

Interviewer/Number of Interview: EG16

Date: 7/16/2019

Name of Interviewee Assigned by Researcher (to protect identity): Respondent

Year of Birth: Late 1970s

Gender: Female

Country of Origin: Indonesia

Year of Immigration: [Sometime between 2012-2014]

Note: In the transcript, *I* refers to Interviewer, and *R* refers to respondent/interviewee. To protect the identity of the interviewee, some responses to questions are not provided. In such cases, this statement will show in the transcript: Information is not being made available. In other responses, specific details that might identify the family members are omitted or made more general.

Abstract:

This respondent was born in Indonesia and immigrated to the United States rather recently. She is the caretaker to her ten-year-old son who has selective mutism. During the interview she talks about the long and confusing road to a diagnosis, inability to afford an evaluation, and bullying that her son experiences. She also discussed the ethnic/cultural/nationalistic divisions within Mosques, which can be obstacles in finding community across these divides.

Key Themes:

ESL; Bullying; Psychological Evaluations and Diagnoses; Struggles managing the child's behavior and emotions; Social isolation of the mother; Gender roles; Lack of affordable care related to the child's ability difference; Sibling rivalry; Ethnic divisions within Mosques; Needs of recent immigrants when they have a child with an ability difference – they may not know what their needs are or where to turn, which could be a function of their being a recent immigrant.

I: So today is July 16th 2019, I'll have you start by just saying your full name and your date of birth.

R: [Information is not being made available.]

I: And where were you born?

R: Born in [Indonesia]

I: And when did you move to the United States?

R: [Sometime between 2012-2014]

I: And why did you choose to move to the U.S.?

R: [Her husband was transferred to the Milwaukee area.]

I: And let's see -- how do you identify yourself in terms of your national background?

R:...myself.. I'm just mother (Both laugh).

I: So I might say that I'm Irish-American, what would you say?

R: Oh I'm Asian, uh huh.

I: Got it, and what is the highest level of education that you've completed?

R: [Respondent has an undergraduate degree. She also attends a local institution to learn English.]

I: Great, and what is your marital status?

R: Ma-Ma..

I: Are you married?

R: Yeah, I'm married (both laugh). Just think of marital? No.

I: Married.

R: Yeah.

I: Mhmm, and do you have any children?

R: Yeah, two kids uh huh.

I: And their genders, and age?

R: [One 10 year old boy and another child who is 7 years old.]

I: Great, and do you currently work outside the home at all?

R: No.

I: Okay.

R: Not now.

I: Got it.

R: Maybe later.

I: Okay, so the next set of questions are gonna focus on the types of differences of ability that you or the person you care for has. We are interested in learning about the following types of differences of abilities- so I kind of have a chart here- so we have physical, chronic illness, learning/intellectual, mental health, speech/language, and addiction. Could you share with me uhm the category that your family member would fall under?

R: We [unintelligible] with the speech language especially for my son.

I: Mhmm.

R: Cause uh when he- when we moved here he already like almost four so he know our language, yeah know? And then first he just started to talk around three, three year uh huh but he understand- I mean before three he understand everything what I say yea know but he didn't say any words but uh at three he just started to [use] long sentences and I just surprised- I just forgot what he said but I ahh yea know my face like (makes surprised face) ahh! Like you say something to me? Like wow! [Unintelligible] and then he was talking, talking, talking we were like oh my god (R laughs)! Sometimes we like "mom" yea know like try to but he don't say anything but that time took (snaps fingers) and blah blah blah blah blah like *unintelligible** yea thank god because that time when he didn't talk – uhh any single word yes on mama and papa like that but that time we- we afraid what to happen with our kid because I mean in that age mostly babies already talking. [A family member wondered if he had autism.] Maybe he have autism. Yeah know make me scared about the issue uh when we searching google more crazy thing too like I try to- try to think positive about my kid even though my- my – uh the doctor uh- what the doctor for the kid name?

I: Pediatrician?

R: The pediatrician said "your kid okay because he understand what you say, don't worry about it, don't worry about it. He's fine." But you know, sometimes us mothers are like "why is my kid like this?, why the other kids not- not the same- not like the same?" You know, for us it's not normal, you know?

I: Mhmm.

R: And then when he talk like, oh my god it's everything is – I just try to erase everything that I try to search yea know (Both laugh). What happen to my kid? But when come back here, I come here at first we afraid because he shy, he quiet uhm he not like- we thought it's maybe typical Asian people yea know? Asian mostly do not – don't show off "hey I can do this! Hey yea know I made something!" Yea know, here I saw many kids like " Oh, blah blah blah blah look at this!" Show-off, show-off too much (Both laugh). Before Asians we just like respect yea know if the older one talking we never say anything, I- we thought- me and my husband thought oh he's Asian he don't want to say something, yea know? But then we realized, no it's different he don't want to say- but he say to me but not in the- in the class -we uh I uh- I put it in daycare class. He don't want to say anything, when the kids say ask to me every time I pick up him, "can [your son] talk?" They said, "Of course he can talk" (Both laugh). "We never heard!" (R laughs) Ohh what must I do, yea know? First we have no friend here, no family here so I really afraid at that time. [The parents put him in 4K and then 5K; eventually, he was put into ESL classes.]

R: And I asked the-the-the-the one who- who uh... how to say in English.. who in charge at ESL and then talking, "what must I do? My kid I don't know he can talk in English or not because he never talk to me. If I ask what happen in- what are you doing- what happened in any class? He never tell me anything." So, I really afraid of what is, even the teacher say "Oh he's okay, it's fine he..." - but we never saw it, what he do, what he feeling. So she put him in speech therapy.

I: Mhmm.

R: Get his therapy from public uh school, cause she said if you put your kid at public school you will get it and it's free she said. Okay whatever, I mean try to help him.

I: Mhmm.

R: So I just put him there, he get three years get speech therapy but this- therapy (therapist) said “he know everything, he just don’t want to say it.”

I: Mhmm.

R: He can say it- he- he can do it and but it’s personality not- not about the-the speech yea know.

I: Mhmm.

R: He just like- maybe like if you- if I don’t need to say something why I have to say something?

I: Mhmm.

R: [When he was in second grade, he saw the school psychologist. That provider left the school so didn’t see their son very long. The respondent never received any reports. When she asked the school for them, they didn’t have any reports on the treatment, either.]

I: Interesting.

R: [Her son is still in ELS. Her other child was also put in ELS but passed the tests rather quickly so didn’t need to stay in ELS. In the car, the son expressed to his mom that he was upset that his younger sibling was no longer in ELS, but he still was.] [The ESL Teacher] called me, like send me email, and said I need to talk to you. We make appointment and then we met and she said “[Son’s name] didn’t have made good progress” she said, “he don’t want to talk, he don’t want to do anything that I say, he just sit in the corner yea know like here and just sit in the corner. He don’t want to do anything, even though I said [Son’s name] [unintelligible] hmm he just like don’t want to be in that room yea know”.

I: Mhmm.

R: And I just I-I forgot about that conversation that we made in the car, you know. What happened with my kid, because he didn’t show me anything, he didn’t let me know what happened yea know. He never says anything to me I try to thinking yea know. I ask him, he don’t want to answer me. What happened? And then I remembered that situation in the car like (gasps), oh maybe is like mad you know.

I: Oh he was mad..

R: Yeah, maybe he tried to like protest to-to [ESL Teacher] “Why me still here? I’m big. I’m fourth grade, my [younger sibling isn’t in ESL] and I can speak English better too?” But he don’t want to say anything to her or to me -- just try to emotion by himself never try to come out [and express what he’s feeling].

I: Mhmm.

R: [The respondent talked to the ESL teacher and suggested that maybe her son’s behavior is related to his feeling bad that he’s still in ESL classes, but his younger sibling isn’t.]

R: And wow, it’s a big deal for me. Even when it’s the test, he don’t want to do anything (R laughs). Oh I’m really afraid for him; I don’t know what I must do; he’s not [Son’s name] anymore. Before he want to talk, he want to- I mean he try to “Hey, I’m [the big brother and want to] show off.

I: Mhmm.

R: After I ask him "is this about this or not?" uh- I ask him and "yea I don't like it, [sibling's name]; I do better in math, I can write, everything" he said, "uh but why [ESL teacher] not pick [sibling's name] up again?" (R laughs).

I: He's stuck on it.

R: Yeah, yeah, yeah but this about his [emotions].

I: Mhmm.

R: That he cannot do maybe he-he want to go but don't want to say anything but he just keep it

I: Mhmm.

R: And at home the sadness is he try to- the emotion is try to doing everything to me especially.

I: Hmm.

R: So he just sometimes if like- he a perfectionist person uh when we come here if we go like to Walmart or something, go to the aisle yea know?

I: Mhmm.

R: And there's a box of a thing yea know, and it's not- it's mess, it's not perfect.

I: Yeah.

R: He will perfect- he will- he will (Makes hand gestures of putting things in order).

I: Mhmm.

R: Yea know like..

I: Organize it.

R: Try... yeah. I go "It's okay, it's okay -- it's not your job." He don't feel like it's okay, you know? He try to fix it.

I: Mhmm.

R: Oh my so we just waiting for him for that after he say okay (R laughs). He is the perfect one. Even though when like he get the speech therapy, there is a test, forget the thing.

I: Mhmm.

R: And uhm somebody ask him to make a circle, it's perfect circle even line yea know. It's perfect line yea know even though his [handwriting] is better than me (Both laugh). So he's the perfect one uh he- so maybe at-at school, I don't know what happened he didn't want to say anything he- but he follow, he follow what the teacher said. Uh who have to do this, this, this until that. [Respondent described a situation that her son had in the second grade about his need to strictly follow rules and to not speak up about his needs. The respondent intervened with the teacher on her son's behalf, so that the teacher would better understand her son and know how to respond to him.]

R: Yeah he follows the rule, oh my god it's not like that [child's name] (I laughs).

I: Mhmm.

R: Many things he just strict.

I: Mhmm.

R: To the- to the rule I-I don't know but outside like that but at home if -if I yea know sometimes my English- my how to listen in English sometimes like what? What can you tell me? "Mama I told you like something like this blah blah blah blah blah" yea know like, yea I'm so sorry my English is not good you just repeat again for me and uh or explain to me. I have no idea what is that. And he like angry, like right away, emotional like. When he was like that, oh my god what happened? Like he want to show "I'm angry"; sometimes he knocks the wall or sometimes he hits me "I don't like you, I don't like you, I don't like you, I hate you very much" you know. Try to make everything just go, you know.

I: Mhmm.

R: "[Child's name] don't do like that to me, I'm your mom" and sometimes I said like that until I'm crying like make him realize don't do that to me. But.. he okay then doing it again, I don't know why he doing that to me, to my husband, to something, but mostly to me (I and R both laugh). I don't know why. I try to understand him; maybe outside at school he don't know how to blow up.

I: Mhmm.

R: Emotional, but at home it's just only my mom. I can do anything to my mom. I can do anything to my mom, [but] there is respect sometimes. When I try to hug him, kiss him, try to make him calm down "come on don't do that to me, please. You are a good boy, you can be anything you want to be". [The respondent discussed her strategies to help calm him down when he gets so angry and emotional.]

I: Mhmm.

R: [Respondent described a situation that happened with another child who was playing with her kids at a play area. Her son got very upset; his sibling explained to their mom that the playmate said something very mean about her son. So her son wanted them to go home. She explained how she tried to help her son cope with this sort of behavior from others.] I mean anything to try and make him okay again, because I realize I cannot follow him everywhere, every day, every hour. So he has to survive, you know.

I: Mhmm.

R: [She discussed her fears of him being bullied.] We try to make him more confident.

I: Mhmm.

R: Nobody perfect but cannot uh do in his mind. Yea know because he's perfectionist one, he have to- he have to do everything in a perfect way...

I: Mhmm.

R: That-that's why I try to uh find uh psychiatrist?

I: Uh-huh.

R: Uh try to register to the uh children hospital, but we didn't realize it would be expensive thing.

I: Mhmm.

R: First uh- first the social worker that- who uh works for the... school.

I: Yeah the school, yup.

R: [The school social worker] said maybe your kid is uh- what do you call it? Mutism syndrome?

I: Okay, so that's why they wanted him to potentially see a psychologist to see if they...

R: Uh-huh.

I: would agree?

R: Yeah. Maybe you can see uh- ask them what to-what- uh as a parent what way..

I: Yes.

R: I can help him out, uh from the school what- just make him- maybe for talking it's his personality?

I: Mhmm.

R: We cannot make people not talking be talking.

I: Yeah.

R: But, at least he can survive, yea know?

I: Yeah, have the tools.

R: He can be in- in that area uh because sometime the-the-the teacher said if in the playground he play but alone, yea know.

I: Mhmm.

R: But if- but if there is a event in the school, "Mama, Mama, Mama can- we have to go to that event, we already late, we already late." I thought I'm very happy because mostly he don't want to go, and then he said "I want to go, I want to go", something make me happy yea know.

I: Mhmm.

R: Okay, then we go. I thought he would play with the kids – but he just play around- alone yea know. I'm so sad that time, oh my god but he happy for him he smile to me, but I'm so sad to see that thing.

I: Mhmm.

R: [The respondent described how last year, he didn't want to go to some particular school events, but this year he really wants to go to them.] For me it's just a good thing he moved another step. [She described how he is beginning to talk in small groups at school.]

I: Awesome!

I: Has your son experienced any prejudice, remarks or discrimination because of his difference of ability? I know you kind of expressed maybe some kids maybe pick on him or that the kids in his class have some questions about that, can you kind of explain.

R: Yea like in the first day yea know, the first day many kids wearing the new shoes, new things, everything knew mostly like that. And my son typical don't want to do that, you know? Even then I want to buy [new clothes or shoes for him], but he don't want to do that "it's okay, it's okay". So he wears the old one. He doesn't like new things.

I: Mhmm gotcha.

R: Uh and on that day, the first day all the kids mostly wear the new one and they know my son doesn't wear [new clothes] -- they know it's the old one, because they play for nine months at the school. "Hey [son's name] your mom didn't buy new?" I didn't say anything I just see.

I: Mhmm.

R: And he just say to me like this "uh it's okay" just said to me like "it's okay" ... he just okay when I say "it's okay" he just like (R makes face and laughs). And then when go back home I ask him "do you want new shoes?" I said. Uh because I afraid maybe he thinking that day "why my mom didn't (R begins to laugh)". I ask him "You wanna buy new shoes? I can buy you new shoes if you feel- and if you want to it's okay." "No ma, it's okay." (R laughs) Okay fine. So I mean uh that thing even though the kid try to make him [feel] bad...

I: ** Ipad stops recording, Interviewer asks about discrimination within the Muslim community***

R: Yea know it's community. Mostly uh Palestine with Palestine, Indonesian with Indonesian, you know.

I: Mhmm.

R: Uh India with India, Pakistan- even though in mosques I-I always go to the mosque in [name of town].

I: Okay.

R: Because it's close from our house. For me as Indonesian, I mean mosque is our home so we can attend but when we see inside, there is two club groups.

I: Mhmm.

R: Which one we have to pick yea know, we don't want to pick anything ... but they also already have a line.

I: That's established.

R: Yea, so somehow it's kind of difficult for me to like ehh "like hey we have an event at the same time", same it's kind of difficult to have this- I have a friend here, I have a friend here "uh I just come in (unintelligible)". I have no idea which one, I just want to be friends to all to everybody.

I: Mhmm.

R: But it's complicated that's why - I don't come here- this uh it's very seldom for me to come to ISM because far.

I: Mhmm.

R: But as I know my friend also said same.

I: Okay.

R: Same. It's this this, this, this one I like them but (R laughs).

I: Mhmm.

R: I don't know the issue in this ISM but I know in [name of town] that's why uh I try to in the middle.

I: Yeah! Friends with everyone.

R: Yeah, right in the middle.