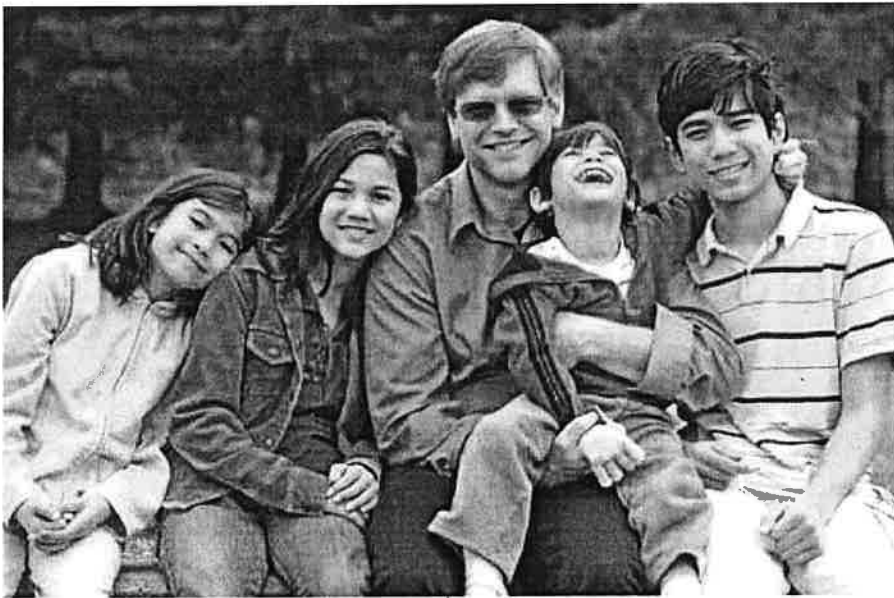# Co-producing Culturally Relevant Services with Families of Young Children with Disabilities

BY MARISA MACY, BEVERLEY ARGUS-CALVO, SARA TORRES HERNÁNDEZ,
& RAMÓN LEONARDO HERNÁNDEZ COLLAZO

To effectively serve young children with special needs, it is essential that early childhood service providers infuse cross cultural competencies into child and family services. Children benefit when services are culturally and linguistically meaningful (Mendoza, Argus-Calvo, & Tafoya, 2006; World Health Organization (WHO) & United Nations Children's Fund (UNICEF), 2012). Language and cultural considerations are needed to co-create culturally relevant services for young children with disabilities and their families (Lynch & Hanson, 2011; Pierson, Myck-Wayne, Stang, & Basinska, 2015).

Approximately 22% of children in the U.S. speak a language other than English in the home (Annie E. Casey Foundation, 2018). Urban, suburban, and rural areas are increasingly more ethnically and racially diverse. For example, the Hispanic population in the U.S. has grown from approximately 4% in 1970 to over 17% (U.S. Census Bureau, 2016). Young children are one of the largest percentages of the population of Hispanic origin in the U.S., and growing. American population studies predict that one in three children will be from a Hispanic family by 2050 (Patten, 2016; Stepler & Brown, 2016). Therefore, it is crucial that early childhood programs are equipped to address the needs of young children and their families from diverse backgrounds, as well as those with special needs.

Importance of Research for Family Services

Longitudinal seminal studies such as the Carolina Abecedarian project (Campbell & Ramey, 1995; Campbell, Ramey, Pungello, Miller-Johnson, & Burchinal, 2001), the Syracuse Family Research Program, and Project CARE (Burchinal, Campbell, Bryant, Wasik, & Ramey, 1997) show the positive impact that early childhood programs can have on culturally and linguistically young children and their families, particularly those with special needs. These studies have shown the importance of collaborating with families to create positive learning outcomes for young children. Early childhood programs like the ones mentioned above are based on sociocultural theory, which supports the necessity of creating an environment for children that focuses on the family (Vygotsky, 1978). The family is the most important relationship in a child's life. For example, newborns are biologically wired to seek out adult faces and mimic caregivers' facial expressions while toddlers copy familiar and unfamiliar motor behaviors of caregivers' when they play a game of peekaboo. Preschoolers learn acceptable behavior from their caregivers such as when taking turns during a conversation at story time. Children's growth and development are contingent upon the people in their life (Guttentag et al., 2014; Harry, Rueda, & Kalyanpur, 1999).

The Need for Family Services

When service providers deliver family-centered practices they are addressing the varied and complex needs of young children and their immediate family members (Grisham-Brown, Hemmeter, & Pretti-Frontczak, 2005; Harry, 1997; Turner, Guzman, Wildsmith, & Scott, 2015). Determining the priorities and concerns of the family are ways to serve the child. Practices that are family-centered build on family strengths. Listening to what the family needs and responding effectively are ways to co-create useful services. Cultural reciprocity and encouraging interactions with families can be informed by degrees of mutual cooperation to empower families. Partnerships are enhanced when professionals and families have the tools to co-produce positive experiences (Bagnato, 2007; Dennis & Stockall, 2015). Cross cultural competency is critical in building rapport and effective collaborative relationships with families from diverse linguistic and cultural backgrounds (Collazo,

2013; Guttentag et al., 2014; Harry, 2008). Before service delivery, service providers should consider antecedents that will foster effective collaboration.

Co-production. We define co-production as the process used by professionals and families for coming together to create services to support young children. Co-production is a strategy for collaboration among individuals seeking a common goal (Jakobsen & Andersen, 2013; Haumann, Güntürkün, Schons, & Wieseke, 2015; Ledger & Slade, 2015). Other sectors use co-production to co-produce a service. For example, many people use co-production when getting a haircut. The hair stylist and client talk about desired outcome, customer concerns and priorities. The final result is dependent upon both entities. Language and cultural barriers must be overcome in order to co-create optimal outcomes. For instance, if the hairstylist and client are unable to communicate effectively, it will be difficult to achieve what they want.

Professionals and families can co-produce services because one knows the child intimately (i.e., the family), and the other is skilled at service delivery (i.e., professionals). Professionals and families need one another and can work in collaboration to provide the child what he or she needs. Communication with one another needs to be clear and understandable for co-production to be a successful service delivery strategy. In order to co-produce meaningful services for young children with disabilities, at least two elements should be considered: antecedents and role expectations.

Antecedents. Cross cultural competency is critical in building rapport and effective collaborative relationships with families (Collazo, 2013; Guttentag et al., 2014; Harry, 2008). Before service delivery, service providers should consider antecedents that will foster effective collaboration. Collaboration is a purposeful activity (Bricker, Macy, Squires, & Marks, 2013). Some antecedents may include, but are not limited to: (a) understanding individual family differences (e.g., demographics, needs/attitudes, abilities, and knowledge), (b) service related expectations (e.g., time, effort of investment, reliability, predictability, speed of service delivery, access to services, enjoyment, outcomes desired), (c) family-provider relationship (e.g., length, atmosphere, and family's social supports), (d) service characteristics (e.g., complexity, organizational requirements

of participation), and (e) service provider behavior (e.g., participation encouragement, investment in family socialization and education). Professionals may individualize practices to reflect the cultural and linguistic needs of children and families.

Role expectations. Another important activity prior to early childhood services, or during, is to determine the family's expectations for roles. Engaging families to co-produce service experiences requires a clear understanding, as well as communication around service delivery (Haumann, Güntürkün, Schons, & Wieseke, 2015; Lynch & Hanson, 2011). Clarity of roles and respect for family preferences will foster understanding needed for effective collaboration. Parental perceptions are integral in co-producing services (Alvira-Hammond, & Gennetian, 2015; Hunton, 1996; Ledger, & Slade, 2015; Troye & Supphellen, 2012). The aim is to develop congruency between actual and perceived expectations. Collaborative efforts can be mapped onto a variety of services which may include on home visits, natural environments, or clinical settings. The next section of this paper shows how these themes and quality indicators are illustrated with two families who both have a child with Down syndrome.

Examples of Families

Theoretical underpinnings like sociocultural theory (Vygotsky, 1978), as well as longitudinal studies support the co-production framework. Co-production of early childhood services occurs when professionals and families collaborate. Positive early childhood outcomes may be possible when culture and language are considered when co-producing services and programs with children's families. Co-production can take place anywhere. We present an example of co-producing services with two families both with young children who have Down syndrome. Rico's family lives in the U.S. while Karen Daniela's family lives in Mexico. Each family has their own service provider and co-produce services for their respective child. These are only samples and not meant to be a standard approach to follow. Both show an example of co-producing services with families in different contexts.

Rico. Rico was born with Down syndrome. He is 18-months and lives with his mother, father, and 5-year-old sister Maria in the Pacific Northwest. The family speaks Spanish at

home. Jessica, the service provider, facilitated the development of Rico's Individualized Family Service Plan (IFSP). Mealtimes are a priority for his parents and as such oral motor goals and objectives were created.

On the day of the home visit, Jessica joins the family for dinner. Rico's parents asked her previously if she could focus on ways to support the family during meal times. Rico has a sensitive gag reflex, and an enlarged tongue which sometimes makes it difficult for him to talk and eat. Jessica gathered prior information about antecedents and learned the family's expectations for service delivery. Jessica prepared for the home visit by gathering support materials in Spanish from Colorín Colorado, a bilingual website with resources for parents and professionals.

Mr. and Mrs. Garcia set a plate at the table for Jessica. Rico sat between Mrs. Garcia and Jessica at the circular table. After saying grace, everyone ate dinner. Jessica asked if they could start the meal doing their usual routine. Mrs. Garcia fed Rico using a spoon. Jessica noticed the spoon was presented in front of Rico's face at eye level. He would look at each spoonful and then start to gag as the food entered his mouth.

Jessica debriefed with Rico's parents about all the strengths she had been observing during meal time including the benefits of knowing two languages. She also discussed how to best help Rico with his meal when eating with a spoon. Jessica suggested to try presenting the spoon to the side of Rico's mouth instead of the front. She started by presenting the spoon of food from the side. The first attempt resulted in no gagging. Subsequent bites were taken by Rico without any gagging. Jessica handed the spoon to Rico's parents who also fed him without Rico gagging on his food. "Muy bien," [very good] said Mrs. Garcia. Role release occurred when Rico's parents implemented the intervention rather than Jessica. When a professional exchanges and/or shares expertise with another (e.g., parent, another professional, etc.) about an intervention strategy role release can occur where the professional is no longer the only person who can implement the intervention (Johnson, Rahn, & Bricker, 2015). The simple adjustment of spoon placement seemed successful that night, but Mrs. Garcia was concerned about what would happen with other foods with different textures. Jessica and Mrs. Garcia planned to check with each

other in the next day by phone to see how things progressed, as well as later in the week.

Karen Daniela. Living in a small community called Sisoguichi, located in the region of the Copper Canyon in the state of Chihuahua (in Northern Mexico) Karen Daniela is a preschooler born with Down syndrome. Her family is Tarahumara (also known as Raramuri) who are the indigenous population native to the region. Luz Maria has been Karen Daniela's primary caregiver and interested in her well-being and education since she was 2-years-old as her biological mother suffers from substance abuse. Karen Daniela is not legally adopted. However, Karen Daniela considers Luz Maria to be her mother.

Karen Daniela's parents visit her when they are able, especially the father. They live alone in a home that has been "loaned" to them on the outskirts of the City of Chihuahua. Their economic situation is very limited. Luz Maria works as a housekeeper when able and she mostly lives on donations that are given to her by people who know her. She does get some government support monthly for basic goods, and Karen Daniela receives a scholarship to pay for her school.

Karen Daniela has an intellectual disability and physical attributes characterized by Down syndrome that include maxillofacial hypoplasia, a heart condition, and poor vision. Luz Maria reported that Karen Daniela is enrolled in a private school that only serves students with Down syndrome, which she has attended since she was 3-years-old. Only for a short period of time she transferred to a public school that serves children with varying disabilities. But Luz Maria preferred the private school due to the limited attention that Karen Daniela received.

Luz Maria indicated that she is pleased with the attention that Karen Daniela gets at school in terms of the educational structure that is provided and the progress she has observed in the development of her social skills and work habits that have helped Karen Daniela tend to daily life skills. Karen is able to care for herself, is developing independence, and the foundations for future work skills.

Reflection

The examples show co-production of services for children with Down syndrome in the U.S. and Mexico. Noteworthy is that each child had a family member who was co-producing early childhood services with an early childhood professional. For example, in the case of Rico, Jessica individualized her practices to tailor services that reflected his home culture and dual language household. Karen Daniela, like Rico, was able to experience home and school connection. Positive child outcomes may be possible when families and professionals co-produce culturally and linguistically relevant services. Familiarity with global perspectives is an advantage for serving children and their families.

Conclusion

This article shared information about co-producing culturally and linguistically relevant services with families. The main point of our article was to define co-production, demonstrate how to co-produce services with families, and then show how it can be use in varied contexts. The two examples show different ways to co-produce services that provide optimal opportunities to meet the child and family needs. The practices may need to be tailored to reflect the cultural and linguistic needs of children and families, as well as professionals. Children will benefit when families are supported. Families deserve high quality services that are culturally and linguistically relevant.

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