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Latino Families' Experiences with Autism Services: Disparities, Capabilities, and Occupational Justice

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Abstract

Rationale—This article examines six cases of publicly-funded Applied Behavior Analysis (ABA) therapy for Latino children with autism spectrum disorder (ASD) in order to contribute to thinking about occupational justice.

Objective—We consider in each case 1) how the families' experiences can be understood occupationally; 2) how ABA affected the *functionings* and *capabilities* of the children and their families; and 3) how the parents' accounts relate to *occupational justice*.

Methodology—This is an ethnographic study of six Latino families of children with ASD in Los Angeles County.

Findings—All families were offered ABA for their children, but five families experienced occupational challenges leading them to insist on modifications of ABA or opt out of the service.

Conclusion—Applying the capabilities approach can help to operationalize the concept of occupational justice as a tool to evaluate social policy across cases.

This paper examines six cases of California state-funded Applied Behavior Analysis (ABA) therapy for Latino children with autism spectrum disorder (ASD) (American Psychiatric Association, 2013). Its purpose is to contribute to thinking about occupational justice in relation to practice situations and public policies (Durocher, Gibson, & Rappolt, 2013;

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Research Ethics and Patient Consent: Ethical approval for the study was obtained from the University of Southern California Health Sciences Review Board (protocol # HS-13-00589). All adult participants reviewed and signed informed consent; parents who shared their children's health records also signed Health Insurance Portability and Accountability Act (HIPAA) forms. Parents gave assent for children with autism in the study, as no children were able to give written informed consent. Study personnel (transcribers) completed standard Institutional Review Board Human Subjects Protections and HIPAA trainings and certifications.

Stadnyk, Townsend, & Wilcock, 2010; Whiteford & Townsend, 2011). We make use of the capabilities approach in welfare economics to consider how California's policy affected the 'functionings' and 'capabilities' of the children and their families (Sen, 1999; see also Bailliard, 2016; Robeyns, 2000). The cases come from an ethnographic study of the experiences of Latino families obtaining services for their children with ASD (Angell, 2016).¹

In 2013, Latino children and adults with ASD were the largest ethnic group receiving services from California's Department of Developmental Services (DDS; 38.1%), but per-person spending on Latino individuals was among the lowest of all groups (16.6% lower than White individuals) (Leigh, Grosse, Cassady, Melnikow, & Hertz-Picciotto, 2016). This disparity exists despite a 1969 law, the Lanterman Developmental Disabilities Services Act (California DDS, 2015), which mandates that "an array of services and supports should be established which is sufficiently complete to meet the needs and choices *of each person with developmental disabilities...* to support their integration into the mainstream life of the community" (2015, p. 52; emphasis added).

Popular stereotypes attribute the disparities to Latino parents' supposed deficits in understanding how to secure services for their children (Zarembo, 2011). Language is often assumed to be a barrier for Latino families, as well as attitudes sometimes characterized as passive and fatalistic (Hunt & de Voogd, 2005). But in Angell's (2016) study, half of the bilingual Latino families opted out of ABA despite believing it to be potentially beneficial for their children, and two families required modifications before continuing. This paper examines data from interviews with the parents to understand the rationale for their decision to stop, modify or accept the treatment as offered.

ABA treatment is considered to be the 'gold standard' for ASD interventions, in part because it involves extensive documentation of quantifiably measurable outcomes (Lovaas, 1987; see also Leaf et al., 2016; Reichow, Barton, Boyd, & Hume, 2014). Consequently, parents are typically eager to secure ABA services for their children with ASD (Pickard & Ingersoll, 2016). The parents in Angell's (2016) study were well informed about ABA, and language was not a barrier. Angell showed that the parents in the study opted out of ABA² because of policy requirements concerning the delivery and dosage of treatment, and because of conflicts about the nature of the treatment itself, such as the apparent distress that it caused for the child.

The parents' reasons for opting in or out of services are relevant to thinking about the relationship between occupational justice and social policies like the Lanterman Act. Consequently, we examine the individual cases as they relate to occupation, occupational justice, and the enactment of policy:

¹This paper presents data collected as part of Angell's (2016) dissertation research. The study methodology was modeled after a federally funded study with African American families of children with ASD, Autism in Urban Context: Linking Heterogeneity with Health and Service Disparities (National Institutes of Health/National Institute for Mental Health, R01 MH089474, 2009-2012, O. Solomon, P.I.)

²The families were also offered other services, including occupational therapy and speech therapy, but did not appear to experience similar challenges with these interventions.

- First, we consider how the parents' accounts of ABA can be understood *occupationally*;
- Second, we turn to the capabilities approach to consider how ABA affected the *functionings* and *capabilities* of the children and their families;
- Third, we relate the functionings and capabilities suggested in the parents' accounts to *occupational justice*.

Disparities in Autism Services for Latino Children in California

The Latino population makes up the largest ethnic group in California (38%) (Pew Research Center, 2011), and Latino individuals qualify proportionately for state-funded disability services (38.1%) (Leigh et al., 2016). Under the Lanterman Act, 21 regional centers provide case management and distribute DDS funds to individuals with disabilities living in each regional center's catchment area. Recently, questions have been raised about whether enforcement of the Lanterman Act's existing regulations is fair and equitable (Vismara, Giovati, & Tadeo, 2013). In 2011, the *Los Angeles Times* reported gross disparities among California regional centers based on public data (Zarembo, 2011). For example, in 2010, the regional center in South Central Los Angeles, serving predominantly low-income Latino and African American individuals, spent \$1,991 per child with ASD between the ages of 3 and 6. This figure contrasts significantly with the regional center in Orange County, serving a higher percentage of wealthier White and Asian American individuals, which spent \$18,356 per child.

Public outcry prompted the formation of a California State Senate Taskforce to exercise oversight of the Lanterman Act. The Taskforce's recommendations focus on communication and outreach (e.g., families must receive information in their preferred language about “consumer rights”). In addition, regional centers are now required to report their annual per capita expenditures by race and ethnicity (California State Legislature, 2012). But the pattern has been found to persist: Regional centers still struggle to reduce disparities for Latino children (e.g., Eastern Los Angeles Regional Center, 2015; South Central Los Angeles Regional Center, 2015).

A 2009 amendment to the Lanterman Act prohibited the purchasing of treatments that have not been “scientifically proven” (California DDS, 2015, p. 122), and ABA is often viewed as the most ‘evidence-based’ ASD intervention because its approach strongly supports reporting quantitative data (Leaf et al., 2015; Reichow et al., 2014). The 2009 changes also mandated that parents actively participate in all ABA sessions (California DDS, 2015, p. 196), which typically take place in families' homes at a recommended frequency of 20-40 hours per week (Reichow et al., 2014).

Assessing Occupational Justice under California's Policy

How can policy like the Lanterman Act be evaluated in terms of justice? The Lanterman Act promoted *social justice* by mandating services for a disadvantaged group of people, those with developmental disabilities, whose ability to participate in society may require

specialized treatments. Further, the recently adopted oversight policy served *justice* by addressing disparities in services among Latino families and ensuring the fair universal application of the law.

Occupational justice is served if the Lanterman Act actually ameliorates the ability of individuals with a developmental disability to participate more fully in society. According to its definition, occupational injustices limit or exclude populations from participating in their society's valued activities based on categories such as race, ethnicity, class, gender, and disability (Stadnyk et al., 2010; Whiteford & Townsend, 2011). As a 1997 amendment to the Lanterman Act states:

The Legislature finds that the mere existence or the delivery of services and supports is, in itself, insufficient evidence of program effectiveness. It is the intent of the Legislature that agencies serving persons with developmental disabilities shall produce evidence that their services have resulted in consumer or family empowerment and *in more independent, productive, and normal lives for the persons served...* (California DDS, 2015, p. 50; emphasis added).

In a scoping review of the literature, Durocher, Gibson, and Rappolt (2013) called for occupational therapists to apply the concept of occupational justice to “tangible individualized and population based practice situations” with a view toward achieving “occupationally just policies and practices” (2013, p. 428). For the concept of occupational justice to inform policy, it must go beyond the individual to address social structural-level factors (Laliberte Rudman, 2013). Guidelines for comparing occupational injustices and evaluating remedies within or across populations, however, are still at a rudimentary stage (Bailliard, 2016).

The capabilities approach (Sen, 1999) is a framework for thinking about opportunities and outcomes for ‘doing and being’ among individuals and populations (Robeyns, 2000). The words ‘doing and being’ resonate particularly with the writings of occupational scientist Ann Wilcock (1998). But while the capabilities approach is relevant to occupational science and to occupational justice (Bailliard, 2016; Townsend & Marval, 2013; Townsend, 2012), concrete applications are needed. Toward that end, *we use the capabilities approach to operationalize the concept of occupational justice as a tool to evaluate policy across cases.* ‘Operationalize’ means here to provide useful elaboration that supports discernment and that has the potential for further development, including possible standards of measurement.

This understanding of operationalizing the capabilities approach appears to us appropriate according to Robeyns (2000). She notes that Sen's capabilities approach operates on three different levels: as a framework of thought, as a critique on other approaches to welfare evaluation, and as a formula to make interpersonal comparisons of welfare. Robeyns argues that for Sen, its most important use is as a framework “offering a way to think about normative issues and make evaluations. It provides a framework to analyse a variety of social issues, such as well-being and poverty, liberty and freedom, development, bias and inequalities, justice and social ethics.” (Robeyns, 2000, p. 3–4).

Robeyns (2000) notes that the major constituents of the capabilities approach are *functionings* and *capabilities*. Quoting Sen, she explains that functionings are more or less limited achievements, while capabilities are the more expansive opportunities that functionings enable.

Functionings are the ‘beings and doings’ of a person, whereas a person's capability is ‘the various combinations of functionings that a person can achieve’... ‘A functioning is an achievement, whereas a capability is the ability to achieve....Capabilities, in contrast, are notions of freedom, in the positive sense: what real opportunities you have regarding the life you may lead’ (Robeyns, 2000, p. 4).

Using this framework, we think of functionings in the data below as the specific behaviors or skills that a child might learn as a result of ABA therapy. We note that the provision of ABA therapy under state law is, in Sen's terms, a ‘commodity’ that must be converted into desired changes in functionings. The final and most important construct, *capabilities*, consists of bundles of functionings (Robeyns, 2000). Thus, capabilities would include expansion of the child's real opportunity to develop as a social being, starting with the family's ability to include the child in a functional social context. In other words, commodities such as state-funded ABA services for children should promote both functionings and capabilities—i.e., what the children and their families are free and able to be and to do.

Methods

A 12-month study was carried out by a pediatric occupational therapy clinician-researcher to learn about the experiences of Latino families receiving DDS services for their children with ASD in Los Angeles County (Angell, 2016). An ethnographic approach (Patton, 2014) was used to elicit descriptions of and observe families' experiences with ASD services in the context of family life. Family narratives were compiled into cases, compared, and interpreted in terms of ‘occupation’ (Clark et al., 1991; Yerxa, 1990; see also Segal & Frank, 1998); occupational justice (Stadnyk et al., 2010; Whiteford & Townsend, 2011; see also Durocher et al., 2013); and the capabilities approach (Robeyns, 2000; Sen, 1999; see also Balliard, 2016). A critical occupational science perspective, with its focus on power, provided a background for the study's focus on remedying disparities, promoting capabilities, and achieving justice for disadvantaged groups (Angell, 2014; Farias & Rudman, 2016; Frank, 2012).

Study Design

In Phase 1 of the two-phase study (Months 1-3), 12 families were recruited from a regional center in Los Angeles County. The cohort included 13 children with ASD. Participants included parents (N=19) and grandparents (N=1). Audio-recorded interviews took place twice with each family.

For Phase 2 (Months 4-12), six families were selected for intensive study from the initial cohort based on heterogeneity sampling, their stories representing diverse experiences (Patton, 2014). Data collection included: (1) Audio-recorded parent interviews; (2) video-recorded (where possible) observations of family occupations (e.g., family meals and

shopping trips) and activities related to the child's services (e.g., therapy sessions and meetings at school); and (3) children's health records (documents related to the child's services; Angell & Solomon, 2014).

The Phase 2 cohort included seven children with ASD (4 boys, 3 girls); 11 parents (6 mothers, 5 fathers); and two ABA practitioners recruited through one family.³ Of these, one ABA supervisor was interviewed and one ABA therapist was observed during a session.

Eligibility and Recruitment

After Institutional Review Board (HS-13-00589) approval, the regional center sent recruitment letters to randomly selected families in their database who met eligibility criteria: Self-identification as Latino or Hispanic; at least one bilingual (English/Spanish) parent; and child 8-years-old or younger with a documented ASD diagnosis by a licensed professional. The first 12 eligible families to respond by phone or email to the first author were included in the study and signed informed consent and confidentiality protocols.

Data Collection and Analysis

Data for the six cases presented here include 44 hours of audio- and video-recorded data (28 interviews, 10 observations), 29 ethnographic descriptions (fieldnotes)⁴ recorded after visits with families; and 23 health records related to the children's ABA services. Data were transcribed verbatim and pseudonyms used for all identifiable information. Visual timelines, chronologies of events related to the children's services, were developed in Phase 1 and used for member-checking (Patton, 2014). NVivo 10 software was used for qualitative coding, keeping families' stories intact (Reissman, 1993). Health records supplemented and triangulated the data.

Findings

Of the six families in the intensive Phase 2 of the study, Families 1-3 opted out (i.e., accepted and then quit or declined altogether), Families 4-5 insisted on modifications of the intervention, and Family 6 accepted ABA as offered. In each family situation, we consider specific problems mentioned by the parents in *occupational* terms (cf. Clark et al., 1991; Segal & Frank, 1998; Yerxa, 1990; see Supplemental Table 1). We consider the *functionings* and *capabilities* (Sen, 1999) at stake for the individual child and for the family, based on the parents' reports. In the Discussion section, we will consider how the capabilities approach relates to evaluating California's policy in terms of occupational justice.

Family 1: "I just need a break."

Fabiana was recently separated from her husband, experiencing health issues, and caring for three young children with little family support. After her two oldest children, Mateo Jr. and Isabella, were both diagnosed with ASD, the regional center offered ABA evaluations for

³We aimed to capture multiple perspectives by recruiting practitioners via invitation from the families, but only two were recruited (see Angell, 2016 for details about recruitment challenges).

⁴Fieldnotes (Emerson, Fretz & Shaw, 2011; Sanjek, 1990) were audio-recorded after each visit with the families. Some visits included an interview and observations. Hence, the number of separate entries to the body of fieldnotes (N=29) is fewer than total number of interviews and observations (N=38).

them, but Fabiana declined. She was familiar with ABA because her husband previously worked as an ABA therapist.

Mateo Jr., almost 5 years-old, had difficulty at school and family events due to behavioral challenges. Isabella, age 3 years, 9 months, often ran off suddenly, sometimes darting into the street. Fabiana thought ABA could help with these challenges, but she was concerned that the “really intense” commitment that ABA required would disturb the current, somewhat delicate, orchestration of family life. The children had just adjusted to their structured school schedule, and Fabiana thought they needed unstructured time after school, not “learning time 24/7.”

Although Fabiana thought that ABA might enhance the children's functionings, the risks for the family outweighed the possible occupational benefits. Fabiana considered the occupational balance of the children and herself:

[The school is] pushing me to get [ABA] because they say...that's going to be helpful. And I get it. I get it. But it's a lot of commitment...and I'm tired, you know?...I'm at the point where I'm just like, “Oh my god, I just want a break a little bit.” Just for a little bit. I just need a break. I don't want people coming [to my house]...I want [the kids] to get the help. But right now, at this point, and like maybe the next couple months, I don't want that.

Family 2: “They were telling me the cancellations were too much.”

Rafael Sr. worked in retail while his wife Nicole cared full-time for their son, Rafael Jr., who at age one was a “bundle of welcoming joy.” They were devastated when Rafael Jr. lost his language and eye contact, becoming “really closed in his own little shell.” Concerned, the family began early intervention, including ABA. Although they said that Rafael Jr.'s ABA therapists “helped him a lot,” Nicole thought, “It's a *lot* for him.” She opted for fewer and shorter sessions than he qualified for.

It was difficult for the family when Rafael Jr. was upset, as he was unable to verbally express his needs. He cried frequently during ABA sessions. Nicole said, “We've been cancelling a lot lately for ABA because he's been triggered, and I don't want him to have a bad session and score low, or, you know, I don't want for them to trigger him more.”

Nicole's framing of Rafael Jr. as receiving a ‘low score’ suggests that she did not perceive pushing him until he was “triggered” as an approach drawing upon his strengths. The parents observed both positive and negative occupational outcomes for Rafael Jr., but they cancelled sessions when, in their estimation, the negative outcomes outweighed the achievement of certain functionings.

After the birth of their second son, Andrew, Nicole wanted to take a break from ABA but said she felt pressured by the ABA supervisors to not cancel any more sessions:

The supervisors, they weren't very understanding. And especially when I had [Andrew], I asked like, “Can we take like a week off?...We need to get adjusted, it's a new baby.” And no, they didn't want to give me that. They were telling me that

the cancellations were too much. Like, I just had a baby! He's not sleeping well, I'm not sleeping well, no one's sleeping well. I don't want nobody here right now...I gave them too many chances, so I was just done with them.

The delivery of the intervention was not flexible enough to enable the orchestration of ABA into the family's routines. When imbalance occurred, they stopped ABA.

A year later, Nicole reported considering a different ABA company, hoping for a different experience. She was apprehensive, however, about having similar negative outcomes (crying) for Rafael Jr., and about his balance of 'work,' rest, and play:

So it's going to be a big change because we haven't had somebody here for the last couple months....We have a routine now like, "Oh yeah, go do your thing," you know, "Get undressed, sit down, eat your snack," you know, "Don't worry about anything. Watch your cartoons, play with your toys." Now it's going to be more structured and...I can already see he's going to have a fit...He cried a lot during other therapies...I just don't want him to cry anymore...So I'm curious to see how it's going to start up again.

Family 3: "I try to keep everyone happy. I'm exhausted by the end of the day!"

Sarah, a single mother, worked full time, attended college, and cared for her daughters, Gabriela and Camila. She was eager for Gabriela, who had recently been diagnosed with ASD, to start ABA because Sarah hoped that if Gabriela learned to speak, it would reduce her tantrums. Sarah told the first author a recent story: Gabriela was crying at bedtime, trying to leave the bedroom. Sarah thought she wanted to go to the front door to play outside. After an hour of tears, Sarah, frustrated, opened the bedroom door. Gabriela ran into the living room to get a comfort item she liked to sleep with. With it, Gabriela immediately fell asleep. If Sarah had known what Gabriela wanted, the agonizing hour could have been avoided. Sarah said, "I think my priority...is for her to grow, and for me to learn to work with her."

Gabriela started ABA, but after a few weeks, they stopped. For Sarah, the required parental participation was "just too much," constituting orchestration challenges and occupational imbalance for herself and Camila, her typically developing daughter, who expressed the need for more of Sarah's attention. Sarah said:

I was always with [Gabriela], I mean Monday through Sunday, from morning to night. And it gets very overwhelming after a while. And I was working and going to school, and then Camila, she's told me so many times, "You have no time for me, you're always worrying about Gabriela."...I try to keep everyone happy...I'm exhausted by the end of the day!

Sarah weighed the occupational losses for the family against the lack of observable improvement in Gabriela's functionings. Gabriela behaved well during sessions, which Sarah attributed to the novelty of having a therapist to play with her and bring "fun toys." Sarah did not see improvement in Gabriela's challenging behaviors outside of ABA sessions and discontinued the treatment.

Family 4: “We shaped that to a large degree.”

When Daniel, the father of this family, lost his job at a financial firm, he took on childcare responsibilities while Sofia, the mother, continued working as an elementary school teacher. Around that time, their son Danny, age 2, qualified for 15 hours of various therapies per week through the regional center. Daniel remembered thinking: “When does he have time to be a kid? Fifteen hours!...It's not that you don't want the help, but it's overwhelming.”

The family began ABA and occupational therapy but delayed accepting other therapies they were offered, such as speech therapy, in order to maintain balance in their son's occupations. Danny's parents were also concerned about the family's occupational balance, given their son's emotional distress during ABA:

Daniel: It was the worst thing I've...I was telling her -, it was horrible.

Sofia: It's hard. Two hours of screaming and-

Daniel: Three hours!

Sofia: And screaming, crying,

Daniel: Three hours! For four days a week, you know?

Sofia: You know, nonstop and it's like-

Daniel: Five days a week! Back then it was 15 hours a week.

Sofia: And as a parent, you're like, “Oh my gosh...Should I walk in there and see what's going on? Can I go in there?”

Daniel: ...You're frustrated. It's your 2-year-old son. And somebody's *Pushing* him like this, so it's difficult.

Sofia: It's difficult to watch.

The negative outcomes for Danny (crying) left Daniel doubting whether ABA was enabling the achievement of functionings for Danny. However, when he and Sofia began to see positive outcomes, such as the first time Danny pointed to make a choice between two objects, their dedication to ABA deepened.

After some time, the parents noticed that the approach was no longer motivating Danny. The therapist asked Danny the same question over and over, even if he responded correctly. Sofia and Daniel believed that this technique, perhaps intended to build compliance, only frustrated Danny, who had minimal verbal skills but an immense capacity for learning.

Just as Sofia and Daniel noticed these negative outcomes, they had a substitute therapist who used a more “naturalistic” style of ABA, teaching skills within the context of play or family activities. When she left and a new therapist began implementing the previous, rigid style of ABA, Sofia and Daniel firmly insisted on a naturalistic style more congruent with their “family philosophy.”

Commenting on a more child-directed ABA treatment session that the first author observed, Sofia said, “We shaped that to a large degree.” She described how building functionings and capabilities for Danny depended on the family situation: “We know what's best for him. He's our son, and this has to work for our family.”

Family 5: “For my son, this isn't quite going to work.”

Sabine, an administrative assistant, and Kyle, a warehouse worker, noticed that their only son Jayden did not smile or make eye contact as a baby. At age 22 months, Jayden began

early intervention. When he turned 3, Jayden was diagnosed with ASD and began ABA. Sabine and Kyle thought that the first ABA therapist, whose energy and liveliness was similar to their own style of engaging Jayden, was “phenomenal” and able to “reach” their son. Sabine described how the therapist used a strengths-based approach to expand Jayden's functionings:

If Jayden knows how to say any words now...it's because of his ABA. They are really good with...their strategy with Jayden...,finding the-, it's not even words, but the sounds that he makes best and making words out of them...He'll [say “oooh”] with no problem. So they started out with, “What does a cow say?” And he can't say “Moo,” but he will say “Mmm” (pause) “oooo.”...He knows how to do that, but it's because of the amazing work of those awesome ABA people.

When the therapist was promoted and Jayden got a new therapist and supervisor, however, he “regressed,” increasing in self-injurious behaviors. The new supervisor told the parents to ignore Jayden's tantrums, a technique intended to withhold reinforcement for undesirable behaviors. Kyle described why this approach was wrong for them:

We came to the realization that...all the acting out and everything else [Jayden] was doing, he was doing it not for attention, but he was trying to communicate he was upset at something. And when we ignored it, it wasn't working in his benefit...He was actually getting worse, because all he wanted to do was communicate he was angry or he didn't like something...I had to go back with the supervisor and let her know, you know, for my son, this isn't quite going to work out having, you know, necessarily ignoring these, because he's actually trying to communicate that he's angry.

The family's view of Jayden, as having a rich inner subjectivity and capacity for communication, was embedded in all aspects of family life. A video-recorded observation of the family on a shopping trip to Target shows how Sabine and Kyle, despite Jayden's minimal verbal skills, interpreted each of his behaviors as intentional and communicative:⁶

When he walked toward the music aisle, Sabine said, “Look, he really-, his favorite area.” As he pulled the shopping cart toward the aisle, she said, “See? He's already pulling us over.” As Jayden entered a music aisle, Kyle, as if narrating Jayden's voice, said, “I know it's here somewhere!” When Sabine pointed out the DVD aisle she thought Jayden was looking for, and he did not respond with recognition but looked toward a display of books, she said, “He's like, ‘I'm not looking for that, mom!’”

Sabine and Kyle asked their ABA company for a “loud, active, boisterous” therapist because, Kyle said, “That's what [Jayden] responds to.” Sabine added, laughing, “Maybe because Mommy and Daddy are very loud.” They were pleased with their next therapist, whose style of engaging Jayden was similar to theirs, including a strengths-based approach of treating his behavior as communicative. Jayden's tantrums diminished, enabling him to gain new skills (functionings).

⁶The description of the family outing to Target is a summary of a scene from the video transcript.

Family 6: “She was progressing, catching on.”

When Olivia was not speaking at 18 months of age, she was referred to early intervention. Her mother Miriam worked for a city Parks and Recreation Department, while her father Dan alternated between construction work and caring full-time for Olivia and her 6-year-old brother Zack.

Olivia began speech therapy at a “hospital-ish setting” where she was not comfortable. During the first session, Olivia “was really resisting, she would scream the whole time.” Miriam said, “The first time we went to speech, the lady was already like, ‘Oh, I don't know if it's going to work.’ We're like, ‘We just got here!’”

Miriam and Dan thought that the speech therapist, like a psychologist who had previously assessed Olivia for eligibility, “gave up too fast” when Olivia did not follow their directions. If the therapists had tried to “get her comfortable,” they said, Olivia was capable of participating.

Miriam and Dan requested to have speech therapy at home, and shortly after, Olivia also started ABA at home. The family developed a close relationship with the ABA therapist. Even though Olivia sometimes “screamed” during ABA sessions, her parents trusted the therapist to handle the situation. The family valued Olivia's ABA program because they observed that the therapist did not “give up on” Olivia but patiently worked with her even through tantrums.

The family also valued ABA because of the way that it enhanced Olivia's functionings. In particular, they were amazed at how quickly Olivia was able to identify words on flashcards and memorize shapes and colors:

The other day I was here and [the therapist] was doing the shapes with [Olivia], so she has flashcards and she goes, “What's this? What's this?” She did like 10 shapes, like oval and heart and star, and Olivia knew them all. And I was like (gasps), and I was sitting like ready to cry.

For these parents, the positive outcomes for Olivia (memorization, increase in language) and positive outcomes for the family (observing that the therapist did not “give up on” Olivia) outweighed the negative outcomes (crying during sessions). They stayed with the same therapist until they moved to another town. Nine months later, as the study ended, they were starting ABA with a new company.

Discussion

To understand occupational justice in these cases, we need to ask whether the policy did what it was intended to do for the children, which was to support their capabilities—that is, their “integration into the mainstream life of the community” (California DDS, 2015, p. 52). All parents reported at least some improved functionings for their children resulting from ABA, such as the reduction of challenging behaviors and improved ability to learn and participate in family life.

But most parents decided to modify or opt out of California's ABA services, doing so mainly because they felt they were unable to integrate the services into their family life. Some parents described difficulties in orchestrating the family's occupations because of the requirement to be present for ABA sessions or the inflexible routine of scheduled treatments. Others expressed concerns regarding the occupational imbalance for the family and the child. Some voiced the desire to protect their children's emotional wellbeing during ABA therapy.

We do not claim that these data represent a distinctively Latino pattern of childrearing or that such concerns account for disparities in ASD services for Latino children. It is conceivable that our findings are more representative of challenges faced by single or newly separated parents, for example, or families that prefer a less authoritarian approach to child rearing.

As we know from a family-centered approach in pediatric services, however, a child's treatment is always embedded in the family context that mediates the benefits of therapy. This would be true of any therapy, not only ABA, and any diagnosis, not only ASD. The child's capabilities must be understood in relation to family occupations (activities, routines, and narratives) (Lawlor & Mattingly, 2014). If the services do not work for a family, and the family then cancels or stops therapy, the opportunity to promote functionings and capabilities is lost, and the intent of the policy is not fulfilled. At the population level, this may constitute an occupational injustice.

Conclusion

We presented six cases of Latino families' experiences with ABA services provided under California law in order to understand why some parents chose to withdraw from or modify the services. First we analyzed the parents' interviews occupationally. Then we applied the capabilities approach (Sen, 1999; Robeyns, 2000) as a framework of thought to examine the cases and compare them in terms of the Lanterman Act's mandate to promote occupational justice.

We suggest that occupational justice requires evidence that the *functionings* of a child (behavioral skills) can be bundled into *capabilities* (the freedom to be and to do). When parents cannot incorporate the services into their lives occupationally, their children are unable to benefit either from improved functionings or enhanced capabilities.

The capabilities framework helps us to work out answers with empirical data from Angell's (2016) study to questions raised by recent contributors to the literature on occupational justice. Balliard (2016) suggests the need for shared definitions to identify and compare actual instances of occupational injustice. Durocher, Gibson, and Rappolt (2013) propose the need for empirical studies of occupational justice in relation to practice situations and public policy. This paper has attempted to move the conversation forward on occupational justice by presenting empirical cases relating to practice situations and policy and by defining and articulating the capabilities approach as a comparative framework.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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References

- American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. Washington, DC: American Psychiatric Association; 2013.
- Angell AM. Occupation-centered analysis of social difference: Contributions to a socially responsive occupational science. *Journal of Occupational Science*. 2014; 21(2):104–116. DOI: 10.1080/14427591.2012.71123
- Angell AM, Solomon O. The social life of health records: Understanding families' experiences of autism. *Social Science & Medicine*. 2014; 117:50–57. DOI: 10.1016/j.socscimed.2014.07.02 [PubMed: 25042544]
- Angell AM. Understanding bilingual Latino parents' experiences of their children's autism services in Los Angeles: A critical ethnography (Unpublished doctoral dissertation). Los Angeles, USA: University of Southern California; 2016.
- Bailliard A. Justice, difference, and the capability to function. *Journal of Occupational Science*. 2016; 23(1):3–16. DOI: 10.1080/14427591.2014.957886
- California Department of Developmental Services. Lanterman Developmental Disabilities Services Act and related laws. 2015. Retrieved July 19, 2016, from http://www.dds.ca.gov/statutes/docs/LantermanAct_2015.pdf
- California State Legislature. Welfare and Institutions Code. Section 4519.5. 2012. Retrieved July 19, 2016 from file:///C:/Users/Amber/Downloads/WIC_4519.5..pdf
- Clark FA, Parham D, Carlson ME, Frank G, Jackson J, Pierce D, et al. Zemke R. Occupational science: Academic innovation in the service of occupational therapy's future. *American Journal of Occupational Therapy*. 1991; 45(4):300–310. [PubMed: 2035601]
- Durocher E, Gibson BE, Rappolt S. Occupational justice: A conceptual review. *Journal of Occupational Science*. 2013; 21(4):418–430. DOI: 10.1080/14427591.2013.775692
- Eastern Los Angeles Regional Center. Total annual expenditures and authorized services by ethnicity or race. 2015. Retrieved July 19, 2016, from <http://www.elarc.org/home/showdocument?id=6362>
- Emerson RM, Fretz RI, Shaw LL. Writing ethnographic fieldnotes. 2nd. Chicago: University of Chicago Press; 2011.
- Farias L, Laliberte Rudman D. A critical interpretive synthesis of the uptake of critical perspectives in occupational science. *Journal of Occupational Science*. 2016; 23(1):33–50. DOI: 10.1080/14427591.2014.989893

- Frank G. The 2010 Ruth Zemke lecture in occupational science occupational therapy/occupational science/occupational justice: Moral commitments and global assemblages. *Journal of Occupational Science*. 2012; 19:25–35. DOI: 10.1080/14427591.2011.607792
- Hunt LM, de Voogd KB. Clinical myths of the cultural “other”: Implications for Latino patient care. *Academic Medicine*. 2005; 80(10):918–924. [PubMed: 16186611]
- Laliberte Rudman D. Enacting the critical potential of occupational science: Problematizing the “individualizing of occupation.”. *Journal of Occupational Science*. 2013; 20(4):298–313. DOI: 10.1080/14427591.2013.803434
- Lawlor MC, Mattingly C. Family perspectives on occupation, health, and disability. In: Boyt Schell BA, Gillen G, Scaffa ME, editors Willard & Spackman's Occupational Therapy. 12th. Baltimore, MD: Lippincott Williams & Wilkins; 2014. 150–162.
- Leaf JB, Leaf R, McEachin J, Taubman M, Ala'i-Rosales S, Ross RK, et al. Weiss MJ. Applied behavior analysis is a science and, therefore, progressive. *Journal of Autism and Developmental Disorders*, Advance on. 2015.
- Leigh JP, Grosse SD, Cassady D, Melnikow J, Hertz-Picciotto I. Spending by California's Department of Developmental Services for persons with autism across demographic and expenditure categories. *Plos One*. 2016; 11(3):1–23. DOI: 10.1371/journal.pone.0151970
- Lovaas OI. Behavioral treatment and normal educational and intellectual functioning in young autistic children. *Journal of Consulting and Clinical Psychology*. 1987; 55(1):3–9. DOI: 10.1037/0022-006X.55.1.3 [PubMed: 3571656]
- Patton MQ. *Qualitative research and evaluation methods*. 4th. Los Angeles: Sage Publications, Inc; 2014.
- Pew Research Center. Demographic profile of Hispanics in California, 2011. 2011. Retrieved July 13, 2016, from <http://www.pewhispanic.org/states/state/ca/>
- Pickard KE, Ingersoll BR. Quality versus quantity: The role of socioeconomic status on parent-reported service knowledge, service use, unmet service needs, and barriers to service use. *Autism*. 2016; 20(1):106–115. DOI: 10.1177/1362361315569745 [PubMed: 25948601]
- Reichow B, Barton EE, Boyd BA, Hume K. Early intensive behavioral intervention (EIBI) for young children with autism spectrum disorders (ASD): A systematic review. *Campbell Systematic Reviews*. 2014; 9doi: 10.4073/csr.2014.9
- Reissman CK. *Narrative analysis*. Newbury Park, CA: Sage Publications, Inc; 1993.
- Robeyns I. An unworkable idea or a promising alternative? Sen's capability approach re-examined. *Discussions Paper Series, Center for Economic Studies, Katholieke Universiteit*: 2000. Retrieved from <https://feb.kuleuven.be/drc/Economics/research/dps-papers/dps00/dps0030.pdf>
- Sanjek R, editor *Fieldnotes: The making of anthropology*. Ithaca, NY: Cornell University Press; 1990.
- Segal R, Frank G. The extraordinary construction of ordinary experience: Scheduling daily life in families with children with attention deficit hyperactivity disorder. *Scandinavian Journal of Occupational Therapy*. 1998; 5(3):141–147. DOI: 10.3109/11038129809035739
- Sen A. *Development as freedom*. New York: Anchor Books; 1999.
- South Central Los Angeles Regional Center. Total annual expenditures and authorized services by ethnicity or race. 2015. Retrieved July 13, 2016 from <http://sclarc.org/pdf/ServByEthnicity.pdf>
- Stadnyk R, Townsend EA, Wilcock AA. Occupational justice. In: Christiansen C, Townsend EA, editors *Introduction to occupation: The art and science of living*. 2nd. Thorofare, NJ: Prentice Hall; 2010. 329–358.
- Townsend EA. The 2010 Townsend & Polatajko Lectureship: Boundaries and bridges to adult mental health: Critical occupational and capabilities perspectives of justice. *Journal of Occupational Science*. 2012; 19(1):8–24. DOI: 10.1080/14427591.2011.639723
- Townsend EA, Marval R. Can professionals actually enable occupational justice? *Cadernos de Terapia Ocupacional Da UFSCar*. 2013; 21(2):215–228. DOI: 10.4322/cto.2013.025
- Vismara L, Giovati B, Tadeo C. A preliminary report by the Taskforce on Equity and Diversity for Regional Center Autism Services. 2013. Retrieved from <http://autism.senate.ca.gov/sites/autism.senate.ca.gov/files/1542-SAutism%26relatedDisordersfortheweb.pdf>
- Whiteford GE, Townsend EA. Participatory Occupational Justice Framework (POJF 2010): Enabling occupational participation and inclusion. In: Kronenberg F, Pollard N, Sakellariou D,

editors Occupational therapies without borders: Towards an ecology of occupation-based practices. Vol. 2. New York: Churchill Livingstone Elsevier; 2011. 65–84.

Wilcock AA. Reflections on doing, being and becoming. Canadian Journal of Occupational Therapy. 1998; 65(5):248–256. DOI: 10.1046/j.1440-1630.1999.00174.x

Yerxa EJ. An introduction to occupational science, a foundation for occupational therapy in the 21st century. Occupational Therapy in Health Care. 1990; 6(4):1–17. DOI: 10.1080/J003v06n04_04 [PubMed: 23931133]

Zarembo A. Warrior parents fare best in securing autism services. Los Angeles Times. 2011. Dec 13, Retrieved from <http://www.latimes.com/local/autism/la-me-autism-day-two-html-htmlstory.html>