What Do Families Really Need?
Insights from Community Work with Autism Families

Hui Zhang, Ph.D.
University of Toledo

“After a few years here, I realized what we called ‘good service’ back home is not the same here. I had to learn to define it again for my child.”
— Parent 9, mother of a 9-year-old child with ASD

Why This Question Matters

- Many autism-related studies aim to understand families, yet families often wonder what changes as a result.
- Families are often expected to navigate diagnosis, school systems, services, and community life all at once.
- What they need is not only information, but also trust, practical guidance, and support that continues over time.
- This talk asks a simple question:
- How can research become part of real, local, and sustainable support for families?

Contents lists available at ScienceDirect

Linguistics and Education

journal homepage: www.elsevier.com/locate/linged

Tracing textual silences and ideological tensions in adopted inclusive education legislation in China

Hui Zhang*, Diana Arya

Gevirtz Graduate School of Education, University of California, Santa Barbara, USA

ARTICLE INFO

Keywords:
Critical realism
Legalization
Textual silence
Critical discourse analysis
Inclusive education

ABSTRACT

A substantial body of literature exists on inclusive education practices in large countries like China, ranging from the introduction of laws and regulations to cross-country comparisons of the implementation of policies. Yet, little is known about the potential role that legal documents play in shaping ideological assumptions and actions among stakeholders, including parents. The authors used critical discourse analysis (van Dijk, 1993) as an analytic guide for exploring explicated and implied meanings within both legal texts associated with China's "learning in the regular classroom" (LRC) model as well as reported data from parents of children diagnosed with

The Transmitter

Feb 21, 2021 ·

Cultural barriers lead clinicians to misdiagnose or miss children with autism in immigrant communities.

USofL

Aug 6, 2020 ·

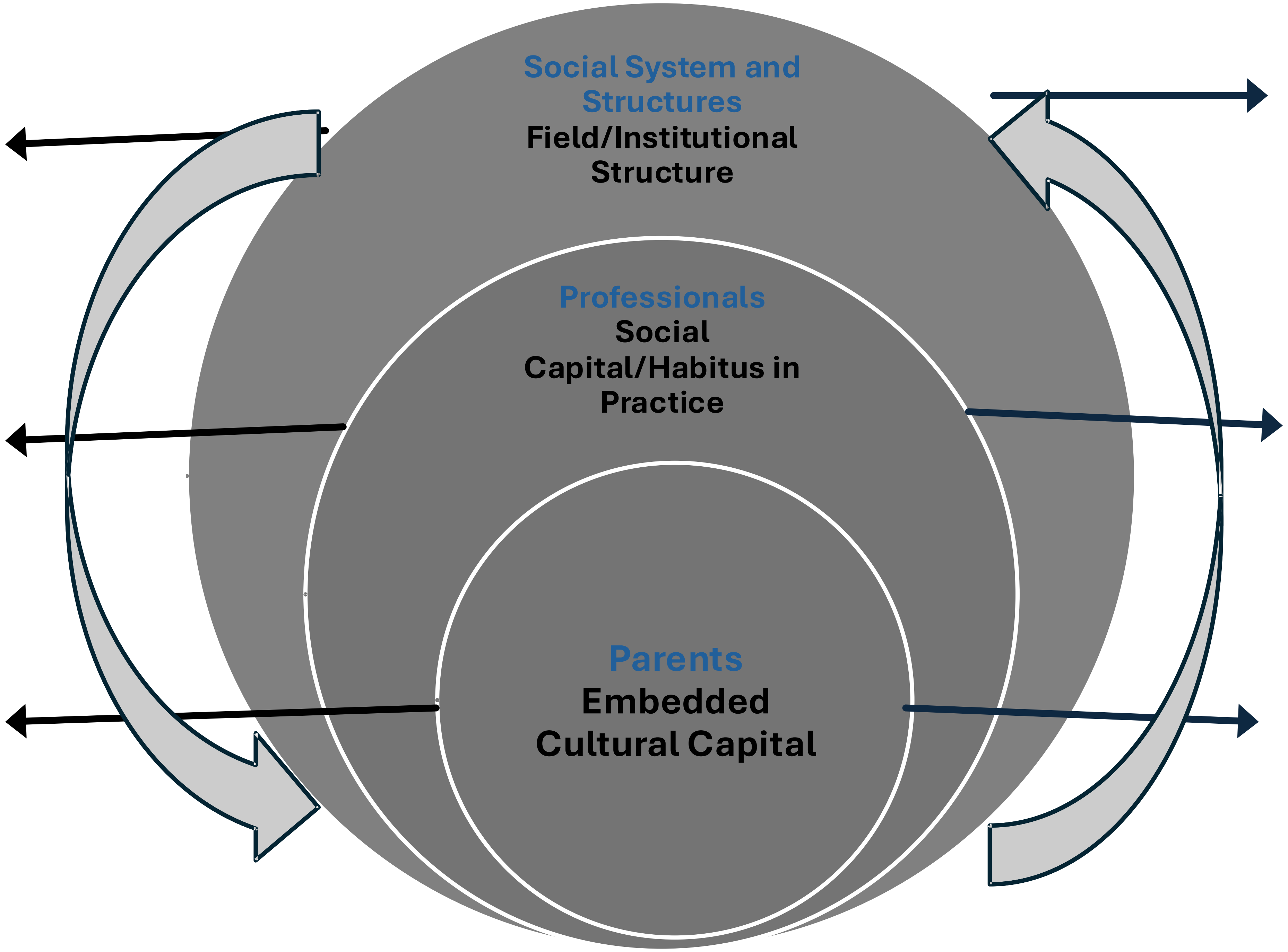
There is something so very heartbreaking about a child being ostracized and ignored for something he or she has no control over. Parents of children who are not on the autism spectrum, we need to have a talk with our children about embracing those who are different from us. The same can be said for immigrant children, racial/ethnic minorities, handicapped children, down's syndrome, or any other difference that causes people to shy away, or actively oppose.

From Research Questions to Family Support

Families do not make decisions in isolation. They respond to policies, institutional rules, and cultural expectations that shape what feels possible.

Their experiences with schools, providers, and community organizations shape trust, belonging, and willingness to keep seeking support.

At home, families are constantly interpreting what support means, what counts as a good service, and what is right for their child.



Social System and Structures
Field/Institutional Structure

Professionals
Social Capital/Habitus in Practice

Parents
Embedded Cultural Capital

System values and expectations

Schools, professionals, and community relationships

Families' lived experiences and everyday decisions

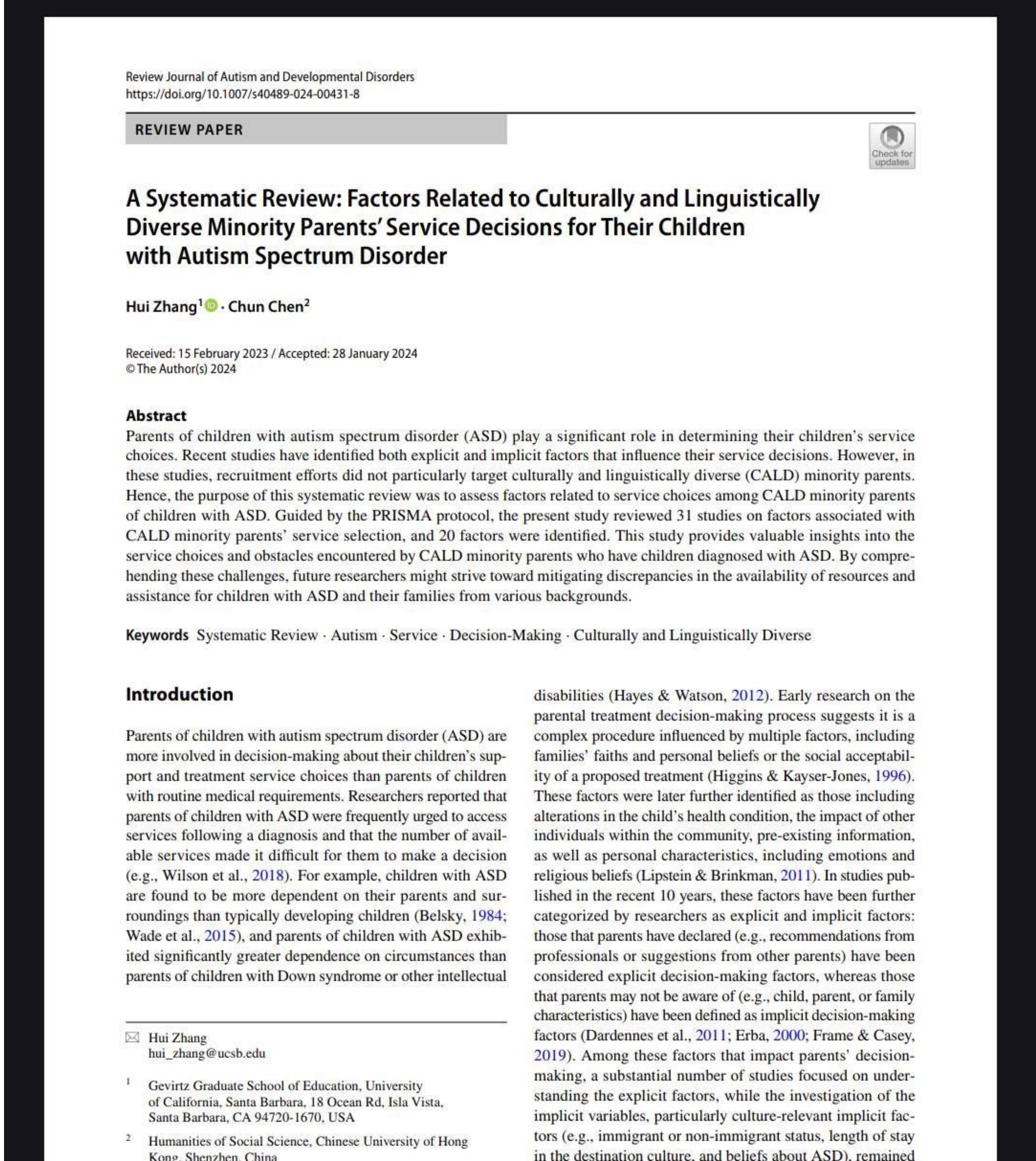
A Parent Story

One parent's journey was not simply about finding a service.

It was about learning a new system, rethinking what "good support" meant, and deciding which voices to trust.

Over time, the parent moved from confusion and comparison to a more active role: asking questions, interpreting options, and redefining support in a way that made sense for the child and family.

That journey reflects what many families experience:
not just choosing services, but learning how to navigate, evaluate, and reshape support over time.



Review Journal of Autism and Developmental Disorders
https://doi.org/10.1007/s40489-024-00431-8

REVIEW PAPER

A Systematic Review: Factors Related to Culturally and Linguistically Diverse Minority Parents' Service Decisions for Their Children with Autism Spectrum Disorder

Hui Zhang[1] · **Chun Chen**[2]

Received: 15 February 2023 / Accepted: 28 January 2024

Abstract
Parents of children with autism spectrum disorder (ASD) play a significant role in determining their children's service choices. Recent studies have identified both explicit and implicit factors that influence their service decisions. However, in these studies, recruitment efforts did not particularly target culturally and linguistically diverse (CALD) minority parents. Hence, the purpose of this systematic review was to assess factors related to service choices among CALD minority parents of children with ASD. Guided by the PRISMA protocol, the present study reviewed 31 studies on factors associated with CALD minority parents' service selection, and 20 factors were identified. This study provides valuable insights into the service choices and obstacles encountered by CALD minority parents who have children diagnosed with ASD. By comprehending these challenges, future researchers might strive toward mitigating discrepancies in the availability of resources and assistance for children with ASD and their families from various backgrounds.

Keywords Systematic Review · Autism · Service · Decision-Making · Culturally and Linguistically Diverse

Introduction

Parents of children with autism spectrum disorder (ASD) are more involved in decision-making about their children's support and treatment service choices than parents of children with routine medical requirements. Researchers reported that parents of children with ASD were frequently urged to access services following a diagnosis and that the number of available services made it difficult for them to make a decision (e.g., Wilson et al., 2018). For example, children with ASD are found to be more dependent on their parents and surroundings than typically developing children (Belsky, 1984; Wade et al., 2015), and parents of children with ASD exhibited significantly greater dependence on circumstances than parents of children with Down syndrome or other intellectual disabilities (Hayes & Watson, 2012). Early research on the parental treatment decision-making process suggests it is a complex procedure influenced by multiple factors, including families' faiths and personal beliefs or the social acceptability of a proposed treatment (Higgins & Kayser-Jones, 1996). These factors were later further identified as those including alterations in the child's health condition, the impact of other individuals within the community, pre-existing information, as well as personal characteristics, including emotions and religious beliefs (Lipstein & Brinkman, 2011). In studies published in the recent 10 years, these factors have been further categorized by researchers as explicit and implicit factors: those that parents have declared (e.g., recommendations from professionals or suggestions from other parents) have been considered explicit decision-making factors, whereas those that parents may not be aware of (e.g., child, parent, or family characteristics) have been defined as implicit decision-making factors (Dardennes et al., 2011; Erba, 2000; Frame & Casey, 2019). Among these factors that impact parents' decision-making, a substantial number of studies focused on understanding the explicit factors, while the investigation of the implicit variables, particularly culture-relevant implicit factors (e.g., immigrant or non-immigrant status, length of stay in the destination culture, and beliefs about ASD), remained

---

✉ Hui Zhang
hui_zhang@ucsb.edu

[1] Gevirtz Graduate School of Education, University of California, Santa Barbara, 18 Ocean Rd, Isla Vista, Santa Barbara, CA 94720-1670, USA

[2] Humanities of Social Science, Chinese University of Hong Kong, Shenzhen, China

Study 2: Understanding within Context

13 voices, 7 states, 5 cultural backgrounds, and one shared journey of navigating ‘good service.’

- **Families are not passive users, and they are active navigators** who learn, adapt, and negotiate within complex service systems.
- **Parents mobilize cultural and social capital** to access and interpret services, reshaping their own understanding of “good service.”
- **Decision-making reflects agency under constraint.** Families balance structural limits with creative strategies and redefinitions.
- **Cultural adaptation is dynamic**, blending home and host values through everyday advocacy and interaction.

“Knowing how school systems work has helped me support other parents as an advocate. Other parents benefit from just watching how we negotiate our way through it.”
— Parent 7, mother of a 12-year-old child with ASD

“We decided that we should group up together to make our voice heard, and I believe unity is strength.”— Parent 5, mother of an 8-year-old child with ASD

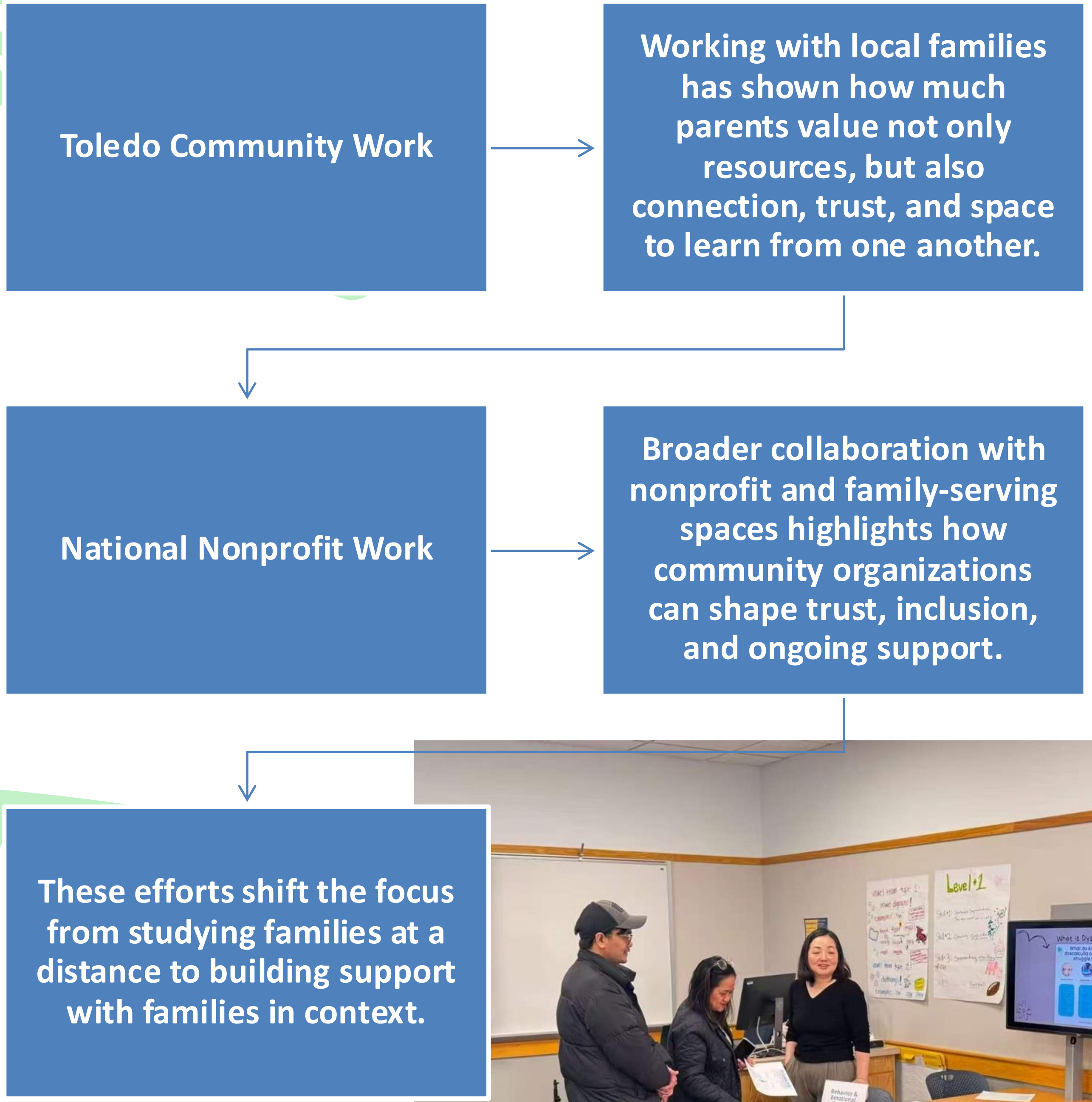
“After a few years here, I realized what we called ‘good service’ back home is not the same here. I had to learn to define it again for my child.” — Parent 9, mother of a 9-year-old child with ASD

“Many Asian parents are scared to speak out about their needs… So, what we’re doing now is helping all the parents who are influenced by Asian culture.”
— Parent 13, father of a 22-year-old with ASD

From Research to Community Work

The goal is not only to understand what families experience, but to help turn that understanding into more responsive, practical, and sustainable support.

Past → Present → Future



Toledo Community Work → Working with local families has shown how much parents value not only resources, but also connection, trust, and space to learn from one another.

National Nonprofit Work → Broader collaboration with nonprofit and family-serving spaces highlights how community organizations can shape trust, inclusion, and ongoing support.

These efforts shift the focus from studying families at a distance to building support with families in context.

What do families really need?

Often, they are already telling us. The next step is to listen in ways that lead to action.