

# Parent-reported Barriers and Facilitators to Obtaining a Diagnosis of ASD: A Systematic Literature Review

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Pang Chaxiong<sup>1</sup>, Alefyah Shipchandler<sup>1</sup>, & Jennifer Hall-Lande<sup>2</sup>

<sup>1</sup> University of Minnesota, Department of Educational Psychology; <sup>2</sup> University of Minnesota, Institute on Community Integration

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UNIVERSITY OF MINNESOTA

## Rationale and Purpose

- Autism spectrum disorder (ASD) can be reliably diagnosed at age two (Wetherby, 2004; Lord, 2006); however, the average age of diagnosis for children in the U.S is after age four (Baio et al., 2018).
- For children from underserved, culturally and linguistically diverse (CLD) communities, this delay to diagnosis can be substantially greater (e.g., Mandell et al., 2009; Shattuck et al., 2009).
- Delays to diagnosis is problematic as it often means delays to early intervention (Goin & Meyers, 2004).

Because parents play a critical role in obtaining a diagnosis of ASD for their child, the purpose of this review is to examine what parents report are barriers and facilitators to obtaining a diagnosis of ASD.

### Research Questions:

- What factors do parents report hinder their ability or willingness to obtain a diagnosis of ASD?
- What factors do parents report enable their ability or willingness to obtain a diagnosis of ASD?
- What are the demographic characteristics of the parents represented in the literature?

## Methods

- Databases:** Education Source, ERIC, PsycINFO, Ovid
- Search Terms:** (autis\* OR asd) AND (identif\* OR diagnos\*) AND (family (belief\* OR perspective\* OR perception\* OR attitude\* OR opinion\* OR experience\*) OR parent (belief\* OR perspective\* OR perception\* OR attitude\* OR opinion\* OR experience\*))
- Selection Criteria:**
  - Peer-reviewed, empirical study conducted in US
  - Published in English
  - Includes 2+ parents of a child diagnosed with ASD
  - Study asks parents about their experience obtaining a diagnosis of ASD
- Data Analysis**
  - Study methodological information, participant characteristics, and parent-reported barriers and facilitators were extracted
  - Both authors read and coded each study
  - Themes were identified through investigator triangulation and collaborative work (i.e., credibility measures for qualitative research; Brantlinger et al., 2005)

## Results

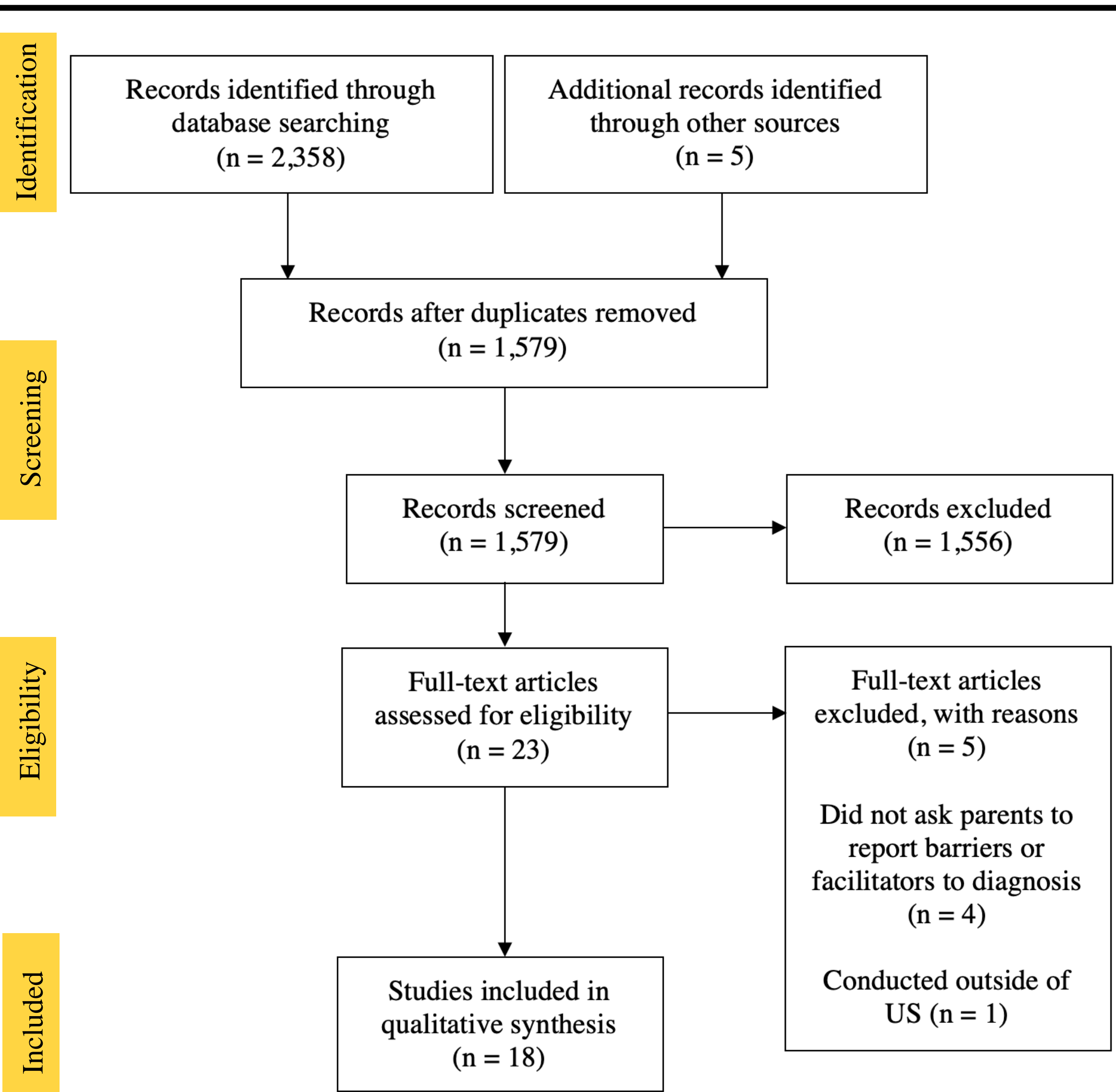


Figure 1. Prisma Flowchart

Table 1

Study Characteristics

Study (N = 18)	Design	Geographic Region	Asked about barriers and/or facilitators	# of Parent Participants (N = 874)	# of Father Participants (n = 126)	# of Non-Caucasian Participants (n = 298)	Race/Ethnicity Reported
Brookman-Frazee et al. (2012)	Qualitative	Southwest, US	Neutral	23	4	5	African American, Asian American, Caucasian, Hispanic, Multiracial
Burkett et al. (2015)	Qualitative	Midwest, US Urban	Neutral	13	5	13	African American
Elder et al. (2016)	Qualitative	Southwest, US Rural	Barriers	Not Computable	Not Computable	1	African American, Caucasian
Estrada et al. (2014)	Qualitative	Southeast, US Urban	Neutral	10	2	10	Hispanic
Hannon et al. (2017)	Qualitative	Northeast, US	Neutral	16	16	4	Multiracial
Hidalgo et al. (2015)	Mixed-methods	Northwest, US	Barriers	54	8	Not Computable	Asian American, Black or Multiracial, Caucasian, Hispanic
Hutton et al. (2005)	Qualitative	Northeast, US Rural	Neutral	21	2	Not Reported	Not Reported
Jagatheesan et al. (2010)	Qualitative	Midwest, US Urban	Neutral	6	3	6	South Asian
Kalash et al. (2012)	Qualitative	Midwest, US	Neutral	12	4	Not Reported	Not Reported
Lappe et al. (2018)	Qualitative	Southwest, US	Neutral	44	22	Not Computable	African American, Asian American, Caucasian, Hispanic, Multiracial, Native American, Pacific Islander
Moodie-Dyer et al. (2014)	Qualitative	Midwest, US	Neutral	19	1	Not Reported	Not reported
Narcisa et al. (2012)	Descriptive Survey	24 States	Neutral	162	18	26	African American, Caucasian, Hispanic, Multiracial
Pearson et al. (2018)	Qualitative	Midwest, US Urban, Rural	Neutral	11	0	11	African American
Sansosti et al. (2012)	Mixed-methods	Midwest, US	Barriers	16	3	6	African American, Caucasian, Multiracial
Wiley et al. (2013)	Qualitative	Midwest, US	Neutral	4	2	0	Caucasian
Wong et al. (2017)	Mixed-methods	Midwest, US	Neutral	78	1	4	Caucasian
Zuckerman et al. (2017)	Descriptive Survey	CA, CO, OR	Barriers	352	27	189	Caucasian, Latino
Zuckerman et al. (2014)	Qualitative	Northwest, US Urban, Rural	Barriers	33	8	23	Caucasian, Hispanic

Parent-related Barriers									
Barrier	Dismissal of parental concerns from friends/family	Limited knowledge of ASD	Mistrust of HCPs	Financial barriers	Denial	Lack of resources	Limited knowledge of development	Unfamiliarity with system	Limited English proficiency
# of Studies (N = 18)	n = 6	n = 5	n = 3	n = 3	n = 3	n = 3	n = 2	n = 2	n = 1

Professional-related Barriers							
Barrier	Dismissal of parental concerns	Limited knowledge of/ training in ASD	Discrediting parents	Poor interaction/ communication	Inaccurate diagnosis	Cultural bias	Blaming parents
# of Studies (N = 18)	n = 14	n = 8	n = 7	n = 5	n = 3	n = 2	n = 2

System-related Barriers						
Barrier	Lengthy, complex, strenuous process	Stigma	Lack of public/ community awareness	Inadequate screening/ diagnostic tools	Limited access to services	Language accommodations
# of Studies (N = 18)	n = 7	n = 4	n = 3	n = 3	n = 2	n = 2

Parent-related Facilitators						
Facilitator	Taking action	Financial flexibility	Knowledge of benefit of diagnosis	Persistence	Supportive friends/family	Knowledge of ASD
# of Studies (N = 18)	n = 5	n = 2	n = 2	n = 2	n = 2	n = 1

Professional-related Facilitator				
Facilitator	Being personable	Making referrals to specialists	Knowledge of/ training in ASD	Voicing concerns
# of Studies (N = 18)	n = 2	n = 2	n = 1	n = 1

System-related Facilitator		
Facilitator	ASD news/media coverage	Community resources for diagnosis
# of Studies (N = 18)	n = 2	n = 1

## Discussion

### Question #1 - Parent-reported Barriers:

- The relatively recent body of literature indicates parents continue to perceive more barriers than facilitators to obtaining a diagnosis of ASD for their child.
- Four times as many barriers (n = 90) than facilitators (n = 23) were reported across all studies. Of the three categories of barriers, professional-related barriers were most frequently reported by parents (n = 41).
- The most frequently reported barrier across all studies was dismissal of parental concerns from professionals (n = 14).

### Question #2 - Parent-reported Facilitators:

- Of the three categories of facilitators, parent-related facilitators were most frequently reported by parents across all studies (n = 14).
- The most frequently reported facilitator across all studies was parents taking action (n = 5).
- Facilitators remain a research gap; whereas 5 of 18 studies probed specifically for barriers to obtaining a diagnosis of ASD, no studies probed specifically for facilitating factors.

### Question #3 – Participant Representation

- There is limited or lacking representation of fathers (14%), parents from rural areas, and CLD parents of (a) Asian, (b) American Indian/Alaska Native, and (c) Native Hawaiian or Other Pacific Islander.

## Questions to Consider

### Where do we focus our efforts?

- Which barriers can we feasibly address to help parents obtain a diagnosis of ASD for their child earlier?
- Which facilitators can we feasibly bolster to help parents obtain a diagnosis of ASD for their child earlier?



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