6

Culture, Stigma, and Intersectionality: Toward Equitable Parent-Practitioner Relationships in Early Childhood Special Education

Susan D. Holloway, Shana R. Cohen,
and Irenka Domínguez-Pareto

Abstract

Parental involvement in the selection and implementation of children's educational services is one of the most important tenets of the Individuals with Disabilities Education Act. However, parental involvement may be less welcome and less effectively supported in families from non-dominant groups (i.e., those with lower social status as a result of their race, ethnicity, social class, or immigrant status) compared to those with more resources. In this chapter, we explore several important conceptual tools related to diversity and stigmatization that support families' equitable access to special education services for their young children. After reviewing how culture has typically been defined in the field of early childhood special education (ECSE), we introduce the critical sociocultural perspective and describe its clear implications for more effective parent-practitioner relations. We subsequently explore the notions of individual and institutional stigma, and show how early childhood practitioners can identify stigmatizing experiences that children with disabilities and their parents may have encountered. We then address the experience of families who are stigmatized for additional reasons other than the disability status of a family member, showing how children and families are located at the intersection of overlapping social identities rather than situated within a single homogenous racial, ethnic, or gender category. We conclude the chapter with specific suggestions for service providers to assist them in addressing stigmatization of individuals with autism, particularly those who are members of non-dominant groups, in the hope of moving the field of ECSE closer to its promise of a free, appropriate, public education for all.

Parental involvement in the selection and implementation of children's educational services is one of the most important tenets of the Individuals with Disabilities Education Act (IDEA) (Trainor, 2010b; Turnbull, 2005). However, this emphasis on parents' advocacy has disadvantaged parents

---

S. D. Holloway (✉)
Graduate School of Education, University of California, Berkeley, CA, USA
e-mail: susanholloway@berkeley.edu

S. R. Cohen
University of California, San Diego, CA, USA

I. Domínguez-Pareto
University of California, Berkeley, CA, USA

M. Siller, L. Morgan (eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism*, Autism and Child Psychopathology Series,
https://doi.org/10.1007/978-3-319-90994-3_6

whose lack of economic, social, and educational resources diminishes their access to special education systems or whose prior experiences have eroded their trust in the efficacy of the services (Kalyanpur & Harry, 1999; Trainor, 2010a; Valle, 2009, 2011; Wang, Mannan, Poston, Turnbull, & Summers, 2004). Parents' ability to be effective advocates can also be hindered by unwarranted and inaccurate stereotypes that practitioners may hold regarding a family's sociocultural background (Domínguez-Pareto, 2015; Ong-Dean, 2009).

As a consequence of these social dynamics, parental involvement may be less welcome and less effectively supported in families from non-dominant groups (i.e., those with lower social status as a result of their race, ethnicity, social class, or immigrant status) compared to those with more resources (Baquedano-López, Alexander, & Hernandez, 2013; Cooper, Riehl, & Hasan, 2010; Lightfoot, 2004). For example, the *Los Angeles Times* reported that in 2010 the California Developmental Services Department spent an average of $11,723 per child on White children but only $7,634 on Latinos and $6,593 on Black children (Zarembo, 2012), a disparity that can only be understood by attending to the ways in which services are dependent on racial/ethnic and class status. These disparities persist despite the formation of a Senate Select Committee to address the issue of inequitable state funding (Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016).

In this chapter, we explain some important conceptual tools that support productive reflection regarding issues of cultural diversity and equitable access to services. Toward that end we introduce three sensitizing concepts – culture, stigma, and intersectionality – and illustrate how these concepts can help early childhood special educators design and implement more equitable and effective practices for families from diverse sociocultural backgrounds rearing young children with ASD. Our goal in introducing these ideas is to engage the readers in a dialogue to stimulate reflexivity, the practice of reflecting on one's own practice and sociocultural position (Bourdieu & Wacquant, 1992; Giddens, 1991).

We begin with a discussion of how culture has typically been defined in the field of early childhood special education (ECSE) and introduce an alternative, more nuanced approach that has clear implications for effective parent-practitioner relations. We then describe the concepts of stigma and intersectionality, and explore how these notions can help ECSE professionals understand the experiences of families from non-dominant groups who care for a child with ASD. We conclude the chapter with specific suggestions for addressing stigmatization toward members of non-dominant groups in the hope of moving the field of ECSE closer to its promise of a free, appropriate, public education for all (Free Appropriate Public Education under Section 504, 2010).

Understanding Culture: The Perils of a Conventional Approach

In the past four or five decades, the field of ECSE has increasingly focused on understanding the diverse cultural pathways traveled by families caring for a child diagnosed with ASD or other intellectual disabilities. However, the conception of culture often endorsed in this literature has unintentionally resulted in a number of misrepresentations and distortions. One significant problem has been a tendency to make essentializing overgeneralizations about particular groups. The term "essentializing" refers to "the assumption that a group has one or more defining features characteristic of all group members" (Gjerde, 2004, p. 142). In this conventional approach, the individuals within a particular ethnic, racial, or geographical group are all assumed to hold similar values and to engage in common activities "because of their culture." This approach is problematic for several reasons. For one thing, it relies on stereotypes rather than acknowledging the wide diversity among individuals and across particular subgroups in terms of language, histories, and ideologies. So, for example, Mexicans are frequently described as "family-oriented" and therefore assumed to be supported by a large network of loving and attentive relatives, when the reality is far more complex (Abrego, 2014; Baca Zinn & Wells, 2005; Cohen, Holloway, Domínguez-Pareto, & Kuppermann, 2013). Ultimately, this tendency to make assumptions about a family member's beliefs or behaviors based solely on membership in a particular sociocultural group can draw a practitioner's attention away from the family's actual experiences and the sources of support they may have as well as ones they may lack.

Another problematic aspect of this essentializing approach is that it often leads members of non-dominant groups to assume that only other groups "have culture." If ECSE practitioners are encouraged to think in terms of sweeping generalizations about groups other than their own, and if they themselves are members of a dominant group that is not described in a similarly stereotypical way, it can be difficult for them to recognize that their own community also shares certain beliefs or practices that are culturally constructed. As a consequence, these practitioners may promote their own ways of thinking, doing, and talking as the "normal" or "common sense" ways without reflecting on the socially constructed nature of all human practices (Geertz, 1983). This is particularly true if an educator's position is in agreement with current early intervention treatments as well as the accepted language and beliefs of those in the early intervention field. Without denying the contribution of scientific knowledge and evidence to the effectiveness of treatments, we note that professional ways of thinking and organizing the world are also socioculturally constructed and are subject to historical change (Foucault, 1972; Grinker, 2007; Kalyanpur & Harry, 1999). In any case, we would argue that practitioners can be more effective if they are careful to recognize the beliefs and practices that are available and salient to members of their own sociocultural group(s) (Derman-Sparks & Ramsey, 2011).

A third drawback of the conventional approach to culture is that it positions each individual as a member of a single culture and ignores the fact that everyone participates in "multiple cultural categories" (Gjerde, 2004, p. 144). For example, in addition to being of Mexican origin, a parent may participate in other sociocultural contexts where members share strongly held beliefs and common practices, whether it be a religious group, an activist organization, or an occupational setting. Furthermore, a person's participation in various cultural settings typically changes over time, leading to concomitant changes in beliefs and practices. For example, a parent may pick up skills or perspectives from working in her child's preschool setting that she later implements in rearing a younger sibling. In that case, it would be important for an early interventionist to appreciate the ways in which the parent's earlier exposure to the ECSE milieu contributes to the approach that she may now take toward intervention.

Last, these conventional perspectives on culture often construe customs as "age-old" and unchanging, not recognizing that individuals adapt cultural practices to respond to opportunities or barriers that parents and children are encountering in their daily lives. For instance, suppose a Mexican immigrant parent is reluctant to let her toddler participate in a group setting that offers an opportunity for peer social interaction. A conventional approach to culture may lead a case manager to worry that this child is being deprived of this opportunity because of a "traditional" Mexican belief that children should interact with family members instead of strangers. But the reality may be far more complex. If the family lives in a dangerous neighborhood, for example, the parent may decide that it would be safer to encourage interaction between the young child and her cousins who live nearby rather than participate in the program. The parent herself may regret that the child is missing a good opportunity to play with same-age peers in a group setting but draws upon her cultural knowledge to find a safer way of supporting her child's social skills in her particular environment. A case manager who reflects on trade-offs in a situation such as this may see the wisdom of the parent's solution rather than blame her actions on "cultural" beliefs.

A Critical Sociocultural Approach to "Culture"

> Imagine cultural pathways themselves as consisting of cultural activities that we "step" into – engage in – and walk alongside throughout life. (Weisner, 2002, p. 276)

> Sociocultural understandings move from an understanding of culture as something that ethnic groups share to culture as systems of meanings and practices that evolve between families, the medical and service community, and larger political, social and economic worlds. (Skinner & Weisner, 2007, p. 310)

To conceptualize culture in a way that avoids the pitfalls described in the previous section, we sketch out a critical sociocultural approach to working with socioculturally diverse families. The fundamental elements of this approach are introduced in the quotations at the beginning of this section. First, and possibly most important, we call attention to culture as systems of meaning that are constructed when individuals participate in common activities over time (Nasir & Hand, 2006). In other words, people who engage in common activities are thereby constructing and reconstructing the norms, meanings, and perspectives that constitute culture (Lave & Wenger, 1991; Wenger, 1998). These authors maintain that culture is "transmitted" not by handing down "lore" from one generation to the next but through the ongoing actions of participants. As a result of their activity in the community, new members move from being peripheral "apprentices" to full participants able to access the language, ideology, and values of the community. By taking a critical sociocultural approach, ECSE practitioners can develop more nuanced understandings of families from diverse communities than they might if they relied on global, "essentializing" ideas about culture.

In addition to facilitating a clearer understanding of families' cultural practices, the critical sociocultural approach is also a powerful way to understand the "culture" of the ECSE system. As Lave and Wenger (1991) discuss, this idea of "community of practice" applies to professional participants in institutional settings like schools or hospitals who interact with each other over time to create acknowledged routines, specialized language, and associated beliefs and values. Although Kalyanpur and Harry (1999) made this point many years ago about the "culture" of special education, it has not, in our view, received the attention it deserves. ECSE professionals are cultural insiders who share certain familiar ways of talking, thinking, and doing. As cultural insiders, it is easy for professionals to take for granted that these customary practices are "normal" or "natural" rather than community-specific. ECSE cultural insiders may be less aware of the effort and time it takes for parents or other outsiders to acquire the "shared repertoire" used by members of the ECSE culture (Wenger, 1998). Moreover, if early childhood special education is seen as a community of practice co-constructed by practitioners and families, it becomes clear how important it is to acknowledge and build on parents' knowledge, skills, and values.

While the notion of a "community" may initially seem to convey an image of harmony and equality, communities of practice do not necessarily allow access to all who wish to participate nor do they assign the same status to all members of the community. Rather, individuals within communities of practice are associated with differential access to power and social status, even in groups that purport to be nonhierarchical, group-oriented, or "collectivistic" (Holloway, 2010). Professionals who view a particular cultural practice as a departure from what is "right" or "normal" may find it difficult to engage with families from groups that are associated with that practice (e.g., Lightfoot, 2004; Valencia & Black, 2002). For instance, a parent whose interactions with educators are perceived as overly confrontational during an IEP meeting may be perceived by an ECSE practitioner as being a disrespectful or incapable advocate (Lareau & Munoz, 2012; McHatton & Correa, 2005), and these difficult interactions may impede the parent from accessing services to which the family is entitled (Domínguez-Pareto, 2015; Ong-Dean, 2009).

Practitioners sensitive to power inequalities between parents and ECSE practitioners can ask themselves various questions throughout the intervention process. *How do I expect parents to communicate their opinions? How much have I tried to listen to other people's points of view? Are there parents I feel more connected to than others? If so, are there class, race, and other background characteristics that we share? If so, what can I do to learn more about those I feel less connected to?* By engaging in self-interrogation, ECSE practitioners can become more conscious of the subtle but powerful messages concerning social status and membership that may be conveyed by cultural "insiders" to "outsiders."

Another powerful implication of using a critical sociocultural approach is that it helps us understand that parents are not simply enacting "traditional" values and practices. Rather, they also have agency, and as agentic, self-reflective individuals, they can also modify cultural practices of child-rearing (Shore, 1996). As we saw earlier in the example of the mother who came up with an alternative to support her toddler's social skills, parents are continually adapting cultural practices in light of the resources they have access to and the daily challenges they experience. In particular, low-income parents from non-dominant groups often use creative and powerful methods to ensure their children's survival and to achieve institutional transformation in the face of many challenges (Collins, 1994). While the work of practitioners is often focused on the development of very specific child competencies, and justifiably so, parents' actions in this regard can be best appreciated when an interventionist recognizes the full scope of powerful, time-consuming, and essential "motherwork" that goes into being an effective parent.

ECSE practitioners who acknowledge parental agency may better understand why a parent may choose not to accept recommended practices. By acknowledging that a practice may conflict with other culturally constructed values or with conditions in the local context, practitioners may also better understand how and why parents within the same community sometimes engage in divergent practices. Again, it is apparent that effective practice involves taking the time to listen to parents' perceptions and to understand their rationale for the decisions and choices they have made.

In order to understand fully the experiences of socioculturally diverse families within the ECSE system, we now turn to the concept of stigmatization. In particular, we seek to describe how stigmatization of ASD is expressed in variable ways toward families depending on their membership in particular sociocultural groups as well as how it is differentially stigmatized within socioculturally diverse communities.

Understanding Stigma: Enacted and Structural Stigmatization

> …autism is really two illnesses. It's all the symptoms we are familiar with, plus the stigma and exclusion that society attaches to it… The paradox is that handicaps that are invisible can actually create more burden, stigma, and shame than those that are easily seen…. (Grinker, 2007, pp. 68–69)

The notion of stigma refers to the assignment by society of inferior status and negative regard to individuals or groups with particular conditions or attributes (Goffman, 1963; Link & Phelan, 2001). Stigma is not a characteristic of the individual but a process by which individuals and societies devalue others and discriminate against them. Individuals experience explicit stigmatization, also referred to as enacted stigmatization, through overt discrimination as well as avoidance or shunning. In spite of significant advances in public understanding of intellectual disabilities, families of children with ASD still confront enacted stigmatization, often on a daily basis. Because their condition is "invisible," individuals with autism and their families are subjected to enacted stigmatization to a greater degree than individuals with visible disabilities such as a physical impairment that requires the use of a wheelchair. In the course of conducting our research, we have spoken with many parents of children with ASD about their feelings of isolation and anger when strangers, friends, or family avoid their child or make accusatory or shaming comments about the child's behavior (Cohen et al., 2013; Cohen & Miguel, 2018; Domínguez-

Pareto, 2014). Not surprisingly, caregivers of children with disabilities who feel stigmatized are more likely to experience emotional distress, social isolation, depression, and suicidal thoughts than those who do not feel stigmatized (Gray, 1993; Green, Davis, Karshmer, Marsh, & Straight, 2005).

A second type of stigma, structural stigma, refers to societal-level conditions and institutional policies that constrain the opportunities, resources, and well-being of those who are stigmatized (Link & Phelan, 2001). Powerful members of these institutions create conditions that stereotype and discriminate against others based on physical, mental, or social characteristics. For instance, if early childhood professionals do not accommodate the sensory sensitivities of children with ASD, they are not only creating gaps between the classroom experience of children with disabilities and those without them but also signaling that the former group's needs are less relevant or important than the needs of the latter group.

Media representations of individuals with ASD can be another source of structural stigmatization. Some media accounts use "stigmatizing cues" in describing people with ASD, inappropriately emphasizing irrelevant social skill deficits or physical characteristics (Holton, Farrell, & Fudge, 2014). Media reports on the developmental origins of health and disease have tended to exaggerate the implications of animal research, minimize the extent to which multiple causal factors are implicated in a child health outcome, focus on maternal factors and downplaying paternal contributors, and ignore the role of social factors such as discrimination and poverty on the intrauterine stressors that have adverse effects on children (Richardson et al., 2014). By highlighting negative and stereotypical aspects of autism, and conveying inaccurate information about the scientific understanding of its origins, these stories contribute to a distorted perception of particular individuals and conditions (Corrigan & Miller, 2004).

Yet another form of structural stigmatization involves the perpetuation of professional discourses that have long been disproven by reputable research. For instance, although the notion that autism is caused by "refrigerator mothers" has been thoroughly discredited, it is still endorsed by individual health service providers (Grinker, 2007). With respect to mental health in general, long debunked theories and stigmatizing assumptions remain at the individual and institutional level, as noted by Mukolo and colleagues: "The institutional context for stigmatization goes far beyond attitudes of professionals in direct contact with consumers… but is reflected also in policies and practices of public institutions that result in the devaluation and discrimination of participants in the mental health sector" (Mukolo, Heflinger, & Wallston, 2010, p. 8).

Practitioners can support families by recognizing that family members may have internalized the stigmatizing narratives circulating in popular discourse about ASD and its causes. Even though a professional may not blame a "refrigerator mother" for causing her child's autism, the complex etiology of ASD makes it likely that parents and others may continue to speculate about the family's role in creating the condition. Even the emerging evidence of a genetic component to ASD can intensify the sense of responsibility attributed to a parent, in spite of the fact that this family "contribution" was not known or controllable by the parent.

Stigmatizing narratives about the role of the parent in "causing" a child's ASD are more available or salient to members of certain sociocultural communities. For instance, Grinker (2007; Grinker et al., 2015) has explored some common narratives or "folk" theories about autism that circulate among some Korean and Korean-American families, including the view that ASD can be attributed to poor parenting and inter-spousal conflict. To the extent that the parent of a child with ASD might internalize these stigmatizing attributions for ASD, she may also experience self-stigma, accepting the social rejection as legitimate or refraining from seeking treatment for her child. However, Grinker also notes that these stigmatizing views are increasingly less common among the younger generation of Koreans who have had more exposure to scientific discourses about the causes of the condition.

This fact prompts us to remember that cultural practices are in constant flux as members of a community constantly experience new conditions and access new sources of information.

It should also be noted that professional sources characterizing parent-professional relationships rarely mention the impact of stigmatization and related discriminatory treatment that is a daily reality for many families. In this section we have argued that by identifying the stigmatizing experiences that individuals with ASD and their parents may have encountered, early childhood providers can better understand parents' challenges and be more aware of their successes (Baquedano-López et al., 2013). By noticing and valuing family experiences, service providers and educators can open the door to the development of strong, positive relationships with parents of young children receiving ECSE services (Dunst, Trivette, & Hamby, 2007; Oono, Honey, & McConachie, 2013; Trivette & Dunst, 2000). We also wish to underscore the need to consider individuals from groups who are stigmatized for additional reasons other than the disability status of a family member. For instance, a woman who has a child with ASD and is Black may be treated differently at an interpersonal level and may encounter more barriers at a structural level than a White father of a child with ASD or than a parent who is not a member of a stigmatized racial group. To fully understand this dynamic process, it is helpful to understand the construct of intersectionality, which we introduce in the next section.

Understanding Intersectionality: Intersecting Categories of Stigma

> There is no such a thing as a single-issue struggle because we do not live single-issue lives (Lorde, 2007, p. 138).

The notion of intersectionality is a key analytic tool in sociology and gender studies that has been relatively underutilized in the fields of education and psychology (Crenshaw, 1989; Ferree, 2010). Intersectionality refers to the notion that individuals are located at the intersection of multiple social identities associated with race, social class, gender, sexuality, ethnicity, nation, disability, and age. These dimensions form mutually constructing features of social organization and potentially of oppression (Collins, 2000). The concept of intersectionality sheds light on the experiences of individuals with multiple stigmatized identities particularly by showing how these identities can't be understood as two or more separate realms of experience; rather, when experienced together they afford a qualitatively different experience that is greater than the sum of the parts. Through this construct, research has been able to describe how people from one identity group (e.g., a particular racial, gender, class, or disability status) have widely different experiences depending on their membership in other groups as well. As Moore argues, it is more effective to understand "the experiences of individuals who lie at the intersection of single dimensions of multiple categories" than to "compare respondents across race or gender categories" (2011, p. 4). These categories or identity statuses take meaning from each other as they intersect in the case of an individual.

The construct of intersectionality is particularly apt as a lens for understanding the experiences of families who have a child with a diagnosis of ASD. Parents who have a child with ASD and who are members of working class or non-dominant racial/ethnic groups are "triple outsiders" in the sense that they are positioned outside the ECSE culture, outside the group of families with typically developing children, as well as outside the dominant US White middle class (McHatton & Correa, 2005). A recent study by Fountain and Bearman (2011) illustrates clearly how intersectional stigma affects parents of children with ASD who are also members of non-dominant ethnic/racial groups. The authors found that subsequent to the passage of California anti-immigration policies limiting access to social services by undocumented immigrants, the number of ASD diagnoses waned among this population. In this case, discriminatory social policies limited access to services for individuals who were positioned at intersecting dimensions of ability status, class, immigration history, and country of origin.

Yet another instance of stigmatization and intersectionality can be seen when professionals respond differently to mothers who have a child with ASD than they do to fathers. It is common for the participation of fathers to be particularly noted and praised by early childhood special educators despite the fact that mothers are far more likely than fathers to manage their children's early educational experiences across ethnic/racial groups and class levels (Lareau, 2000). For instance, Domínguez-Pareto (2014, 2015) found that the activities of Spanish-speaking immigrant mothers who participated in special education advocacy trainings were perceived by program staff as "natural" and were not a source of praise, whereas participation by fathers was celebrated and held up as a sign of exemplary parenting. Thus, participatory fathers who were unusual among their own gender group were accorded institutional goodwill, whereas mothers who participated at the same level did not receive these accolades because they were not unusual among women, even though they too may have sacrificed a great deal or put a great deal of energy into their participation. As the concept of intersectionality would have us understand, however, gender-based expectations do not inevitably lead to the over-recognition of fathers. Within other groups, active involvement by fathers may be overlooked or misunderstood. For example, a study of Haitian immigrant families found that teachers consistently expected mothers to participate at the school even though it was fathers who most often attended teacher-parent meetings because of their higher level of spoken English (Doucet, 2011). Within this group, fathers' engagement was not recognized or appreciated, even though they were frequently the more active participants in school-based involvement activities.

In summary, we have argued in this chapter for a critical sociocultural approach that includes awareness of power and power inequalities within communities and between families and practitioners. We have also noted that the specialized norms, language, and meanings salient in the early childhood special education system constitute a socially constructed community of practice that parents need to grasp in order to act as effective cultural insiders. We have introduced the concept of structural stigmatization to capture the idea that discriminatory conditions can be instantiated not just at the level of individual beliefs and interactions but also at a societal level through policies, institutions, and programs. Lastly, we have shown that the process of stigmatization occurs not only through interpersonal interactions between family members or individuals with ASD and dominant outsiders but also how stigmatization is a function of multiple intersecting social categories, including gender, race/ethnicity, and social class.

We have also suggested that educators use these constructs to examine their personal heritage, membership in a professional community of practice, and institutionally rooted status vis-à-vis the families they are working with. By engaging in reflexive practice, ECSE practitioners can also identify the ways in which families caring for a child with ASD are themselves positioned at a nexus of cultural and class dimensions and are multiply impacted by positive forms of professional and informal support as well as intersectional processes of stigmatization and discrimination. In the final section of our chapter, we provide additional suggestions for how practitioners and policy makers can build on these nuanced understandings of culture, stigma, and intersectionality to strengthen programs and practices.

Implications for Service Providers

We begin by suggesting strategies for early childhood special educators, interventionists, and other service providers to use with families from non-dominant backgrounds to minimize stigma and promote true partnership between parents and practitioners. We then identify broader policy changes to improve the way the ECSE system functions for non-dominant families and their children.

Reflect on the possible consequences of one's own personal position. We encourage ECSE practitioners to reflect on their membership in various sociodemographic categories, including race, disability/ability status, country of origin, and gender, and examine how experiences in those groups shape their perceptions about family dynamics in general and ASD in particular (Ayers, 2010; Banks, 2013). Some questions to ask oneself include the following: *Do these personal experiences sensitize me to certain parent behaviors and not others? Do my personal experiences lead to evaluative or emotional responses that may be unwarranted? Or do they help me be more empathic?* By reflecting upon their own cultural beliefs and the sources of those beliefs, practitioners can avoid stigmatization and explicit or implicit discriminatory treatment of families.

Reflect on the possible consequences of one's professional training and experiences. By recognizing that the norms and practices of the early childhood special education system themselves constitute a complex cultural world (Kalyanpur & Harry, 1999), practitioners can be more conscious of how to support parents to become cultural "insiders" but also to be respectful of those who choose not to be. In addition, by considering parent-professional partnerships as a community of practice, practitioners can identify parents' strengths and knowledge that should be incorporated into practices involving that family. By reflecting on the study and experience that it took them to learn the language, attitude, assumptions, and values of the early childhood special education profession, practitioners may feel less evaluative of parents who do not appear to have internalized these same norms.

Engage in antibias teaching practices in ECSE classrooms. We encourage teachers to implement an antibias curriculum in their classrooms with children and their families. Antibias education is an approach that supports individual children and their families with the goal of affirming their sense of agency and acknowledging their social status (Derman-Sparks & Ramsey, 2011; Kuh, LeeKeenan, Given, & Beneke, 2016). Within an antibias approach, teachers are encouraged to reflect on their own practice, on the materials and books they use, and on the context where they teach in order to evaluate which cultural communities are privileged and which ones are silenced. They are also encouraged to identify "entry points" for teaching about individual differences, modeling reflective practices, and responding to children's questions and comments in an emergent setting during a typical day (Banks, 2013; Derman-Sparks & Ramsey, 2011). For example, a child may ask for a turn on the "wobble cushion" used by a classmate with a diagnosis with autism. The teacher can acknowledge the question and encourage a conversation with the class about various ways that help each of them to pay attention and learn during group time. Similarly, providers can listen to families' concerns and elicit their experiences about addressing bias. For example, if a parent is worried that her child may be teased for flapping his hands when he gets excited, the teacher can respond by explaining how she conducts discussions in the classroom regarding emotions and can ask the parent to describe personal experiences that have helped family members and friends become comfortable with the child's modes of self-expression.

Observe and identify family goals, strengths, and practices. Practitioners can identify beliefs and practices that may be salient within particular communities, as well as learning about the beliefs, routines, and experiences of the individual families in the community. Rather than assuming that members of a particular class, ethnic, or racial group share similar values, it may be helpful to learn about the individuals' narratives about parenting and about disability. Furthermore, practitioners can learn to recognize and work constructively with parents who express resistance or disagreement with certain therapeutic or educational goals. They can also recognize the forms of stigmatization that a family may be encountering from members of their own community and work with practitioners to identify strategies for alleviating stigma and promoting acceptance within their community.

Provide documentation and data about the child to the parents in a nonjudgmental way. The purpose of documentation is for the practitioner to learn, share, and gain insight into how a child learns. The effective use of documentation has been thoroughly illustrated in the writing of educators associated with the Reggio Emilia school system, who provide resources and training for teachers not only in how to undertake this documentation but also how to interpret and review it with colleagues and parents (Rinaldi, 1998). Practitioners working with parents of children with ASD can draw upon the Reggio Emilia model to assess how well the child responds to a specific intervention and also to identify the child's strengths and interests. For example, practitioners can document a first attempt of a child writing his name and praise the child for his effort in approximating certain letters. The teacher can continue documenting progress as the child develops his fine motor skills and begins to write his name using an appropriate hand grip. This documentation of the child's fine motor development can be shared with parents to collaboratively address developmental challenges (Gilman, 2007).

Encourage parents to provide observations and documentation to support collaborative lesson planning. Some parents may not see documentation as a part of their role or feel unsure how to go about doing it. Educators can offer the opportunity and can collaborate with parents on how to take notes or photographs, save artifacts, and otherwise share their observations of the child engaging in play at home. Parents can use these observations to make practical suggestions that would benefit the child in the classroom or for the adaptation of the child's IFSP or IEP goals. When parents' observations and opinions are valued, the power dynamic becomes more equal, and there is less opportunity for stereotyping and stigma (Link & Phelan, 2001). Parents and teachers can also use this extensive documentation to collaborate in developing activities based on the child's interests that can be implemented at home and at school and that promote the child's educational goals.

Open up space for parents to shape pedagogical and therapeutic practices. As we have seen, professional discourses and knowledge have shifted historically and thus must always be a target of reflection by practitioners who draw upon them. Furthermore, there are often multiple pathways to achieve a desired goal, and it is important to identify pathways that are viewed as legitimate by parents. Attending to parents' views in a truly equitable manner requires the practitioner to engage in the reflexive practices that we have discussed earlier in this chapter. However, if parents choose not to become engaged in the activities suggested by the practitioners, we believe it is crucial that they not be stigmatized or labeled as "noncompliant" or "uninvolved." Even if they receive genuine offers to participate, ample guidance and information, and attention to their goals and strengths, parents may choose to take other measures to promote their child's development, or their life circumstances might force them to prioritize issues of survival and sustenance that don't afford time or space for other forms of participation. Valuing different ways in which parents engage, and utilizing the practitioner's expertise and knowledge to support/promote the types of child engagement and learning that parents do with their child, even if it is outside the practices recommended by professionals, is a fundamental way to relate to parents in a more socially equitable way.

Identify sources of family "capital." Parents with ample community resources and supportive networks of friends and family are generally more able to effectively advocate for their child than those who are socially isolated (Benson, 2012; Trainor, 2010a, 2010b). However, as we have shown in this chapter, the experience of enacted stigma can undermine parents' sense of competence and discourage them from persisting with suggested interventions. Practitioners can help parents identify positive and constructive sources of support available to assist them in caring for their child as well as providing emotional support. By the same token, practitioners can also help parents identify stigmatizing experiences and minimize their negative impact. Participation in supportive social networks may also ameliorate feelings of social isolation and depression caused by stigmatizing experiences (Gray, 1993; Green et al., 2005). This may be particularly important when a parent is subjected to stigma from family or community members with greater social power.

Implications for Policy

Improve early childhood special education programs to include reflexive practice, knowledge about systemic inequalities, and a conceptual understanding of intersectionality and stigmatization. ECSE credential programs and professional development programs for early interventionists should utilize the practices highlighted above to help practitioners become aware of their own biases, learn to reflect on their beliefs about ASD and education, and examine how they may be different from those beliefs of the families whom they serve. Teacher education programs should also help students acquire historical information about systemic inequalities affecting early childhood special education. Coursework should feature open discussions of stigma and discrimination when examining the applicability of certain early interventions for children with ASD from non-dominant groups. Increasing the sociocultural diversity of pre- and in-service educators will also promote the goal of enhancing the quality of ECSE programs and the ECSE workforce.

Support interactions among families, early childhood special educators, and other community members. Prolonged and meaningful interactions can only occur when sufficient time and financial resources are available to allow busy individuals to come together and discuss their common interests, identify obstacles and opportunities, and build a sense of community and joint commitment to improving services. It is particularly essential to support parent-led organizations that reflect community values and promote the type of peer networking that has been shown to be effective in promoting family-school relations in the K-12 public school system. What is more, a seamless integration of developmentally appropriate educational and related services for children from birth through early elementary school has been shown to enhance long-term child outcomes (Peisner-Feinberg et al., 2001).

Support communication and collaboration among early childhood professionals and with families. We encourage early childhood service providers to engage in meaningful dialogue and communication with families. The individualized family service plan (IFSP), Part C of IDEA, was put in place to promote collaboration among the adults involved in the care of the child with disabilities (20 U.S.C. 1400 et seq.; 34 C.F.R. §§ 303 et seq.). In our experience working with young children with ASD and their families, this IFSP process often becomes a "training" session for parents to learn the "right way" to play and teach their children. We encourage early educators and families to build the child's educational/intervention program together, utilizing the knowledge and expertise of everyone involved to develop a unique program that incorporates the strengths and abilities of the child, and the priorities, educational expectations, and resources of the family.

Engage in more frequent and comprehensive media training around the topic of ASD. Policy makers, researchers, and educators can serve as brokers to translate research findings and improve the media's ability to provide public coverage of ASD that is less stigmatizing of parents and of individuals with ASD. For example, media outlets can build public awareness of the structural stigma that may impede access to appropriate ASD diagnosis and treatment. Additionally, members of the media can be encouraged to avoid the pitfalls of intersectional stigmatization, including the pervasive practice of stigmatizing mothers from non-dominant groups for the health outcomes of their children rather than undertaking a comprehensive analysis of the complex array of contributing social conditions.

Address systemic disparities in socioculturally diverse families' access to quality early interventions for ASD. Nationwide, 1 in 68 children is diagnosed with ASD (CDC, 2014). Research shows that ASD symptoms do not vary by race or ethnicity, but the diagnosis of ASD depends substantially on the income level of the family (Chaidez, Hansen, & Hertz-Picciotto, 2012). Children from Latino families, who tend to come from low-income households, are identified and diagnosed at a rate that is 50% below the national average (CDC, 2014). These disparities are only beginning to be addressed through comprehensive changes in state healthcare systems. For example, recent collaboration between researchers and government officials in California resulted in better coverage for early intervention through state-funded health insurance policies, leading to greatly improved access to high-quality interventions targeting underserved populations (SB 946, California Government Code, §§ 121022 et seq., 2011). In addition to initiatives like this one in California, states can also provide comprehensive support for families to successfully navigate the service system. For example, in order to ensure that families fully understand their role in gaining access to services their children need, states should provide increased funding for cultural/language brokers to help them navigate the system and advocate effectively to attain the appropriate services.

Attend to the unintended stigmatizing effects of public policies. As we have noted, sometimes policies inadvertently have a disproportionately negative effect on certain groups. To prevent this from occurring, policy makers and analysts can identify the likely effects of a new initiative on families located not just by comparing one broad sociodemographic category with another but rather by considering families' position at the intersection of multiple social dimensions. This more nuanced framework will permit reflection on how the available resources as well as barriers to opportunities within that group will shape policy impact.

References

Abrego, L. J. (2014). *Sacrificing families: Navigating laws, labor, and love across borders*. Stanford, CA: Stanford University Press.

Ayers, W. (2010). To teach: The journey of a teacher. New York, NY: Teachers College Press.

Baca Zinn, M., & Wells, B. (2005). Diversity within Latino families: New lessons for family social science. In A. Skolnick & S. Jerome (Eds.), *Family in transition* (pp. 420–445). Boston, MA: Pearson.

Banks, J. A. (2013). *An introduction to multicultural education* (5th ed.). Upper Saddle River, NJ: Pearson.

Baquedano-López, P., Alexander, R. A., & Hernandez, S. J. (2013). Equity issues in parental and community involvement in schools: What teacher educators need to know. *Review of Research in Education, 37*(1), 149–182. https://doi.org/10.3102/0091732X12459718

Benson, P. R. (2012). Network characteristics, perceived social support, and psychological adjustment in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 42*, 2597–2610.

Bourdieu, P., & Wacquant, L. J. D. (1992). *An invitation to reflexive sociology*. Chicago, IL: The University of Chicago Press.

Centers for Disease Control and Prevention. (2014). Prevalence of autism spectrum disorder among children aged 8 years – Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *Morbidity and Mortality Weekly Report, 63*, 1–21 Retrieved from: http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6302a1.htm

Chaidez, V., Hansen, R. L., & Hertz-Picciotto, I. (2012). Autism spectrum disorders in Hispanics and non-Hispanics. *Autism, 16*, 381–397. https://doi.org/10.1177/1362361311434787

Cohen, S. R., Holloway, S. D., Domínguez-Pareto, I., & Kuppermann, M. (2013). Receiving or believing in family support? Contributors to the life quality of Latino and non-Latino families of children with ID. *Journal of Intellectual Disability Research, 58*, 333–345. https://doi.org/10.1111/jir.12016

Cohen, S. R., & Miguel, J. (2018). Amor and social stigma: ASD beliefs among immigrant Mexican parents. Journal of Autism and Developmental Disorders, 48.

Collins, P. H. (1994). Shifting the center: Race, class, and feminist theorizing about motherhood. In E. Nakano Glenn, G. Chang, & L Rennie Forcey (Eds.), Mothering, ideology, experience, and agency. (pp. 45-66). New York, NY: Routledge

Collins, P. H. (2000). *Black feminist thought: Knowledge, consciousness, and the politics of empowerment*. New York, NY: Routledge.

Cooper, C. W., Riehl, C. J., & Hasan, A. L. (2010). Leading and learning with diverse families in schools: Critical epistemology amid communities of practice. *Journal of School Leadership, 20*, 758–789.

Corrigan, P. W., & Miller, F. E. (2004). Shame, blame, and contamination: A review of the impact of mental illness stigma on family members. *Journal of Mental Health, 13*, 537–548.

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory and antiracist politics. *University of Chicago Legal Forum, 1989*, 139–168.

Derman-Sparks, L., & Ramsey, P. (2011). *What if all kids are white? Anti-bias multicultural education with young children and families* (2nd ed.). New York, NY: Teachers College Press.

Domínguez-Pareto, I. (2014). *Learning advocacy: Decentering parental involvement discourse through the experiences of Latina mothers of children with disabilities in northern California* (Doctoral dissertation). University of California, Berkeley, CA.

Domínguez-Pareto, I. (2015). *Gendered involvement, unequal parenthoods: Examining the role of gender in Latina mothers' parental advocacy from an intersectional perspective*. Unpublished manuscript.

Doucet, F. (2011). Parent involvement as ritualized practice. *Anthropology & Education Quarterly, 42*, 404–421.

Dunst, C., Trivette, C., & Hamby, D. W. (2007). Meta-analysis of family-centered helpgiving practices research. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 370–378.

Ferree, M. M. (2010). Filling the glass: Gender perspectives on families. *Journal of Marriage and Family, 72*(3), 420–439. https://doi.org/10.1111/j.1741-3737.2010.00711.x

Foucault, M. (1972). *The archeology of knowledge and the discourse on language*. New York, NY: Pantheon Books.

Fountain, C., & Bearman, P. (2011). Risk as social context: Immigration policy and autism in California. *Sociological Forum, 26*, 215–240. https://doi.org/10.1111/j.1573-7861.2011.01238.x

Free Appropriate Public Education under Section 504. (2010). Retrieved from: http://www2.ed.gov/about/offices/list/ocr/docs/edlite-FAPE504.html

Geertz, C. (1983). *Local knowledge*. New York, NY: Basic Books.

Giddens, A. (1991). *Modernity and self-identity: Self and society in the late modern age*. Stanford, CA: Stanford University Press.

Gilman, S. (2007). Including the child with special needs: Learning from Reggio Emilia. *Theory Into Practice, 46*, 23–31.

Gjerde, P. (2004). Culture, power, and experience: Toward a person-centered cultural psychology. *Human Development, 47*, 138–157.

Goffman, E. (1963). *Behavior in public places*. New York, NY: Free Press.

Gray, D. (1993). Perceptions of stigma: The parents of autistic children. *Sociology of Health and Illness, 15*, 102–120.

Green, S., Davis, C., Karshmer, E., Marsh, P., & Straight, B. (2005). Living stigma: The impact of labeling, stereotyping, separation, status loss, and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry, 75*, 197–215.

Grinker, R. R. (2007). *Unstrange minds: Remapping the world of autism*. Cambridge, MA: Basic Books.

Grinker, R. R., Kang-Yi, C. D., Ahmann, C., Beidas, R. S., Lagman, A., & Mandell, D. (2015). Cultural adaptation and translation of outreach materials on autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*, 2329–2336. https://doi.org/10.1007/s10803-015-2397-6

Holloway, S. D. (2010). *Women and family in contemporary Japan*. New York, NY: Cambridge University Press.

Holton, A. E., Farrell, L. C., & Fudge, J. L. (2014). A threatening space: Stigmatization and the framing of autism in the news. *Communication Studies, 65*, 189–207.

Kalyanpur, M., & Harry, B. (1999). *Culture in special education: Building a posture of reciprocity in parent-professional relationships*. Baltimore, MD: Brookes Publishing Company.

Kuh, L. P., LeeKeenan, D., Given, H., & Beneke, M. R. (2016). Moving beyond anti-bias activities: Supporting the development of anti-bias practices. *Young Children, 71*, 58–65.

Lareau, A. (2000). *Home advantage: Social class and parental intervention in elementary education*. Lanham, MA: Rowman & Littlefield Publishers.

Lareau, A., & Munoz, V. L. (2012). "You're not going to call the shots": Structural conflicts between the principal and the PTO at a suburban public elementary school. *Sociology of Education, 85*(3), 201–218. https://doi.org/10.1177/0038040711435855

Lave, J., & Wenger, E. (1991). *Situated learning: Legitimate peripheral participation* (19th ed.). New York, NY: Cambridge University Press.

Lightfoot, D. (2004). "Some parents just don't care": Decoding the meanings of parental involvement in urban schools. *Urban Education, 39*(1), 91–107. https://doi.org/10.1177/0042085903259290

Leigh, J. P., Grosse, S. D., Cassady, D., Melnikow, J., & Hertz-Picciotto, I. (2016). Spending by california's department of developmental services for persons with autism across demographic and expenditure categories, PLoS ONE 11: e0151970 https://doi.org/10.1371/journal.pone.0151970

Link, B. G., & Phelan, J. C. (2001). Conceptualizing stigma. *Annual Review of Sociology, 27*, 363–385.

Lorde, A. (2007). *Sister outsider: Essays and speeches by Audre Lorde*. Berkeley, CA: Crossing Press.

McHatton, P. A., & Correa, V. (2005). Stigma and discrimination: Perspectives from Mexican and Puerto Rican mothers of children with special needs. *Topics in Early Childhood Special Education, 25*(3), 131–142. https://doi.org/10.1177/02711214050250030101

Moore, M. (2011). *Invisible families: Gay identities, relationships, and motherhood among Black women*. Berkeley, CA: University of California Press, Ltd.

Mukolo, A., Heflinger, A., & Wallston, K. A. (2010). The stigma of childhood mental disorders: A conceptual framework. *Journal of the American Academy of Child and Adolescent Psychiatry, 49*, 92–198.

Nasir, N. S., & Hand, V. M. (2006). Exploring sociocultural perspectives on race, culture, and learning. *Review of Educational Research, 76*, 449–475.

Ong-Dean, C. (2009). *Distinguishing disability: Parents, privilege, and special education*. Chicago, IL: University of Chicago Press.

Oono, I. P., Honey, E. J., & McConachie, H. (2013). Parent-mediated early intervention for young children with autism spectrum disorder. *Evidence-Based Child Health, 8*, 2380–2479.

Peisner-Feinberg, E. S., Burchinal, M. R., Clifford, R. M., Culkin, M. L., Howes, C., Kagan, S. L., & Yazejian, N. (2001). The relation of preschool child-care quality to children's cognitive and social developmental trajectories through second grade. *Child Development, 72*, 1534–1553.

Richardson, S. S., Daniels, C. R., Gillman, M. W., Golden, J., Kukla, R., Kuzawa, C., & Rich-Edwards, J. (2014). Society: Don't blame the mothers. *Nature, 512*, 131–132. https://doi.org/10.1038/512131a

Rinaldi, C. (1998). Projected curriculum constructed through documentation—progettazione: An interview with Lilla Gandini. In C. Edwards, L. Gandini, & G. Foreman (Eds.), *The hundred languages of children: The Reggio Emilia approach—advanced reflections* (pp. 113–121). Greenwich, CT: Ablex.

SB 946, California Government Code, § Section 121022 et seq. (2011).

Shore, B. (1996). *Culture in mind: Cognition, culture and the problem of meaning*. New York, NY: Oxford University Press.

Skinner, D., & Weisner, T. (2007). Sociocultural studies of families of children with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews, 13*, 302–312.

Trainor, A. A. (2010a). Diverse approaches to parent advocacy during special education home – school interactions: Identification and use of cultural and social capital. *Remedial and Special Education, 31*(1), 34–47. https://doi.org/10.1177/0741932508324401

Trainor, A. A. (2010b). Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly, 41*(3), 245–263. https://doi.org/10.1111/j.1548-1492.2010.01086.x.245

Trivette, C., & Dunst, C. (2000). Recommended practices in family-based practices. In S. Sandall, M. E. McLean, & B. J. Smith (Eds.), *DEC recommended practices in early intervention/early childhood special education* (pp. 39–44). Longmont, CO: Sopris West.

Turnbull, H. R. (2005). Individuals with Disabilities Education Act reauthorization: Accountability and personal responsibility. *Remedial and Special Education, 26*(6), 320–326. https://doi.org/10.1177/07419325050260060201

Valencia, R. R., & Black, M. S. (2002). "Mexican Americans don't value education!" On the basis of the myth, mythmaking, and debunking. *Journal of Latinos and Education, 1*, 81–103.

Valle, J. W. (2009). *What mothers say about special education: From the 1960s to the present*. New York, NY: Palgrave Macmillan.

Valle, J. W. (2011). Down the rabbit hole: A commentary about research on parents and special education. *Learning Disability Quarterly, 34*(3), 183–190. https://doi.org/10.1177/0731948711417555

Wang, M., Mannan, H., Poston, D., Turnbull, A. P., & Summers, J. A. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*(2), 144–155. https://doi.org/10.2511/rpsd.29.2.144

Weisner, T. (2002). Ecocultural understanding of children's developmental pathways. *Human Development, 45*, 275–281.

Wenger, E. (1998). *Communities of practice: Learning, meaning, and identity*. Cambridge, MA: Cambridge University Press.

Zarembo, A. (2012, May 1). California agency ripped over disparities in autism spending. *Los Angeles Times*. Retrieved from: http://articles.latimes.com/2012/may/01/local/la-me-0501-autism-hearing-20120501