

Symposium Title: Needs, Treatment acceptability, and Culturally Appropriate Intervention for Asian families of children with Autism and other Developmental Disabilities.

Chair: Yue Xu¹

Discussant: Esther Son²

Overview: Asians account for approximately 60% of the World population (United Nations, 2019). In the United States, Asians are the fastest growing immigrant group (PEW Research Center, 2017). However, in the body of research for children with developmental disabilities (DD), White English-speaking children of autism and other developmental disabilities account for most study participants (West et al., 2016). This lack of representation despite the growth of Asians is alarming. Asian families may hold very different views about their children's diagnosis, needs, and treatment choices due to their unique cultural background, values, and culturally embedded stigma of DD (Son et al., 2018). There is pressing needs for more studies to include Asians to explore the needs, treatment acceptability, and design culturally appropriate interventions for Asian families.

We adopt Kilbourn et al. (2006)'s stages of health disparities research framework as we discuss the process of developing interventions to reduce disparities faced by Asian families of children with DD. The framework identifies three stages of health disparities research i. e. detecting disparities, understanding disparities, and reducing disparities. The first paper focuses on detecting and understanding the unmet needs of Asian families of children with DD in the United States. The second paper explores treatment acceptability of Chinese families of children with autism. Understanding the preferences and acceptability in treatment is the first step in developing culturally appropriate interventions. Finally, the third paper present the process of culturally adapting an evidence-based parent psychoeducational intervention for Chinese immigrant families of children with autism in the United States. Collectively, these presentations showcase the process of how needs are detected, and culturally appropriate interventions can be developed to address these unmet needs for the fast-growing Asian families of children with DD.

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Paper 1 of 3

Paper Title: Service needs of Maryland Asian American Caregivers Raising Children with Developmental Disabilities

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Introduction: Parents raising children with developmental disabilities (DDs) must navigate multiple systems to access appropriate health and community services. Studies have found that early intervention improves long-term developmental outcomes, such as improved language abilities, adaptive skills, and social behaviors across the life span (Clark et al., 2018). However, multiple studies highlight racial and ethnic disparities in DD health care and service use, including in diagnosis and early intervention (Magaña et al., 2016). While the literature focused on historically underserved communities is growing, there is little known about Asian children with DDs and their families. In order to begin to fill in the large gaps of knowledge related to Asian American families of children with DDs, we conducted a needs assessment to explore how Asian American parents of children with DDs navigate health care and community services.

Methods: We used quantitative research methods. We developed a comprehensive parent-reported survey which included questions on child's diagnostic process and service use. A national advisory board and parents of children with DDs provided feedback on the survey. After we finalized the survey, we professionally translated it and a recruitment flyer into Chinese, Japanese, Korean, and Vietnamese. We collected data mainly through Qualtrics, but we also provided paper surveys to participants when requested. We targeted a sample using the following inclusion criteria: 1) primary caregiver of a child with a DD (aged 0-18 years) living in Maryland; and 2) self-identifies as Asian or Asian American. We collected data between October 2019 – July 2020 using several recruitment approaches. We conducted outreach to local service agencies, community-based DD organizations, public schools, Asian American-specific service organizations, religious institutions, language schools and other related groups in Maryland. We analyzed data using descriptive statistics.

Results: A total of 73 Asian American parents of children with DDs in Maryland completed the survey. About half of the participants were Chinese; the remaining were Korean (20.5%), Indian (6.8%), Japanese (6.8%), Filipino (5.5%), Vietnamese (5.5%), Bangladeshi (1.4%). Most of the participants were married (94.5%), mothers (87.7%), high-income, and college educated (79.4%). Their children had autism (68%), Attention Deficit Hyperactivity Disorder (27%), a developmental delay (18%), an intellectual disability (15%), Down syndrome (14%), or Cerebral Palsy (1%). The majority of parents reported they trusted their providers' advice, yet experienced delays in obtaining a timely developmental evaluation. On average, parents had early concerns about their child's development (28 months), but their children were not diagnosed until 40 months old. Nearly three-fourths of the parents said they raised their concerns about their child's development to their child's healthcare provider. In response to parents' concerns, only about one-third of parents said the professionals conducted a developmental screener or referred the child to a specialist. Of parents who spoke English as a second language, 41% reported interpreters did not help them understand what the professionals were saying. About 80% of parents had no experience with a parent advocate; however, of those who did, 70% found them to be helpful. Many respondents said their children received early intervention services (65%) and speech and language therapy (71%). Just one-third of the respondents reported using dental services (37%) or respite care (7%) for their children, citing barriers such as lack of awareness of the service, ineligibility, unavailability in their area or in their preferred language, being on the waitlist, cost, and distance. Nearly half of parents paid for some therapeutic services out-of-pocket.

Discussion: To our knowledge this is the first study examining diagnostic processes and community service use among Asian American parents who raise children with DDs. Given the barriers and delays parents cited in their child accessing timely services, providers should listen to parents' concerns and act quickly to refer children for evaluation. In particular, providers should be aware that cultural and language barriers might make it more difficult for providers to recognize developmental delays or understand parents' concerns. Professionals and organizations along with individuals and organizations specific to families' ethnic groups, can work together to connect families to services. Given various barriers make it difficult for children to obtain necessary services, more financial supports, in-home services, and culturally relevant programs are needed.

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Paper 2 of 3

Paper Title: Acceptability of Treatments for Challenging Behavior Among Chinese Caregivers of Children with Autism Spectrum Disorder

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Introduction: Challenging behavior is one of the major clinical concerns in the field of autism spectrum disorder (ASD). An increasing recognition of parent-focused behavioral treatment facilitated greater availability of behavioral parent training (BPT) programs in well-resourced countries, but previous research has rarely been conducted with parents in low-resource countries. In China, a country with more than two million children with ASD under age 12, non-behavioral eclectic treatments are still commonly adopted to improve autism symptoms and challenging behavior (Chang & Zaroff, 2017). Chinese parents of children reported an urgent need for knowledge on behavior management skills (Huang et al., 2014). But a lack of professional resources, expenses associated with professional services and the shame associated with help-seeking behavior prevented them from obtaining behavioral treatment for children. These barriers to service utilization reflect the critical need of Chinese parents to actively learn and deliver behavioral treatments themselves. Therefore, assessing treatment acceptability among Chinese parents will have great value for parents' future treatment adherence and the broader dissemination of behavior-analytic treatments to culturally diverse populations (Jones et al., 2020; Kazdin, 1980). Additionally, important factors associated with treatment acceptability such as severity of challenging behavior and Chinese child-rearing values require further examination, as they can provide guidance to professionals delivering parent training.

Methods: The current sample included 216 Chinese caregivers of children with ASD (aged 2-12 years) who were recruited via an online rehabilitation platform hosted on WeChat. Caregivers' acceptability toward six behavioral treatments: noncontingent reinforcement (NCR), teaching appropriate behavior, positive reinforcement, extinction, positive punishment and negative punishment were assessed through self-administered questionnaires (demographic questionnaire, Chinese Child-Rearing Beliefs Questionnaire, Behavior Problems Inventory-Short Form and one hypothetical vignette). Descriptive statistics, bivariate correlations, one-way-repeated-measures analysis of variance, and multiple regressions were used to analyze differences in acceptability ratings toward treatments, as well as relationships between severity of challenging behavior, child-rearing values and treatment acceptability.

Results: Overall, positive strategies including NCR, teaching appropriate behavior and positive reinforcement were more acceptable than extinction and negative punishment; positive punishment was the least acceptable. When severity of challenging behavior and child-rearing values served as predictors, positive punishment was more acceptable for children with severe challenging behaviors and for Chinese caregivers who had greater approval of *shaming*. Positive strategies including NCR, teaching appropriate behavior and positive reinforcement were more acceptable for caregivers who had greater support for *training*. Severe challenging behavior and higher support for *shaming* were associated with higher acceptability of positive punishment. In contrast, challenging behavior did not have an effect on acceptability of other behavioral treatments, when child-rearing values were held constant.

Discussion: Despite cultural differences, Chinese caregivers appear to have similar attitudes toward behavioral treatments compared to American caregivers, i.e., positive treatments were more acceptable than restrictive procedures. This finding indicated that evidence-based treatments relying on positive treatments, e.g., functional communication training, will be highly acceptable among Chinese populations so that minimal modifications may be required to increase their buy-in. The present

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study also reveals the necessity of improving Chinese caregivers' acceptability for extinction. It is possible that spending more time explaining the rationale underlying extinction procedure, showing its effectiveness over time and explicitly discussing potential risks associated with the procedure would improve caregivers' acceptability. Moreover, this study points to the need to value the role of child-rearing beliefs in influencing treatment acceptability. Particularly, when working with caregivers who have strong approval of inducing self-blame, using verbal reprimands and spanking to discipline their child, professionals may explain the side effects associated with punishment-based procedures to modify the values of caregivers. This shift in child-rearing values may decrease the likelihood of caregivers' use of restrictive procedures and increase the utility of positive strategies to generate long-term changes in their child's behavior.

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Paper 3 of 3

Paper Title: Culturally Adapting an Evidence-Based Parent Psycho-Educational Intervention for Chinese Immigrant Families of Young Children with Autism Spectrum Disorder

Authors: Yue Xu¹, Feifei Chen⁶, Mansha Mirza¹, Sandy Magaña⁷

Introduction: The US is becoming increasingly diverse. Asian Americans are the fastest growing racial minority, and Chinese Americans are the largest ethnic group among them (US Census Bureau, 2017). Meanwhile, there is a steady growth of children diagnosed with Autism Spectrum Disorder (ASD). There is evidence showing that Asian American children with ASD are under-diagnosed (Baio et al., 2018). In addition, Asian parents of children with developmental disabilities experience barriers accessing quality health care that is culturally and linguistically appropriate (Son, Parish & Igdalsky, 2017). There is a critical need for appropriate and accessible interventions that address this gap and the associated health disparities. The current study aims to culturally adapt an evidence-based parent psycho-educational ASD intervention, "Parents Taking Action" (Magaña et al., 2020), for Chinese low-income immigrant families of young children with ASD.

Methods: Six Chinese immigrant caregivers of children with ASD and six providers serving this population in the Chicago metropolitan area were recruited to participate in two separate focus groups. The first author who is bilingual in Chinese and English facilitated the two focus groups. Focus group data were transcribed and then analyzed using deductive qualitative analysis (Gilgun, 2013). The first two authors coded the data independently using a predeveloped coding list based on Wiltsey's intervention adaptation framework (Wiltsey et al., 2017) and Bernal's ecological validity framework (Bernal, Bonilla, & Bellido, 1995) for culturally adapting interventions. Member checking phone interviews were conducted with two participants from each focus group upon completion of the data analysis.

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Results: Caregivers provided insights on the intervention structure and contextual elements such as family dynamic and cultural stigma against ASD while providers put more emphasis on content modification. Caregivers emphasized the benefits of delivering the intervention entirely in group format as opposed to a combination of group-based and one-on-one delivery. This preference for group delivery was based on contextual issues such as feeling isolated from other family members who do not have much knowledge on ASD due to the lack of information available in Chinese. Therefore, being with other families sharing similar experiences can be validating and empowering. Providers emphasized that it is critical to help parents become “better consumers” who are informed and involved in therapeutic and educational goals for their children. This way parents can help reinforce skills acquired from therapeutic and educational settings in their child’s natural environment. Parents and service providers agreed that it was important to integrate individualized goals and consultation to encourage participation and practice of using the techniques introduced in the intervention. Member-checking yielded additional suggestions from caregivers but not from providers.

Discussion: The lack of culturally and linguistically appropriate interventions for Chinese immigrant families of children with ASD is alarming given the fast growth of this population. The process of culturally adapting “Parents Taking Action” for Chinese immigrant families of children with ASD sets up an example on how to adapt existing evidence-based interventions for this population.

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