main factor loadings: the parenting task factor and the challenging behavior factor; the two factor loadings are moderately intercorrelated (r=.51) (Crnic & Greenberg, 1990). As the parenting task factor was too generic, and the challenging behavior factor was more germane to the autism core deficits, only the sum scores of the items related to challenging behavior were used in the statistical analysis.

#### Family Resources

The Family Resources Scale (FRS; Leet & Dunst, 1987) is a 30-item Likert scale, which measures the adequacy of family resources in households with young children. It was administered at entry, exit, and 3-month follow-up. Each item is rated based on a 5-point scale, from 1 "not at all adequate" to 5 "almost always adequate." The family resources include a) basic resources, like food, housing, and healthcare, b) financial resources, such as money to pay bills and to save, and c) time availability (e.g., time to get enough sleep, time to socialize or be with a

spouse or close friends). The sum scores of FRS were used in statistical analyses as a predictor for parenting stress at all time points.

#### ADOS

The Autism Diagnostic Observation Schedule (Lord et al., 2000) is a standardized, semistructured assessment that measures autism symptoms through observations and probes of social behaviors, communication, and play. All participants in this study were administered the ADOS to determine eligibility. The ADOS severity scores at entry were used in the statistical analyses as a controlling variable.

### Individual Characteristics

Other variables that will be explored as potential predictors include treatment group status (i.e., JASPER or EDUCATION), race and ethnicity, and residential location. The treatment group is a dichotomous variable (i.e., JASPER or EDUCATION) as the participants were assigned randomly to either JASPER or EDUCATION group at the beginning of the study. The race/ethnicity and household income information were collected at entry as part of the demographic information. Lastly, there were five study sites as the original RCT is a multi-site study; the study site will be used to indicate the participants' residential location.

#### **Analytic Plans**

Preliminary analyses were conducted using jamovi to test whether the data meet the necessary assumptions for linear mixed-effects models (LMMs). Missing data were imputed.

First, a correlation model was used to determine the relationship between household income and family resources scale (FRS) as the two measures have overlapping items assessing participants' monetary assets. The result showed that income and FRS were significantly correlated (r= .43, p<.001). Therefore, only FRS would be used in the following models as a

covariate and explored as a potential predictor because the measure covers monetary and intangible assets (i.e., time and social network), whereas household income only measures the monetary aspect.

Second, parenting stress was further teased out into parenting-task stress and challengingbehavior stress, according to the factor loadings provided by Crnic and Freenberg (1990). A correlation model was used to determine whether the parenting-task stress is correlated to the challenging-behavior stress for this dataset. The results showed that the two types of stress are highly correlated (r=.83, p<.001). Therefore, only the challenging-behavior stress would be included in the models as the outcome, as parenting-task stress seems more generic and less related to the core deficits of autism.

Third, a total of five mixed effect models were utilized to examine different predictors and their effects on the stress related to challenging behaviors. All models included the ADOS severity score as the controlling variable, and time and treatment as predicting factors. Interaction terms were added in the models to examine interactions among the predictors. All non-significant interaction terms were dropped from the models.

### Model 1

An LMM was used to examine the main effects of time and treatment on challengingbehavior stress. ADOS severity score at entry was entered in the model as a controlling variable, and time and treatment were entered in the model as predictors.

### Model 2-5

Family resources, site, race/ethnicity were entered separately into Model 2, 3, and 4, respectively, to examine their main effects on parenting stress. All interaction terms with time

and treatment were included, with ADOS severity score at entry as a controlling variable The interaction terms of Family resources, site, and race/ethnicity were explored in Model 5.

#### Results

### **Model 1: Time and Treatment**

The result showed no significant time by treatment interaction. Therefore, the time by treatment interaction was dropped from the model. After rerunning the model without the interaction term, the result showed that there was no significant main effect of treatment group (F[1,103]=0.423, p=.517) or time (F[2,181]=0.753, p=.472) on parenting stress (see Tables 3 and 4), meaning that time and treatment did not predict parenting stress related to challenging behaviors (see Figure 1).

#### **Model 2: Family Resources**

There were no significant interaction terms, therefore all interaction terms were dropped from the model. The result showed that the level of family resources was a significant predictor (F[1,236]=15.409, p<.001) for parenting stress such that low family resources significantly predict high stress related to challenging behavior (see Figures 2, 3, and 4); no main effects were found for treatment group or timepoint. There was no main effect of time (F[2,176]=.630,p=.534) or treatment (F[1,100]=.187, p=.666) on stress related to challenging behaviors (see Tables 9 and 10).

### Model 3: Site/Location

The two-way and three-way interaction were not statistically significant. Therefore, all interactions were dropped from the model. The results showed no significant main effect of site on stress related to challenging behaviors (F[4,103]=.092, p=.985). There was no main effect of time (F[2,179]=.742, p=.478) or treatment (F[1,99]=.438, p=.510) on stress related to

challenging behaviors (see Tables 7 and 8). Site, time, and treatment did not predict parenting stress (see Figures 5 and 6).

#### Model 4: Race/Ethnicity

Three-way and two-way interactions were tested, and none were statistically significant. Therefore, the interactions were dropped from the model. Result shows that there is no main effect by the child's ethnicity on stress related to challenging behaviors (F[4,97]=.465, p=.761). There's no main effect of time (F[2,180]=.899, p=.409) or treatment (F[1,96]=.512, p=.476) on stress related to challenging behaviors (see Tables 5 and 6). Ethnicity, time, and treatment do not predict stress related to challenging behaviors (see Figures 7 and 8).

### Model 5: Family Resources, Site, and Race/ethnicity

All the interactions were not significant, therefore dropped from the model. FRS remained a significant predictor (F[1,241]=11.857, p<.001) for parenting stress such that low FRS predicts high stress. There were no main effects of time (F[2,173]=0.725, p=.486), treatment (F[1,89]=.476, p=.492), site (F[4,94]=.321, p=.863), or ethnicity (F[4, 92]=.358, p=.838) on stress related to challenging behaviors (see Tables 11 and 12). Time, treatment, site, and ethnicity do not predict stress related to challenging behaviors.

### Discussion

Parenting stress has been well documented in autism literature, but not necessarily for lower-resourced families who are rearing a child with autism. This study is a secondary data analysis that examined the parenting stress of a group of lower-resourced parents. As parenting stress can be influenced by various factors in parents' ecological system, it is important to tease apart the potential stressors and explore what factors predict the parenting stress.

### **Time and Treatment**

The result from Model 1 showed that there was no significant main effect of time and treatment on parenting stress, which means that the two treatment groups were comparable in terms of parenting stress levels across three time points. Such findings are different from another study by Kasari et al., (2015), which utilized similar intervention modules (i.e., parent education and JASPER). Kasari et al., (2015) found significant difference in child-related parenting stress between the two treatment groups (i.e., parent education and JASPER) such that the parent education group reported more reduction in child-related stress than their counterparts in the JASPER group. However, there are two main differences between the parent education modules used by Kasari et al. (2014) and Kasari et al., (2015). First, the education module in Kasari et al. (2014) is a group-based intervention whereas Kasari et al. (2015) employed a 1:1 model. And second, the education module used in the present study by Kasari et al. (2014) had similar materials as the JASPER group, whereas the psychoeducational intervention used in the study by Kasari et al., (2015) was a manualized intervention by Brereton and Tonge (2015) which has materials specifically related to managing parental stress. Therefore, it is possible that the parent education group did not experience significant reduction in challenging-behavior-related parenting stress because of the group-based model and lacking knowledge related to stress management.

### **Family Resources**

The result from Model 2 showed that family resources is a significant predictor for parenting stress, such that having low family resources predicts high parenting stress related to challenging behaviors. This finding is aligned with existing literature, such that the adequacy of family resources is predictive of parents' psychological wellness. According to Dunst (2022a), higher levels of family resources were related to positive psychological well-being as adequate

family resources serve as a buffer for negative life events or other stress triggers. Moreover, a previous study by Zaidman-Zait et al. (2017) suggested that high levels of social support predict a reduction in parenting stress whereas low levels of familial functioning predict an increase in parenting stress. Such findings resonate with the result of the current study that high family resources predict low hassle, as family resources include not only monetary capitals but also intangible assets like social support and time for marital partner (Leet & Dunst, 1987).

### Site/Location

The results from Model 3 showed that parents who lived in different locations were not that different in terms of the parenting stress they experienced. It is possible that parents from different areas have similar stress levels because the stress related to their child's challenging behaviors is comparable regardless of where they reside. However, the number of resources and services the families from different sites receive may differ as different states have their own eligibility criteria for special education services (MacFarlane & Kanaya, 2009).

### **Race/Ethnicity**

The result from Model 4 showed that race/ethnicity does not have a main effect on parenting stress, meaning that race/ethnicity does not predict parenting stress. One explanation could be that the parenting stress related to challenging behaviors has little to do with race/ethnicity, and instead is more related to the severity of autism or whether child's behaviors are easily managed.

### Family Resources, Site, and Race/Ethnicity

The result from Model 5 showed that the variables do not interact with one another, and that family resources remain a significant predictor for stress related to challenging behaviors. As the participants of this study all met the criteria of being low-resourced, it is possible that

meeting such criteria evened out the playing field in terms of levels of family resources, therefore residential location and race/ethnicity or the racism and hardship experienced by certain groups became a less significant factor contributing to parenting stress.

### **Limitations and Future Directions**

There are several limitations of this study. First, certain sites have less participants than the others, which may affect the statistical power of the analysis that explores site/location as a predictor for parenting stress. Second, the racial composition of each site is different such that some sites are diverse whereas certain sites are predominantly White. Certain racial groups might not be well represented. Third, many families did not fill out the questionnaires assessing parenting stress and family resources, especially at exit and follow-up for Site 4, resulting in missing data, which compromises the statistical power. The third limitation was addressed by imputing data. For future directions, researchers should examine whether the low resource and high parenting stress affect the parents' ability to implement interventions.

#### Conclusion

Aside from the child-related factors, such as challenging behaviors, other parental characteristics like income and family resources should be further examined as such factors could interact with individuals' ecological system, affecting the amount of or the access to resources. Having resources like free time and social support could alleviate the daily hassles perceived by parents of children with ASD. To reiterate, different treatment modules may be differentially suitable for families with various levels of resources.

This study may not be representative of all families who are lower resourced, as the time of data collection for the original study was right after the financial crisis in 2008. There still could be inequality in access to healthcare and knowledge (i.e., an opportunity to participate in

clinical trials) amongst the participants. Researchers should assume healthcare inequality and aim to eliminate barriers to access and participation, and practitioners should identify the services available within the families' ecological system that can be built into the families' routines easily without strenuous means like long driving times and high price tags. The parent training and counseling services that Part B of IDEA provides would be helpful and should be considered. Such accessible services may be especially crucial for low-resourced families—including lower income and education levels, less spare time, unstable housing, unreliable transportation, or weak familial and social support.

# Appendix A – Tables

Child Characteristics, N (%)	EDUCATION, N=52	JASPER, N=60
Chronological age in month: mean (SD)	42.8 (10.2)	41.9 (10.0)
Gender		
Male	43 (82.7%)	50 (83.3%)
Female	9 (17.3%)	10 (16.6%)
Race/ethnicity		
White	16 (30.8%)	23 (38.3%)
Hispanic	7 (13.5%)	9 (15.0%)
African American	18 (34.6%)	13 (21.7%)
Asian	4 (7.7%)	5 (8.3%)
Multi-ethnic/other	7 (13.5%)	10 (16.7%)
Language child hears most at home		
Non-English	5 (9.6%)	10 (16.6%)
Receives other early intervention services		
No	10 (19.2%)	10 (16.7%)
Yes	42 (80.8%)	48 (80.0%)
Missing	0 (0%)	2 (3.33%)
Mullen age equivalency in month: mean (SD)		
Mental age	26.3 (11.8)	23.6 (11.6)
Receptive language	23.3 (13.2)	22.1 (14.4)
Expressive language	24.1 (13.5)	20.1 (12.6)
Fine motor	29.1 (10.8)	25.5 (9.3)
Gross motor	28.8 (12.2)	26.4 (12.7)
ADOS severity score: mean (SD)		
Module 1	7.5 (1.8)	7.6 (2.3)
Module 2	6.3 (1.1)	6.4 (1.9)
Module 3	6.0 (0)	7.7 (0.6)

Table 1 Child Characteristics at Baseline by Treatment Group

Note. ADOS= Autism Diagnostic Observation Schedule

Caregiver Characteristics, N(%)	EDUCATION, N=52	JASPER, N=60
Maternal education		
<12 <sup>th</sup> grade	3 (5.8%)	4 (6.7%)
High school diploma or GED	8 (15.4%)	9 (15.0%)
Some college/college degree	29 (55.8%)	36 (60%)
Graduate work/graduate degree	12 (23%)	9 (15%)
Unknown	0 (0%)	2 (3.3%)
Low income		
No	19 (36.5%)	19 (31.7%)
Yes	31 (59.6%)	38 (63.3%)
Unknown	2 (3.9%)	3 (5.0%)
Medicaid		
Yes	16 (30.8%)	23 (38.3%)
Any assistance		
Yes	27 (51.9%)	35 (58.3%)

Table 2 Caregiver Characteristics at Baseline by Treatment Group

	F	Num df	Den df	р
Timepoint	0.753	2	181	0.472
ADOS_CSS	0.745	1	101	0.390
Treatment	0.423	1	103	0.517

*Table 3 Fixed Effect: LMM Predicting Treatment Effect on Challenging Behavior Related Stress Over Time* 

Table 4 Parameter Estimates: LMM Predicting Treatment Effect on Challenging Behavior Related Stress Over Time

				95% Co Inte	nfidence erval			
Names	Effect	Estimate	SE	Lower	Upper	df	t	р
(Intercept)	(Intercept)	19.317	0.499	18.338	20.296	104	38.681	<.001
Timepoint1	Exit-Wk12 - Entry	-0.683	0.571	-1.802	0.436	183	-1.196	0.233
Timepoint2	Follow up - Entry	-0.481	0.595	-1.648	0.686	182	-0.807	0.421
ADOS_CSS	ADOS_CSS	-0.213	0.247	-0.697	0.271	101	-0.863	0.390
Treatment1	JASPER - EDUCATION	-0.648	0.997	-2.601	1.305	103	-0.650	0.517

	F	Num df	Den df	р
Timepoint	0.899	2	180.0	0.409
ADOS_CSS	0.432	1	95.3	0.512
Treatment	0.512	1	96.5	0.476
ChildEthnic_collapsed	0.465	4	97.0	0.761

*Table 5 Fixed Effect: LMM Predicting Child Ethnicity and Treatment Effect on Challenging Behavior Related Stress Over Time* 

Table 6 Parameter Estimates: LMM Predicting Child Ethnicity and Treatment Effect onChallenging Behavior Related Stress Over Time

				95% Confidence Interval		_		
Names	Effect	Estimate	SE	Lower	Upper	df	t	р
(Intercept)	(Intercept)	19.481	0.561	18.382	20.581	97.8	34.725	<.001
Timepoint1	Exit-Wk12 - Entry	-0.758	0.573	-1.881	0.365	180.9	-1.323	0.187
Timepoint2	Follow up - Entry	-0.485	0.595	-1.651	0.681	182.3	-0.816	0.416
ADOS_CSS	ADOS_CSS	-0.169	0.257	-0.673	0.335	95.3	-0.657	0.512
Treatment1	JASPER - EDUCATION	-0.737	1.030	-2.756	1.282	96.5	-0.715	0.476
ChildEthnic_collapsed1	2 - 1	1.295	1.760	-2.156	4.745	94.8	0.735	0.464
ChildEthnic_collapsed2	3 - 1	0.649	1.339	-1.976	3.275	95.9	0.485	0.629
ChildEthnic_collapsed3	5 - 1	2.109	1.637	-1.100	5.318	100.5	1.288	0.201
ChildEthnic_collapsed4	7 - 1	0.472	1.580	-2.624	3.569	94.7	0.299	0.766

	F	Num df	Den df	р
Timepoint	0.7415	2	179.9	0.478
ADOS_CSS	0.4580	1	97.6	0.500
Treatment	0.4378	1	99.6	0.510
Site	0.0918	4	103.8	0.985

Table 7 Fixed Effect: LMM Predicting Site and Treatment Effect on Challenging Behavior Related Stress Over Time

*Table 8 Parameter Estimates: LMM Predicting Site and Treatment Effect on Challenging Behavior Related Stress Over Time* 

				95% Confidence Interval				
Names	Effect	Estimate	SE	Lower	Upper	df	t	р
(Intercept)	(Intercept)	19.3200	0.539	18.264	20.376	109.9	35.8493	<.001
Timepoint1	Exit-Wk12 - Entry	-0.6806	0.572	-1.801	0.440	182.2	-1.1902	0.236
Timepoint2	Follow up - Entry	-0.4719	0.598	-1.643	0.700	180.2	-0.7896	0.431
ADOS_CSS	ADOS_CSS	-0.1777	0.263	-0.692	0.337	97.6	-0.6767	0.500
Treatment1	JASPER - EDUCATION	-0.6762	1.022	-2.679	1.327	99.6	-0.6617	0.510
Site1	2 - 1	-0.3472	1.869	-4.011	3.317	120.8	-0.1857	0.853
Site2	3 - 1	-0.7914	1.455	-3.643	2.061	92.5	-0.5439	0.588
Site3	4 - 1	0.0218	1.553	-3.022	3.066	102.2	0.0141	0.989
Site4	5 - 1	-0.3291	1.498	-3.265	2.606	94.5	-0.2197	0.827

	F	Num df	Den df	р
Timepoint	0.630	2	176.4	0.534
Treatment	0.187	1	100.1	0.666
ADOS_CSS	1.216	1	98.2	0.273
RESOURCES	15.409	1	236.3	<.001

Table 9 Fixed Effect: LMM Predicting Resources and Treatment Effect on Challenging Behavior Related Stress Over Time

*Table 10 Parameter Estimates: LMM Predicting Resources and Treatment Effect on Challenging Behavior Related Stress Over Time* 

				95% Confidence Interval		_		
Names	Effect	Estimate	SE	Lower	Upper	df	t	р
(Intercept)	(Intercept)	19.3125	0.4692	18.3929	20.2321	100.7	41.160	<.001
Timepoint1	Exit-Wk12 - Entry	-0.6062	0.5654	-1.7143	0.5019	176.5	-1.072	0.285
Timepoint2	Follow up - Entry	-0.4749	0.5975	-1.6459	0.6962	178.2	-0.795	0.428
Treatment1	JASPER - EDUCATION	-0.4050	0.9362	-2.2399	1.4299	100.1	-0.433	0.666
ADOS_CSS	ADOS_CSS	-0.2550	0.2312	-0.7082	0.1982	98.2	-1.103	0.273
RESOURCES	RESOURCES	-0.0635	0.0162	-0.0952	-0.0318	236.3	-3.925	<.001

	F	Num df	Den df	р
Timepoint	0.725	2	173.6	0.486
ADOS_CSS	1.005	1	89.4	0.319
ChildEthnic_collapsed	0.358	4	92.2	0.838
Treatment	0.476	1	89.7	0.492
Site	0.321	4	94.8	0.863
RESOURCES	11.857	1	241.5	<.001

Table 11 Fixed Effect: LMM Predicting Resources, Sit, Ethnicity, and Treatment Effect on Challenging Behavior Related Stress Over Time

				95% Confidence Interval				
Names	Effect	Estimate	SE	Lower	Upper	df	t	р
(Intercept)	(Intercept)	19.5220	0.6417	18.2643	20.7797	102.4	30.4228	<.001
Timepoint1	Exit-Wk12 - Entry	-0.6680	0.5688	-1.7828	0.4467	172.8	-1.1745	0.242
Timepoint2	Follow up - Entry	-0.4708	0.5997	-1.6463	0.7046	175.7	-0.7851	0.433
ADOS_CSS	ADOS_CSS	-0.2578	0.2572	-0.7619	0.2463	89.4	-1.0024	0.319
ChildEthnic_collapsed1	2 - 1	1.6749	1.7796	-1.8130	5.1629	88.5	0.9412	0.349
ChildEthnic_collapsed2	3 - 1	0.4440	1.3798	-2.2605	3.1484	92.1	0.3218	0.748
ChildEthnic_collapsed3	5 - 1	1.7516	1.8265	-1.8283	5.3315	99.3	0.9590	0.340
ChildEthnic_collapsed4	7 - 1	0.9974	1.6793	-2.2940	4.2889	89.6	0.5939	0.554
Treatment1	JASPER - EDUCATION	-0.6931	1.0044	-2.6618	1.2755	89.7	-0.6901	0.492
Site1	2 - 1	0.0573	2.2215	-4.2968	4.4114	105.0	0.0258	0.979
Site2	3 - 1	0.1985	1.5285	-2.7973	3.1943	87.1	0.1299	0.897
Site3	4 - 1	0.9969	1.5412	-2.0238	4.0177	96.0	0.6468	0.519
Site4	5 - 1	1.5641	1.6490	-1.6679	4.7961	89.7	0.9485	0.345
RESOURCE	RESOURCES	-0.0612	0.0178	-0.0961	-0.0264	241.5	-3.4434	<.001

Table 12 Parameter Estimates: LMM Predicting Resources, Sit, Ethnicity, and Treatment Effect on Challenging Behavior Related Stress Over Time







Figure 2 Linear Relationship Between Challenging Behavior Related Hassle and Family Resources by Treatment Group at Entry





Figure 3 Linear Relationship Between Challenging Behavior Related Hassle and Family Resources by Treatment Group at Exit



Timepoint = Exit-Wk12

Figure 4 Linear Relationship Between Challenging Behavior Related Hassle and Family Resources by Treatment Group at Follow Up



# Timepoint = Follow up

Figure 5 Change in Challenging Behavior Related Hassle Over Time by Site for EDUCATION Group



# Treatment = EDUCATION

*Note*. Site 1= University of California, Los Angeles. Site 2= Florida State University. Site 3= Kennedy Krieger Institute. Site 4= University of Washington. Site 5= University of Michigan Autism and Communication Disorders Center.

Figure 6 Change in Challenging Behavior Related Hassle Over Time by Site for JASPER Group



**Treatment = JASPER** 

*Note*. Site 1= University of California, Los Angeles. Site 2= Florida State University. Site 3= Kennedy Krieger Institute. Site 4= University of Washington. Site 5= University of Michigan Autism and Communication Disorders Center.

Figure 7 Change in Challenging Behavior Related Hassle Over Time by Ethnicity for EDUCATION Group



### Treatment = EDUCATION

*Note.* Ethnicity 1= White. 2= Asian, including Pacific Islander (originally 6). 3= African American. 5= Hispanic. 7= Other, including Native American (originally 4).

*Figure 8 Change in Challenging Behavior Related Hassle Over Time by Ethnicity for JASPER Group* 



# Treatment = JASPER

*Note*. Ethnicity 1= White. 2= Asian, including Pacific Islander (originally 6). 3= African American. 5= Hispanic. 7= Other, including Native American (originally 4).

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