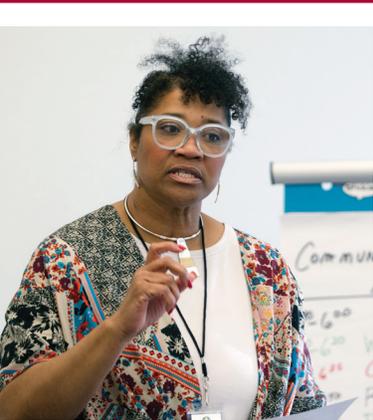


SPRING 2019

# ENGAGE!

*Co-created knowledge serving the city*



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# IUPUI

1969–2019

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# welcome

DR. KHAULA MURTADHA, EDITOR

Welcome to the inaugural publication of ENGAGE! IUPUI's first journal dedicated to community-engaged and community-based participatory research. IUPUI is recognized locally, nationally, and internationally as an urban-serving research and health sciences university. This issue is dedicated to celebrating the campus' 50th anniversary and recognizing its decades of public facing scholarship.

Community-engaged research (CER) in city settings is focused on the processes and results of inquiry-focused relationships between community partners and representatives of the university. Guiding principles of social justice, mutuality, and reciprocity are practiced through dialogue, co-learning, and long-term commitments to participation. In the urban setting, community-engaged research is attentive to the rich diversity of cultures and languages as well as poverty and wealth; to privilege and marginalization. CER practices are equity-driven and intentionally change-oriented. This means acknowledging issues of power and the critical importance of cultural humility.

The external peer reviewers were deliberate in their assessments of submissions that were attentive to these issues. Manuscripts that demonstrated the central involvement of community partners and advanced the guiding principles of community-engaged scholarship were given favorable consideration. This resulted in the contributing authors for this issue making a strong case for community/university trust building and community

self-determination. The articles demonstrate how working together, we can better support the well-being of families, from the infant to the elder.

Many thanks are due to Amy Warner, IUPUI Vice Chancellor for Community Engagement, and Simon Atkinson, our Vice Chancellor for Research, who gave the editorial team their unwavering commitment and support for carrying the journal's vision forward. Our IUPUI editorial team, Drs. Silvia Garcia, Carolyn Gentle-Genitty, Jack Turman, and our dedicated graduate assistant Kevin Hillman, an IUPUI School of Education Urban Education Studies doctoral student, dedicated countless hours to ensuring that this issue advances the importance of CER. The editorial team not only conducted preliminary reviews of journal submissions but solicited external peer reviewers from around the country and mentored our Office of Community Engagement (OCE) professional staff and PhD students, Richard Bray, Myron Duff, and Nicole Oglesby. Our national associate editors Drs. Sarah Stanlick, Javiette Samuel and Tyann Parker Dominguez gave much needed guidance and editorial support.

The online presence of ENGAGE! could not be possible without the careful attention given to its development by Ted Polley, the IUPUI University Library Social Sciences & Digital Publishing Librarian, and our incredibly supportive OCE communications colleague, Annie Goeller.

Enjoy, ENGAGE! and give us feedback at [engagejo@iupui.edu](mailto:engagejo@iupui.edu).

# bienvenidos

DR. KHAULA MURTADHA, EDITOR

**B**ienvenidos a la publicación inaugural de ENGAGE! La primera revista de IUPUI dedicada a la investigación participativa basada y comprometida con la comunidad. IUPUI es reconocida local, regional e internacionalmente como una universidad orientada a la investigación y ciencias de la salud que presta servicios a comunidades urbanas. Esta edición está dedicada a la celebración del 50 aniversario del campus en reconocimiento a décadas en la academia pública.

La investigación comprometida con la comunidad (CER, por sus siglas en inglés) se focaliza en los procesos y resultados de las relaciones orientadas por la investigación que realizan miembros de la comunidad y representantes de la Universidad. Los principios rectores de justicia social, mutualidad, y reciprocidad se practican a través del diálogo, el co-aprendizaje y de compromisos duraderos de participación. En los entornos urbanos, la investigación comprometida con la comunidad presta atención a la diversidad de las culturas e idiomas, a la pobreza y a la riqueza, así como al privilegio y la marginalización. Las prácticas de CER están impulsadas por la equidad e intencionalmente orientadas al cambio. Esto significa reconocer las relaciones de poder y la importancia crítica a la humildad cultural.

Los revisores externos deliberadamente evaluaron que los artículos enviados trataran estos temas. Se dio una consideración favorable a manuscritos que demostraran el involucramiento de miembros de la comunidad y que promovieran los principios que subyacen a los estudios comprometidos con la comunidad. Esto dio lugar a la contribución de autores para esta edición que aportaran argumentos sólidos para

el fomento de la confianza entre la comunidad y la universidad y la autodeterminación de la comunidad. Los artículos demuestran cómo al trabajar juntos, podemos apoyar y mejorar el bienestar de las familias, desde los más pequeños hasta los más ancianos.

Muchas gracias a Amy Warner, Vicerrectora de Participación Comunitaria en IUPUI, y a Simon Atkinson, Vicerrector de Investigación, quienes dieron al equipo editorial su inquebrantable compromiso y apoyo para llevar adelante la visión de la revista. Nuestro equipo editorial en IUPUI, los Doctores: Silvia García, Carolyn Gentle-Genitty, Jack Turman y nuestro dedicado asistente doctoral Kevin Hillman, estudiante del doctorado en Educación Urbana en la Escuela de Educación en IUPUI, dedicaron innumerables horas para garantizar que esta edición promoviera la importancia de CER. El equipo editorial no solo realizó revisiones preliminares de los artículos, sino que también contactó revisores externos en todo el país y asesoró a nuestro personal profesional y estudiantes de doctorado de la Oficina de Participación Comunitaria (OCE), Richard Bray, Myron Duff y Nicole Oglesby. Nuestros editores asociados los Doctores Sarah Stanlick, Javiette Samuel y Tyan Parker Domínguez dieron la muy necesaria orientación y apoyo editorial.

La presencia en línea de ENGAGE! no podría ser posible sin la cuidadosa atención puesta en su desarrollo por Ted Polley, el Bibliotecario en Ciencias Sociales y Publicaciones Digitales de la Biblioteca Universitaria de IUPUI, y nuestra increíble colaboradora y colega de comunicaciones de OCE, Annie Goeller.

Disfrute, ENGAGE! y envíenos sus comentarios a [engagejo@iupui.edu](mailto:engagejo@iupui.edu).

# Vice Chancellor's letter

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AMY CONRAD WARNER

Urban communities bring together myriad populations, global experiences, rich traditions, and a desire to make a difference in the world. This combination of creativity, diversity and positive energy positions us well to address challenges and issues that face urban communities.

While urban centers bustle with economic vitality, the urban core citizenship can experience health disparities, high poverty rates, and chronic conditions that resist resiliency. At the same time, higher education institutions are home to scholars and students who are passionate about finding solutions to society's most complex problems. Through partnerships, research projects and collective impact strategies, collaborative efforts, with strong representation from the community, can create effective ways to observe and understand trends, find life-saving solutions, and develop predictive models to improve the health, safety and quality of life of community members.

As a major urban research institution with a Carnegie Classification as an engaged institution, IUPUI and our community partners enjoy 50 years of engagement experiences. IUPUI releases this first edition of the ENGAGE! Journal to highlight the multitude of community-university engaged participatory research activities in the central Indiana region.

Since urban settings provide such a wide tapestry of challenges and strategies we are entrusted with preparing our faculty and developing mutual agendas with community partners that harness and embrace innovation and cultural traditions that result in meaningful solutions to the issues that face all of us in our community.

We look forward to many more issues of ENGAGE!

## ARTFUL SPACES/SAFE PLACES: A GALLERY PROVOKES VOICES THAT INTERROGATE COMMON NARRATIVES OF LATINO IMMIGRANT CHILDREN

CINDY BIXLER BORGMANN AND STACY PEÑALVA

### ABSTRACT

What do Latino immigrant children's voices say as they are provided a safe community space to be heard and soft clay through which to speak? Through art work, focus groups, gallery exhibitions, and filtering data (Peñalva, 2018) this critical ethnographic research (Madison, 2012; Merriam & Tisdell, 2016; Wolcott, 2008; Thomas, 1993) exposes the complex political nature of linguistic, cultural, and national negotiations in which Latino children and their families in this study engage daily. This work troubles stereotypic mainstream narratives (Dillard, 2012; Hooks, 1990, 1994; Janks, 2010) and points out the need for strong community/university collaborations to impact the excavation of deeper understandings of people in our neighborhoods. This ethnographic portrait of families, part of a larger study, involved the community director in an urban Spanish speaking church and faculty from literacy education and visual art at IUPUI. In this study children created clay objects called "hanging journals" during a summer program. These clay artworks acted as semiotic mediators (Kress, 2010; Pahl & Rowsell, 2012; Borgmann & Berghoff, 2005) for voices of this group—voices which routinely go unheard, or are devalued. In other words, the clay became a container for meaning and was imbued with life stories and memories of the young artists. Using theoretical frameworks from the fields of literacy and art, layered

with ethnographic tools of observation, dialogue, reflection, interview, video, and analysis, the volume on these important and complicated voices was turned up to hear buried stories and to interrogate commonly accepted narratives that swirl around Latino immigrants and their families.

This study provides a peek into the authentic narratives of children as they share daily navigation across national, cultural, and language boundaries and shows the power of the arts to communicate across contested spaces - spaces of fear, tension, and resistance. This study embraces the necessity of authentic university/community collaborations as a two-way street to understand and empower Latino youth, to better prepare future teachers as agents of change, and to expose versions of immigrant ways of being and knowing that are misconstrued.



*Stacy: Are you all able to speak Spanish in school?*

*Carla: Oh yes, we speak Spanish with our friends.*

*Stacy: Really! So your teacher lets you speak Spanish at school?*

*Carla: Well, we hide under our desks and that's where we speak Spanish with our friends at school.*

Peñalva, 2016. Focus group with children from first generation, Latino immigrant families



Stacy has known Carla since she was born. Her parents are immigrants from Honduras, and have been members of the church (where the community center site of this research is housed) for many years. While she has worked among the Latino immigrants at this site for decades as a pastor's wife and teacher, this was one of her first conversations with the children at the site as a researcher.

The literal as well as the metaphorical impact of Carla's statement did not go un-noticed. Here the voice of a strong, bilingual and confident little girl was being "shoved under the desk," hidden, devalued, not welcomed in that school room. There was a strong disconnect between the community center and the school; between a place where immigrant voices were heard and welcomed and a place where native language and all the identity and family history wrapped up in that tongue were rendered unimportant and forced to be hidden. Subsequent research grew from this desire to hear and value the voices of immigrant children and their families—what would these voices say if they had a safe place to speak? How could the volume on these voices be turned up to understand their deep undertones, histories and nuances?

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## SITUATING THE STUDY

This paper, part of a much larger research study, explores how spaces can be created to truly hear voices of immigrant children and their families. The study strains to hear what those voices are *really* saying by examining the children's artwork and the voices that flow from that work, and interrogates ways that academia and community spaces can work together to hear, value and learn from those voices.

## THE RESEARCHERS

### *Stacy*

I was born in Pennsylvania and grew up in a monolingual, predominantly white, middle class world. Upon attending college, I met people from other countries who spoke other languages and had much different histories than mine. I married a man from Honduras, and went to live in the mountains outside the capital city of Tegucigalpa for 5 years. There I lived my life as "the other," learning a new language and muddling through an unfamiliar culture. My two oldest sons were born there, and I watched with wonder as they learned two languages simultaneously and navigated the countries and cultures of their birth with apparent ease. This is where my curiosity began regarding the ways that people navigate daily across the borders of language, nations and cultures - translingual, transnational, and transcultural.

For the last 30 years I have worked in a church and community center where first generation Latino immigrant families congregate and form bonds, sharing histories, languages and struggles. In recent years I have worked among this group as the pastor's wife and community director but also as a researcher, digging into stories they willingly share and trying to honor their voices—all the while in awe of their resilience and resourcefulness as they carve out a life in this country (Peñalva, Coggin and Medina, 2014; Peñalva, 2016). My stance as an advocate and partner with those who "come to a new awareness of selfhood, looking critically at the social situation in which they find themselves" (Freire, 1970/2009) is unapologetically evident in this research.

### Cindy

I was born in Indianapolis and, like Stacy, grew up in a monolingual, predominantly white, middle class world. As an art teacher I taught in the suburbs of Indianapolis, completed graduate school working with colleagues from different cultures, nations, and languages, and entered higher education at Indiana University Purdue University Indianapolis. For the last 30 years I have taught in the urban teacher preparation program at Herron School of Art and Design working with schools and teachers across the city. Our school now sits where a long history of immigrants once resided and our campus is neighbor to Latino residents. Like many major cities, Indianapolis schools have experienced a rapid increase in immigrant populations, though curricula have not been as quick to change. In my work with urban teachers I have seen the struggle of crossing language barriers in a scripted curriculum and empathize with students and teachers as they negotiate new terrain. Through my research, studying the impact of arts-integrated curricula in general urban classrooms, I have seen the power of the arts in providing equal access to knowledge where high stakes testing, dominant language curricula have denied it to all but the mainstream culture. I have witnessed the transformative power of the aesthetic experience afforded through the arts, to unleash personal voice, nurture agency and empathy, and change dispositions in students and teachers. Teachers have used this newfound agency to push back against test prep, pre-packaged curricula that privilege one way of knowing, and to bring student voice back to their classrooms (Borgmann & Berghoff, 2013). Art provides an avenue for personal expression, empathy,

and meaningful narrative often denied learners outside the dominant language. Providing space in classrooms for a visual language where all can communicate helps break down stereotypic narratives and biases in both learners and teachers.

The arts allow teachers to cross language barriers, to find space in the general curriculum for children's voices, to honor multiple ways of knowing and being, and to provide more equitable and caring learning communities for all. (Borgmann & Berghoff, 2011, 2013).



*If teachers have passion for the arts, for storytelling, and for the cultural histories of their students they will push art into the cracks of tightly packed curricula to elicit evocative responses from those students and allow everyone to be heard.*

Through this work Stacy, a language arts doctoral student at the time, invited me onto her doctoral committee to join in this study on the voices of Latino youth using art media. On visiting her youth group at the community center it was apparent these children were comfortable in their "habitus" (Bourdieu, 1998/1991) space of the church - at home with the Director. As the gatekeeper of this group, Stacy provided access that would be the envy of any teacher/researcher. Here students spoke openly and candidly of their opinions, faith, and their responses to the day - in English and Spanish. We interpreted the work of Maria Lomas Garza's work, an artist who paints the rich stories and histories of Latino culture,

and the children painted important objects, food, and traditions from their daily life. As these children painted, defenses were down and the voices flowed in this safe, faith-based community space. Stacy continued curating that safe, artful space using children's clay objects strung together to tell stories of daily life – life as immigrants. These clay objects became “hanging journals” operating as visual text and are the focus of this present manuscript.

### THE SITE

To the west of campus sits an old church, built in 1924 and a longtime home to immigrant families in the city. For 30 years Stacy and her pastor husband have served a dominant Latino population at this site with 150 church members from many different Latin American countries and a community center which provides classes and services for the neighborhood around the building. The church/community center is a place where Latino immigrant families come to share language, faith, and fellowship. They share a similar story in their struggle to arrive at this city and make a life here. They hope for a better future for their children, many who were born here in the U.S., resulting in mixed status families or families where the parent(s) are *undocumented* and the children are citizens.

This church is an in-between space where English, Spanish and the hybridization (Medina, 2010; Canagarajah, 2013) of the two are routinely heard through the building. It is a place where children eat pizza and play on their phones while parents prepare tamales and laugh in Spanish. A place where the mixing of cultures, languages and national affiliations create a “zone of contact” (Pratt, 1991) allowing and

even welcoming the bumping together and jostling around of cultures, languages, ways of doing and knowing. It is an in-between space where these *transnavigations* -- flowing through available cultures and languages, become common and every day. For example, when the children were shown a picture of food (see photo 1) and asked to talk about it, they noted nothing out of the ordinary. The Mexican crema and typical American macaroni and cheese sit on the shelf side-by-side at a neighborhood store just down the street from the community center as unceremoniously as the children in the church mix their stories from native lands and current residence. This is a powerful narrative, yet has become so embedded into the lives of the people in this “in-between” space that they do not notice it as conversation-worthy. It just IS.



(Photo 1: The ordinary side-by-side nature of transnavigation as seen on a neighborhood store shelf -- a reflection of how immigrant children understand their lives.)

How could spaces be opened to explore the complex choreography of this intricate dance through

languages, cultures and national identities which seemed to be such a natural way of life for the children? How could the volume on voices at this church/community center be turned up to allow typically non-sanctioned topics to be interrogated freely (Jones, 2004)? Only by genuinely and profoundly hearing these voices could one come to know (Palmer, 1993) and understand this complex group who are often characterized by stereotypical or simplistic narratives.

### THE PARTICIPANTS

The research discussed in this publication is part of a much larger study but due to limited space, we will *focus* our discussion around data obtained from one child (Maria). However, each of the 20 children-artists who participated in the original study share certain characteristics with Maria. They are all children from first generation Latino immigrant families. All know the story of their parents' journey to this new land—some are more horrendous than others. Each one is bilingual, with Spanish as their first language. Each child's family is involved in this church and each child attended a summer program at the community center located there. It was during the summer program that the children engaged in an art making project called "hanging journals" that became a focus of this research.

All the children in the annual summer program were between the ages of 6 and 12 during this project. Maria was 8 at the time. When Maria speaks, it is hard to tell that she spoke Spanish exclusively for the first few years of her life, since she speaks English as clearly as any other L1 English speaker. Maria was born in the U.S. Her parents are from Mexico, and while her father

has permission to live and work in this country, her mother does not. She has two brothers, one older and one younger, who were also born in the U.S. Maria's family is typical of many families at this church. Her parents work long, hard hours. Her father has a painting business. Her mother helps with the business and does other work as it is available. They own a home not far from the church, and are deeply involved in the life of the church. Stacy had known Maria for 4 years at the start of the research since she had participated in many of the programs at the community center. This study using art as a mediator (as a conduit to hear voice) helped to understand and know her in ways not previously imagined.

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### CRITICAL ETHNOGRAPHIC METHODOLOGY/DATA ANALYSIS

Ethnography as a research methodology is devoted to describing the ways of life of human kind -- in this case, children from immigrant families. Goodall says that "voice is the sound of the ethnographic world being called into being" (Goodall, 2000, p. 139-140 as cited in Madison, 2012, p. 228). In this study, criticality blends with ethnography as the work involves an effort to confront issues of power and injustice through the sharing of voice...



*The critical ethnographer resists domestication...by using the resources, skills and privileges available to her to make accessible...the voices and experiences of people whose stories are otherwise restrained and out of reach. This means the critical ethnographer contributes to emancipatory knowledge and discourses of social justice.*

*Madison, 2012, p. 6*

During the summer program, the children participated in a curricular activity called “hanging journals.” Here they were asked to think about their lives and to remember important events. Next they thought of a way to represent this event by forming clay objects. These objects were hung from sticks decorated with colorful yarn that created a visual story of the child’s life -- a text full of storied significance (see photo 2).

Each child was asked to talk about his/her hanging journal with a videographer who created a video with snippets from each interview.



(Photo 2: Maria’s hanging journal)

A gallery was created where the journals hung alongside words the child used to talk about that journal (see photo 3). A video monitor in the gallery

showed the movie created during the interviews on a loop. The gallery was called “Voices/Voces.” It had a grand opening and became a popular space in the church/community center for both the children artists and other visitors.



(Photo 3: The Gallery called *Voces/Voces* located at the church/community center)

A few months after the gallery installation went up, Stacy held a focus group with a dozen of the artists. We met in the gallery and talked about their art and topics that emerged from their hanging journals. Shortly after that, another focus group with 8 of the artists’ mothers provided yet another layer of data to understand the deep historical narratives contained in the artwork. Transcribed voices were coded for emerging themes and axial analysis -- examining the data across all the sets collected -- (Merriam, 1998; Cresswell, 2007; Patton, 2002) revealed explanations that interrogated the simple “one story” of immigrant families, providing a peek into what it truly means to live as a child in such a family.

## HEARING MARIA

### THE HEART

Maria chose to put a heart on her hanging journal (see photo 4).



(photo 4: Maria's clay heart)

She briefly told the videographer about this part of her journal:

*Maria: I put a heart because my family is always with me.*

We might expect this comment from an eight-year-old girl as she talks about her mother -- this feeling of closeness and love. But as Maria's voice continued, other nuances and more obscured narratives seem to peek out from those sweet words. Why did she and many of the other children seem to emphasize this sense of *always*? Linda and Gabby, for example, also

seemed to focus in on the importance of permanence in family love...

*Linda: This is my family and I will cherish them forever.*

*Gabby: And I put three family, and it's important to me 'cause if something happens to my family, it's my family still.*

I wondered if I was hearing a barely audible message of family togetherness as a tenuous or fragile condition.

Later, during the artist focus group in the gallery, Maria's artful voice was articulated in deeper ways, as she turned up the volume on the message mediated by her clay heart. Apparently, the heart told of a story deeper than just affection shared by a young girl and her family.

*Maria: My mom uses the other side of this (she is wearing a necklace with half a heart) and this reminds me of her when I'm at school. 'Cause I always wear it, but if I wear it inside the shower it will get ruined.*

The clay seems to be speaking louder now -- it is actually a model of her necklace, a physical connection between the two -- a way to feel her mother close even when they are apart. Now it becomes clearer why she said the heart meant that her family is *always* with her.

Later in the artist focus group, Maria uncovered the meaning contained in that little clay heart even further. Listen to the voice of this citizen child from an immigrant family as she and her friends got around to the topic of deportation:

*Maria: We can't go to Mexico. My mom said we are not going to go anywhere. We are just going to stay here until they kick us out of our house.*

While this may be an unsanctioned topic in many settings, here at this in-between space (Soja, 1996; Gutierrez, 2008) where citizen children live in mixed status households, the topic was not only sanctioned but a daily lived experience. All the children have been touched in one way or another by deportation. Those who have parents without proper documentation take on the life of hiding and fear so common of undocumented people. Maria, a U.S. citizen, hides in her house, close to her mother with whom she shares the heart, in fear that they will be kicked out.

She is not the only child who lives this fear...

*Gaby: Yeah, that's what I'm worried about. A couple just came to my house and say you need to go back to where you are from and your kids too. You'd have to live with others, other members. You might have to go to a place where kids don't have parents.*

The most terrifying scenario for the children in this group seemed to be the possibility of separation from their parents. They talked openly about the fear of being taken away from parents who could be deported. This fear became clearer and the aching anxiety and love pulsing in the clay heart more profound as Maria's mother spoke at our mother's focus group.

*Gracia (Maria's mother): The question you asked, Miss Stacy, about it being a carga (burden or heavy load) that we give our children knowing if we are legal. For me, yes, it was a*

*carga because when she (Maria) listened to things in school, she cried. She would come home crying saying, 'I don't want them to send you to Mexico and with whom will we live?' And I told them not to worry because your dad at least has a permit. If something would happen, if I would not come home, don't go out in the street looking. Just wait for your dad and he will take care of things because one never knows what could happen.*

The voice flowing from the mediator -- that clay heart -- became more meaningful after hearing the words and seeing the heart as situated in Maria's lived histories and everyday realities.

*Maria: I put a heart because my family is always with me.*

The art along with the dialogue around it turned up the volume on the voice of this young girl from an immigrant family. Now we hear her saying that the clay heart presents narratives that swirl around a piece of jewelry she shares with her mother -- narratives that speak about fear of separation, of hiding in the house together, of hoping to be together *always*. As this little girl sits in a classroom each day, wearing her precious half-heart necklace, how many know about her hidden terror, her obscured narratives of potential separation from her family on any given day, her fear about what she might encounter as she arrives home from school?

## **THE FLAG**

Maria also chose to put an American flag on her hanging journal. Of all the many memories or important events that she could have included on her journal, she chose to craft the flag (see photo 5). In

fact, many of the children voiced deep connections to the United States. Notice the clay is structured with American stripes colored in red and white but in place of stars is a field of green, the color of the flag of Mexico – a blending of cultures.



(Photo 5: Maria's flag)

She spoke of her flag:

*Maria: This is the flag of the United States. Every time I go to school in the morning I say the Pledge of Allegiance.*

In fact, Maria pledges allegiance to the flag which stands for the same government from which she hides, which might snatch away her home and her family. This citizen-child lives in the world of the undocumented with all the feelings of powerlessness and fear wrapped up in that existence. Does her teacher hear the conflicted voice as she wears a heart that assures connection to her mother, while pledging allegiance to the same country that could rip her mother away? In the everyday-ness of Maria's recitation is a political message that could only be heard as the artful mediator opened up safe spaces at

this community center for talk that is often unwelcome or misunderstood in schools (Garcia, 2002). Maria's voice now sounds loud and political -- the outcry of a citizen-child who has put on the fear and powerlessness of her "illegal" parent. It is a voice that grapples with both entitlement and fear. This is a narrative not often acknowledged in the typical *immigrant story*.

### **THE T.V.**

Maria chose to put a television on her hanging journal to represent this part of her life story (see photo 6). She states...

*In this one I tried to draw me watching T.V. with my family. Sometimes I watch movies with my family and it makes me feel good.*



(Photo 6: Maria's T.V. artwork)

Her story around family togetherness is contained in this artwork, creating a picture of warm times, gathered around the T.V., watching favorite movies in her home. Her mother's voice from the parent focus group adds complexity to this simple narrative providing deeper insights...

*Gracia: For me, I watch cartoons with the children, because they repeat and repeat so that children can learn things, and for me it is easier. I have been here almost 14 years and don't know how to speak English, but it's because I was always watching everything in Spanish, until my husband said, 'No more. We are going to take away all that so you can learn English watching cartoons with the children.' And so now I watch T.V. in English. I cannot speak, because I get nervous and tongue tied, but I understand most of what they are saying. If I put a movie and watch with the children, I can understand 80%. I have realized that it is a good way to learn English, watching the television with the children in English. And when I say a word wrong, they correct me.*

In this new portrait, painted with deeper and more historical colors, Maria and her family sit on the couch to watch T.V. not just for fun times but for learning a language that provides access to the dominant culture and to power (Bourdieu, 1983/1991). Re-interpreting that clay piece, we now hear a story of a mom who has been willing to surrender her place as the one in charge, and become the student. She watches children's programs and learns a new language from her children who have become the patient and capable language instructors. This is the "resistance

story" (Whitehead, 2012, p 36) that when told counters stereotypic narratives and positions Latino youth as assets (Cosier, & Gude, 2012). This story was completely missed in that clay piece, until re-interpreted and shared through dialogue during the parent focus group. As parents spoke together, sharing common stories and engaging in dialogue full of trust and caring with others who share similar narrative, they provided a profound and powerful backdrop to meanings contained in the children's clay artifacts!

This little clay medallion unwrapped a story full of unexpected scenes: a mom watching cartoons together with her children, children patiently helping her to understand the English dialogue, children softly and maybe laughingly correcting mom's mispronunciations, and lots of good feelings and love. This scene is one that makes Maria "feel good."

Maria's hanging journal was tacitly telling this story of family support and caring all along, but the buried and obscured narrative was not uncovered until all the voices were heard and the volume carefully turned up. By considering the data across all available sets (the artifact, the children's stories and the parents' voices), powerful counter-stories could be heard.

### **THE BORDERLANDS CREATED AT THE GALLERY THRESHOLD**

The children in this group live in the borderlands -- linguistically, culturally and geographically -- navigating the choppy waters of their lives as children who have ties to more than one language, historical storyline, and national affiliation (Campano, 2007). But these are not the only kinds of borderlands these children pilot through. Sometimes the children in the research study constructed their

own borders, and these borders reflected lived stories, real life struggles, and the enactment of agency.

For example, the threshold into the gallery -- a place that contained the life stories of the children molded into clay -- was constructed as a line that was meant to keep some in and some out. The children defined the boundary line at the doorway and acted as the sentries there. Maria and many of the other children understood this borderland, and were clear about who could cross and who could not. Their comments seem to be emblematic of a much larger narrative that examines the notions of *knowing* and *caring* (Noddings, 1984) -- things that Maria and her friends wish they had more of at school. They believe the gallery may be the type of place to elicit that love and compassion.

*Stacy: Why do you think it's important that other people from outside our group see your work [in the gallery]?*

*Maria: So that they can see that we worked hard, cause at school let's say someone comes to church from your school and you tell them that you have been working really hard on your art, and they don't believe you, but if they come and you can prove it cause it's in the gallery.*

The gallery seemed to be a place where the art was validated -- those who came across the borderlands would be able to believe that you really did work hard. Those who did not come in may not believe that you had worked hard.

*Stacy: What would be important for your teacher to know about you that maybe you never had a chance to tell her or she never asked you?*

*Maria: Like, more stuff about you, 'cause when I go to school I just tell them about my week and I want them to know more about me.*

*Hector: Sometimes people don't know you ... your teacher could know that you are unique.*

*Gaby: If my teacher came in here and it was just me and her I would tell her about my life and about my journal and now she can understand what happens in my life and home and at school.*

This community space promoted conversation around the need for *knowing* and *caring* in the form of teacher action (Noddings, 1984, p. 10) so coveted by the children. One wonders if Maria's teacher realized how desperately this little artist longed to be known in deep and intimate ways. Maria wanted her teacher to know more than simply what she does in her week. Maria goes on to converse with her friends in the gallery, noting the frustrating disconnect that she feels with her teacher.

*Maria: One day my teacher was just eating an apple, that's all, just eating the apple. And I said I wanted to tell her something and she was like, "I'm eating right now."*

*Stacy: Maybe she can't eat and talk at the same time.*

*Maria: But when we are eating she bothers us!*

*Gaby: Yeah, because they just don't want to hear it -- they say "hold on, I'm busy" but then you look at them just doing nothing and you're like, come on!*

While the teacher's voice seems to be considered important and valid, Maria feels like she is being pushed away and that her voice does not matter.

In this case the powerful teacher demands respect at all times (demanding attention when she speaks and silence when she does not want to listen), while the docile student is expected to comply - here the teacher talks and the students meekly listen (Freire, 1970/2009). Various children in the group used their voice and the notion of the gallery border to express their yearning for a teacher who hears them. They would gladly open the border of the gallery for this teacher and invite her to truly hear their voices.

There is quite a contrast in reaction when the artists were asked what they would say if President Donald Trump came into the gallery -- across that same borderline. Reactions ranged from running away, to lying about the hanging journal to telling him to get out or locking him in the gallery and not letting him out. These citizen children held firm to secure a boundary where powerful forces threatening their families attempted to cross. In fact, Maria had a question for President Trump:

*Stacy: Maria, what would you tell Donald Trump?*

*Maria: Why are you going to build a wall?*

She questioned the construction of a border wall, just as she constructs her own border, trying to keep out a government that she sees as a threat to her family unity.

The children defined and decided who would be welcomed across this border and who would not. Maria and the other children longed for the teachers to cross the border into the gallery, to hear about their journals and truly get to know them -- something that had not been happening in school. On the other hand, they guarded the border from government and power,

pushing the President of the United States out and telling him lies.

*Stacy: Kenzie, what would you want Donald Trump to know about you.*

*Kenzie: Nothing!*

*Gaby: If Donald Trump came in here I would open up the thing and throw him out of the thing.*

*Camila: I would run away, because one of my friends got deported back to Mexico.*

It is the same space, the same border, and yet extremely different decisions and demonstrations of agency at the line. The same space defined by the same border became at once a place of welcome (for teachers) and a place of contention and dispute (for the president).

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#### DISCUSSION: PERSONAL NARRATIVE AS COUNTER DISCOURSE

The arts are forms of communication about things that count (Anderson, et.al., 2010) Anderson & Milbrandt, 2005, Dewey, 1958/1934). Through the mediated sign of visual imagery artists of all ages shape media into personal expressions that dance around the core of life -- big issues such as identity, power, or place. (Walker, 2001, Robertson & McDaniel, 2017)

These hanging journals had culturally significant meaning encoded into the bits of clay that told complex stories of their identity. In a classroom where teachers are taught to unwrap these artworks to hear the powerful narratives of all children, the results can be transformative.

Humans construct what they know and who they are through narrative -- or story -- in word, text,

gesture, visual imagery, or song. As a way of knowing, narratives seek to establish personal truth. Narratives emerge from an individual's reflections on life. As we tell our stories, we organize and re-organize our memory, and construct our own reality (Bruner, 1985). It is not only critical that students have opportunities to create these narratives, but that they have time to reflect on and dialogue with others about these stories.

These Latino children share their fears, struggles, and joys as they work, each with unique families and stories, but a common theme begins to emerge. The cultural histories of separation from border crossing and the threat of deportation or separation from loved ones is a constant fear. Yet, these children build bridges of resilience around the threat that looms close, finding normalcy in this way of life. It is through the voices of children that we see beyond the black and white of immigration. These children are active participants that do not take family responsibility lightly -- they shoulder the burden together.

The Latino children in this study do not see themselves or their families as helpless victims of a political system or as ones who break the law. Their voices offer counter discourses to stereotypic narratives of Latino youth by the mainstream culture (Alarcón, 2014). They are not slow, uneducated, lazy, or disrespectful. They love school, follow the rules, and desperately want to be valued as worthy, respected contributors of their class. They are resourceful, exuberant, and full of agency. And, they have taken on heavy family responsibilities as they navigate through the in-between spaces of different cultures, nations, and languages. Spaces that are further troubled with

the social stereotypes of an often-misinformed mainstream culture.

Curricula focused on high stakes testing of the dominant culture privilege one way of being in the world. They create invisible boundaries which leave little room for empowering projects such as these in schools. As O'Loughlin (2009) explains,

Schools are the chief ideological instruments of governments ... and are therefore likely to be held on a tight ideological leash. Teachers are part of the establishment, and any subversive leanings that they might have are typically disciplined through extensive mandated curricular requirements and onerous regulation that appears to be increasingly global in reach. (O'Loughlin, 2009, p. 146)

However, teachers can find gaps in the daily curriculum through which to integrate the arts and support the personal narratives of all students, not just those of the dominant culture. Providing curricular spaces for these personal narratives or counter discourses offers a prime opportunity to break down stereotypes and turn up the volume on all voices. Here O'Loughlin (2009) explains the critical role of the community group:

Such counter discourses need to emerge organically out of community members and must be cultivated from the felt needs of particular groups rather than being handed down from on high. O'Loughlin, 2009. p. 147)

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## IMPLICATIONS FOR COMMUNITY/ACADEMIC COLLABORATIONS

This community center space, an in-between space with regards to languages, cultures and national

ties, presents certain affordances when it comes to accessing voices of children from immigrant families.

In the case of Maria and the children in the summer program at the community center, narratives were permitted to unravel out of hanging journal -- stories that may not have been expected and that are often not welcome in schools or more formal settings. The arts intersecting with open and safe community space sanctioned topics that may often be absent from discourse in academic settings. These rich stories, full of insights around what it means to be a child in a mixed status Latino immigrant family, are beautiful and powerful but often hidden or buried in the regimentation of school or academia. Through collaborative art making and subsequent dialogue and reflection around artwork, stories spilled from the artists. The stories told of struggle, fear and agency. They told of critical political issues of deportation, family separation, the upside-down picture of family power regarding language, and the real ways that children construct and act as sentries to their personally created borderlands.

There is nothing mindless or disconnected in the art experience. When children form clay into significant shapes from their world a story evolves. The form becomes a visible placeholder for this thought. Each time we encounter that form we bring new information to it, but the form remains to invite us in -- the viewer or the artist -- for yet another interpretation. The beauty of art is that it is presentational -- its very form presents the idea providing wide access not bound by language (Eisner, 2002). Another critical part of this study was the dialogue shared while interpreting the clay pieces as

conversations that might have otherwise never been spoken flowed from reflecting around the art and the themes it posed.

This dialogue around the stories with which the clay was imbued gave the works meaning that was mediated in such a way that we -- the outsiders -- could "get it." Not to be overlooked, however, is the way that the art allowed the children and parent participants to gain deeper understanding of themselves, their conditions and their connections with others of like history. While the project informed us -- the outsiders -- it also provided a consciousness raising (Freire, 1970/2009 experience for those engaged in dialogue around the art, unraveling and reflecting upon their own stories collaboratively. Using visual imagery with clay as well as dialogue allowed for multiple ways of presenting information and making meaning (Serafini, 2014). As the unexpected narratives emerged, a more profound and intimate picture of Maria (and her family and friends) came to light. Suddenly, through her *simple* artwork, we began to understand her fear of separation from her mother. We felt her patience and admiration for her mom as she worked so hard to learn English. We felt her longing for a teacher who cared enough to know her. We began to relate to her frustration with a government who would, for some reason, want to keep her and others like her out with a wall.

This little girl is a student in any school. She could be a student of any teacher. She sits quietly at her desk, says the Pledge of Allegiance, and comes to school each day with the blessing of her mom and dad. She longs for a teacher and her peers to know and respect her, and strives to understand why anyone

would want to kick her, or people like her, out of the United States. She is a citizen of the United States, reciting the Pledge of Allegiance, and yet takes on the cloak of an “illegal” hiding in her house until she gets kicked out. Does her teacher *know* this complex and powerful girl? Does her teacher ask her about her life, her struggles, and her fears? Does her teacher recognize her strengths, gifts and resourcefulness which she lives day to day? Or does her teacher administer high stakes tests and characterize her as a number or a level -- understanding her through the common and stereotypical “one story” of Latino immigrant families in this city, and labeling her rich and diverse historical gifts as a problem to be solved.

As neighborhoods, families and academic entities partner together, we envision a wide open and caring space where identity and authentic story enter the classroom as welcomed ingredients to a community of learning that sees families, histories, languages and cultures as important parts to the recipe for inclusive and equitable learning sites. We envision caring as:



*Stepping out of one's own personal frame of reference into another's. When we care we consider the other's point of view.*

(Noddings, 1984, p. 24)

We see the nurturing of a “social imagination” -- envisioning possibilities that attend to the justice and equity of all humans (Greene, 2003). We see a place where obscured stories are heard, sanctioned and valued. We see classrooms where children like Maria

are seen as capable, full of strengths, and with voices important enough to be valued and heard. We hope to see teachers who open up their arms and hearts and even become learners (Freire, 1980), willing to truly know and appreciate their students. We hope that stories, though hard to talk about and uncomfortable for those of us who have not lived them, are invited in and entertained.

In this work, we have noted the ways that art can open up those spaces, unravel those narratives and create collaborative communities willing to reflect upon topics shared by voices that may have been “shoved under the desk,” but are now loud, clear and full of beauty. We have shown here how visual art transcends language and provides all equal access to learning. If teachers have passion for the arts, for storytelling, and for the cultural histories of their students they will push art into the cracks of tightly packed curricula to elicit evocative responses from those students and allow everyone to be heard. These alternative discourses trouble stereotypical narratives and begin a process of understanding of and empathy for “the other.” Teachers and community places can collaborate to make sure all children can find a sense of identity and self-respect as they construct personal narratives of possibility.

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## TRUST IN PARTICIPATORY ACTION COMMUNITY-ENGAGED PARTNERSHIPS: RELATIONSHIPS AND HISTORIC TRAUMA MATTER

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### ABSTRACT

University-community participatory action partnerships can be mutually beneficial. Universities often work alongside communities to establish new and innovative community-based programming and research that are intended to benefit communities from these efforts. However, mistrust has been found to be a major issue in creating and maintaining strong relationships. This paper will marry a model of trust that forms when partners exhibit relational capital, relational embeddedness, and transparency within the principles of trauma-informed care as established by the Substance Abuse Mental Health Services Administration (SAMHSA) (2014).

A group of university researchers and community activists/organizers analyzed their work on a project to bring a community-engaged participatory action design team intervention to develop and implement trauma-responsive care in an established transitional African American community located in a large urban Midwestern city. Through our analysis we identified three major reasons for mistrust: objectification of community members; lack of real change in the community; and lack of transparency. Additionally, we found that paying attention to power differentials between the university researchers and community partners is key. Major findings around best practices mirrored the SAMHSA trauma-informed care principles and included developing “not just trust but

trusting relationships,” sharing “voice and choice” with all who seek to participate, understanding the historical trauma within the community, using cultural guides and long-time seasoned community organizers to facilitate processes, “showing up” and being interested in the community beyond the research or intervention by finding a way to give back to the community beyond the project.

KEYWORDS: Community-engaged participatory-action research; Trust; Trauma

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## TRUST IN PARTICIPATORY ACTIONS COMMUNITY-ENGAGED PARTNERSHIPS: RELATIONSHIPS AND HISTORIC TRAUMA MATTER

Establishing trust in partnerships is a hallmark of good practice for university researchers who work in the field of community-engaged participatory action (CEPA) intervention research (Khodyakov, Mikesell, Schraiber, Booth, & Bromley, 2016; Israel, Schultz, Parker, & Becker, 2001). Medical and research mistrust is common in the United States, especially in communities of color. Two well-known incidents of past research that led to mistrust are the Tuskegee Study of Untreated Syphilis in the Negro Male (Katz, Kegeles, Kressin, Green, Wang, James, Russell, & Claudio, 2006) and cervical cancer cell research study which appropriated the cell-line of Henrietta Lacks (Skloot, 2010) without her permission or



compensation. In the community in which our research team is working, a community grandmother described this mistrust as, “You people keep coming into our community and promising to help us but all you ever do is collect your data and leave. We don’t even know what your data says.” It is not surprising that African American communities are especially wary. Yet, in a study that identified people’s willingness to participate in research, Katz et al., 2006, surveyed 1,133 adult Black, Hispanic, and Non-Hispanic White individuals and identified Blacks were 1.8 times more likely than Whites to express fear of participating in research. However, there was no statistically significant difference in actual willingness to participate in biomedical research. In addition to the past unethical medical research practices, fear and mistrust stems from not acknowledging systematic oppression that has resulted in historical trauma and ongoing trauma experienced in predominately low-income communities of color. Current community-engaged researchers must work to undo this fear and mistrust. Using participatory action processes may help to some degree however, establishing and maintaining trust remains a key issue.

To help researchers develop, implement, and evaluate CEPA interventions, this paper will marry a theory of partnership trust (Pierce, McGuire & Howes, 2015) with principles of trauma-informed practice (SAMHSA, 2014) to identify best practices in CEPA research using the example of one community project which the author team is working. To be clear, our definition of CEPA is working in deep partnership with community stakeholders to identify issues and interventions as defined by the stakeholders to

ameliorate a community issue. For this work to occur university and community stakeholders must establish and maintain trusting partnerships.

Trust, as defined here, is the mutual and complementary respect that partners have so that each can perform their work with integrity (Mayer, Davis, & Shooreman, 1995). Becerra, Lunnan & Huemer (2008) studied trust in partnerships and identified strong partnerships as having the ability to share explicit and tacit or implicit information. This sharing happens when people feel comfortable enough to form relationships by working together on shared processes (Polanyi, 1967) in a transparent manner. It is when community partners share their “insider knowledge and experience” within a community that the day-to-day work of participatory action community-engaged projects occurs and forms trust. However, trust is easily eroded and the three components of trust -- relational capital (relationships), relational embeddedness (working together on processes), and transparency -- must be ever present (Pierce, et al., 2015; Hall, Imburgia, Jaggars, Pierce, Bloomquist, Richardson, Danh, & Hensel, 2017). In university-community partnerships, absence of trust erodes the work together and leads to the decay of the partnership (Becerra, et al. 2008). A case study completed by Pierce, et al. (2015) identified the rise, fall and rise again of a large university-agency partnership over the course of a number of years possibly due to issues of lack of trusting relationships, and especially transparency and working together daily to accomplish recognized goals. Further, Hall, et al. (2017) has identified similar results in establishing and maintaining trusting research relationship

partnerships within a university-agency research relationship.

In communities that experience high oppression and historical mistrust of university researchers, partnerships may be able to facilitate mutually beneficial research to improve conditions for the community. Yet, historical trauma is ever present in many communities in which researchers work and must be acknowledged and addressed. Historical trauma occurs when groups of people have experienced “subjugation” by the dominant societal group (Sotero, 2009, p. 99). Sotero’s (2009) model of historical trauma suggests that four elements are present in these groups: overwhelming violence, segregation or displacement, economic deprivation, and cultural dispossession. Given the history of slavery in the African American population with its violence, segregation, deprivation and cultural dispossession, this population group certainly has experienced historical trauma. In addition, given the alarming treatment of this population by researchers, it is not surprising that participation with researchers is fraught with difficulty and leads to the need for trusting and trauma-responsive research practices in order to partner authentically with communities to improve the health or well-being of their community.

Trust and attending to historical trauma are two trauma-informed principles that have been endorsed by the Substance Abuse Mental Health Services Administration (SAMHSA) (2014) who have been integrally involved in educating the public about trauma in general (Harris and Fallot, 2001). These principles based upon the work of Harris & Fallot (2001) and Elliot, Bjelajac, Fallot, Markoff, & Reed,

(2005) include: safety; trustworthiness and transparency; peer support; collaboration and mutuality; empowerment-voice and choice; and attention to cultural, historical, and gender issues. Further, these principles identified and tested in many different community settings appear to be generalizable and, we argue, inform development of trusting and trauma-responsive CEPA partnerships.

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## METHOD

This study examines participatory research practices of our community-engaged partnership with a historical African American community and analyzes responses to questions around concerns and best practices regarding the university and community relationship needed for this project. Thematic analysis was conducted on answers to the two questions posed to the team by the team leaders. The research team, all authors of this paper, essentially formed a virtual focus group to discuss concerns and best practices for CEPA on this project to bring trauma-responsive interventions to the identified community. The research team was asked to respond to the following questions:

- *What are the major areas of concern for people in the community regarding working with university researchers?*
- *What are the main best practices that university researchers can do to enhance partnership with the community?*

Thematic analysis included line-by-line and axial coding on the quotations in the transcribed data. Further analysis used the constant comparison

approach within and across data points (Braun & Clark, 2006).

This project is bounded by the work of this research team between 2016 and present and centers on the initiation of a project to bring trauma responsive services to one African American community. The case method overarches this paper (Stake, 2005) while content thematic analysis was used to explain results of concerns and best practices.

### **Case Setting**

The work of this research team had its origins in a health fair planning group as three of the university researchers participated in the development of a health fair for the community during the summer of 2016. In developing the health fair with various community partners including residents of the community, it became clear that members of the community were frightened by the overwhelming violence and poverty in their community as well as the lack of ability to cope with the trauma that they, and especially the children in the community, were experiencing. Further exploration of this concern indeed led to a member of the community asking for trauma-responsive expertise. Researchers then identified a broader team of community engagement specialists who work daily within the community to develop a Learning Collaborative Project in order to bring trauma-responsive services to agencies working with children and families in the community. The research team convened a major stakeholder meeting to listen to community needs. Themes based on these needs were identified and reported back to the community. The research team extended project participation applications to community agencies who

wished to work with the Learning Collaborative. Few community agencies actually applied and only a few people from those agencies began participating. Out of this, however, came an enlightening small group community discussion around historical trauma in their community that identified ways to bridge gaps between researchers and the community. As a result of this discussion, the research team expanded their team to include more community members and began to pay close attention to political forces both personal and community-wide which serve to confound work in the community or erode relational capital. The research team continued open communication (transparency) and work within the community on other projects (relational embeddedness), used cultural guides and community engagement staff more diligently, and paid attention to partnering using these new trust forming changes. Researchers recruited four community agency teams with which to work. Those community-based teams became energized and ready to work on the Learning Collaborative and continue this work today to bring trauma-responsive practices to schools and community.

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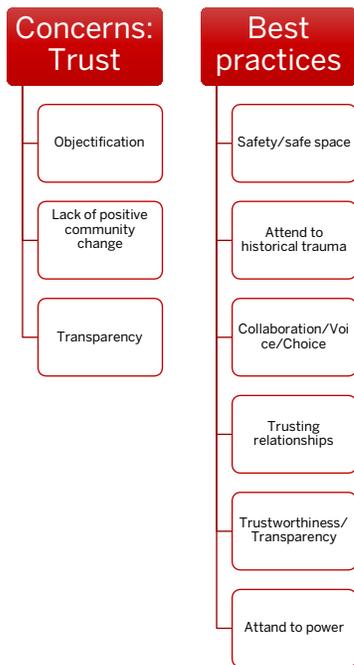
## **RESULTS**

### **Demographics**

The focus group members include 7 participants; 6 are female, 4 are Caucasian and 3 are African American. There are 2 doctoral students, 4 community organizers, and one researcher. The other researcher on the team conducted the data collection and analysis and therefore did not participate in the focus group.

All quotations in this results section are directly reported from the data and represent the answers to the two focus group questions. We endorse the practice of grounding results in direct quotations from participants.

Table 1. *Themes of Concerns and Best Practices*



**Question 1 -- Major areas of concern: Trust**

Overwhelmingly, the team expressed that the major area of concern for people in the community is lack of trust. This is expressed in three areas of mistrust: objectification, lack of positive community change, and lack of transparency in reporting data.

Five of 7 focus group participants identified that lack of trust due to **objectification** by university researchers is a major concern for them mainly because community members report feeling like

objects to be used for a purpose. One participant noted, “Historically, many researchers have taken from the community for their own benefit and not necessarily for the benefit of the community. Often times community members are weary of being ‘used’ for data purposes only for a journal article.” Another noted “the greatest concern for individuals in a community is being made an object of study versus being seen as a dynamic and evolving member of a community.” The understanding that researchers have an agenda of their own rather than helping to create an agenda which comes from within the community leads to the sense of being objectified, as well. “Unintentional objectification by researchers led to a community with understandable trust issues,” remarked one research team participant. Clearly another team member noted, “The community, first and foremost, wants to be recognized as an active, equal partner in all endeavors with university researchers.” “The ‘know it all’ attitude that university researchers have” creates deficit reactions and leads to objectification, as well.



*One participant noted, “Historically, many researchers have taken from the community for their own benefit and not necessarily for the benefit of the community. Often times community members are weary of being ‘used’ for data purposes only for a journal article.’ Another noted “the greatest concern for individuals in a community is being made an object of study versus being seen as a dynamic and evolving member of a community.’”*

Erosion of trust also evolves from **not producing positive change** within the community. “Often the findings do not serve the community in a way of producing real change,” noted one participant. Another, strongly stated, “I have heard community members express concerns that once the researchers left, the funding and programs also left, so then the community ends up back where they started, but the researchers have their data.” This selfish attitude then does not leave sustainable change. “Once the university completes involvement they leave behind a gap in services.” “They generate a great deal of conversation but no real solutions get implemented ... a bunch of talk and no action.”

Participants also discussed the community attitude toward not receiving reports back on data collected within the community which leads to trust issues due to **lack of transparency**. “Some community members have voiced their opinions in the past and their suggestions have been ignored” which leads to gaps in transparency and not hearing all of the voices in the community that erodes their trust further.

#### **Question 2 -- Best practices to enhance CEPA**

The themes related to best practices emerged as creating safety/safe space; attention to historical trauma; collaboration/empowerment/voice and choice; create and maintain trusting relationships; being trustworthy and transparent; and attending to power differentials.

The research team members reported the creation of **safety or safe space** was a foundational skill of CEPA work and offered various ways in which to do this. Creation of this space involves ideas such as “having a meal together;” “providing transportation;”

“hiring community members or researchers who look like the community;” “paying attention to power dynamics;” avoiding the “savior complex;” and “engaging in cultural humility.”

Attending to **historical trauma** is also a major theme in this project in particular. Research team members indicated that “learning the history of the community” and “practicing cultural humility” is important. One research team member said, “We must see the community as people, not as a project, not as a program.” Inherent in this statement is the sense that the community has experienced trauma as a result of being “just a project.” Another mentioned “community members are taking a risk by inviting outsiders into their community when past partnerships have the community members feeling like they were exploited.”

Being a good collaborator and promoting empowerment through voice and choice within the CEPA project is vital to its success. “Find out what the community wants and give it to them,” and another stated that community members have “a plethora of wisdom, knowledge and skills, that help us see their priorities and vision.” “We need to embrace their expertise.” “The community is the expert!” Another clearly stated, “Ignoring voices decreases trust and increases disengagement.” Collaboration also involved hiring for the project “from within the community.” Further, inclusion of team members from the community endorsed power sharing with the community team members to provide trainings and opportunities to “lead from within.”

Creating and maintaining **trusting relationships** is another theme crucial to best practice. The team, building trusting relationships over

time, “becomes involved in the community by attending things that are not necessarily tied to the research.”

“Building authentic relationships with the community consists of spending time with and in the community. Attending events, forums, and gatherings as an informal participant sans title. I know from experience that I put in a lot of evenings and weekends in one particular community as a part of the relationship building stage.”

Trusting relationships are built through sharing power and voice and through a “dialogic engagement that all voices are respected and heard.” Relationship is best expressed, says one team member, by “training and empowering them ... investing in the relationships from an authentic standpoint” so the findings of the research are “owned by the community and the researchers alike.”

The last theme involves being **trustworthy and transparent**. While the data endorses ideas such as using non-jargon and transparent language it is also important to note the inherent power differential that is important to name and claim as a result of the work. Being trustworthy typically means that researchers should say what they are going to do and follow through by doing it. However, also found in the data was the idea that researchers should be particularly careful not to take advantage of the community participants. Trustworthy in the data here means that as researchers we “do not leave the community” and that we provide “sustainable interventions that do not disappear when the researchers leave the project.” It is so important that “the interventions that are developed need to be practical and do not leave the community

without the possibility of sustainable services.” In addition, the research team endorsed that “change needs to be real” for the community.



*Trustworthy in the data here means that as researchers we “do not leave the community” and that we provide “sustainable interventions that do not disappear when the researchers leave the project.’*

Encompassing all aspects of these data is the theme of **power**. Researchers and community organizers all noted that a major difference between the university participants and the community participants is power. “Researchers who adopt a stance of conducting research ‘on’ a community perpetuate an imperialistic form of research that seeks to ‘fix’ and ‘help.’ Instead, researchers should adopt a stance of conducting research ‘with’ a community ... the goals and purposes have to be decided ideally by the community in conjunction with the researchers.” Other aspects of power include timing of meetings, who is in the room, sharing of processes and data, and “meeting members of the community where they are in the community in small groups on their turf ... demonstrates that they are the priority.”

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## DISCUSSION

Identification of trust as the major theme that emerged from the research team is not surprising. The literature makes clear that trust building in university-community partnerships appears to be paramount. In the instance of this case study however, the identification of various aspects of trust is novel

learning. In CEPA partnerships the identification of mistrust due to objectification, lack of positive community change, and lack of transparency appear unique to the research relationship. While these three areas of mistrust may be unique to this particular community, it seems unlikely. Historically, as we have already described, researchers have not been trustworthy partners nor have they named the historical trauma inherent in the process. While many social science researchers genuinely want to implement positive community change, reflecting on, and defining the mistrust issue in terms of historical trauma has not been common. It is true that researchers need to collect data as part of the process. However, to aid in community acceptance and trust building, while combating the effects of historical trauma, the researcher must make the data collection as well as analysis processes clear and include community members in the process. Further, this practice helps to sustain change over time. Being completely transparent about the relationship and process from the beginning may also increase trust. Understanding the avenues of mistrust enhances understanding of university-community partnerships and provides researchers with methods of community engagement to prevent mistrust from the beginning of a new project.

Given the level of historical trauma inherent in the target community of this study, it is clear the research team members were focused on finding best practices to help to ameliorate the community's historical trauma in this particular project. Yet, the research team members were not asked to answer the questions posed to them from a trauma-responsive

stance. In fact, they were asked to answer the questions as CEPA researchers. Interestingly, as the themes emerged from the answers to the best practices question, these practices mirrored most of the basic trauma-informed care principles as endorsed by SAMHSA. Further, while peer support, a hallmark of the SAMHSA principles did not emerge, another important principle did -- that of power differentials. The SAMHSA trauma-responsive principles did not use the term "power", yet the literature from which SAMHSA derived them clearly identified power as an issue (Harris & Fallot, 2001). The CEPA literature outlines equal partnerships as one way to cope with power differentials in the researcher-community relationship (Khodyakov, et al. 2016; Israel, 2001). We strongly endorse that research teams reflect on power and identify ways to share power equally with their community partners. Being trustworthy and developing trusting, collaborative partnerships can help with power sharing.



*We strongly endorse that research teams reflect on power and identify ways to share power equally with their community partners. Being trustworthy and developing trusting, collaborative partnerships can help with power sharing.*

The analysis of the data strongly identified the theme of trustworthiness and transparency. A trustworthy partner does not objectify, is transparent, and helps the community to produce positive change.

Essentially, being a trustworthy partner could then ameliorate the three forms of community mistrust identified by this research team.

Our research team brought a quality improvement intervention strategy to the community to enhance trauma services. Inherent in our practice is teaching our Learning Collaborative teams to use this intervention independently thereby enhancing the capacity of the community. Essential practices then related to this finding include being genuinely interested in positive change within the community; building capacity by collaborating with as well as teaching the community members to use any tested interventions independently; and producing sustainable change.

A trustworthy university partner also learns the history of the community and takes historical trauma into consideration. They engage in building collaborative trusting relationships with members of the community within a trauma-responsive manner.

Creation of relationships must occur in safe spaces in which partners can speak freely and honestly (voice and choice) about needs and concerns as well as attending to power differentials in relationships. Developing a process where both the university and communities identify and define common terms up front and set appropriate group process standards helps partners feel equal and safe. It also builds collaboration and provides for empowered voice and choice. Using common non-jargon language, or if necessary defining or explaining issues or concepts, helps the community to understand interventions and/or research processes. Strategically embedding researchers across a room full of community

stakeholders can also allow for relationships to form. Eating meals together as part of the relationship building process has been a good way for our team to get to know our partners more personally. Further, our research team includes community organizers and people of color, one of whom currently lives in the community, and others who have long standing familiarity and trust built within the community. The above practices fulfill our promise to the community to help devise supportive trauma strategies. This effort also begins the process of healing from past experiences with researchers.

Within a trauma-responsive frame and given the level of historical and present day trauma within our served community, we endorse identifying the strengths of the community and using those strengths to enhance the partnership. As one of our team reported, there is “lots of wisdom in communities.” Trauma-responsive practice is inherently strengths-based and encourages the paradigm shift in thinking from what is wrong with a community to what happened to them. When we use community strengths and build upon those we build capacity.

Given the literature around the need to establish trust in CEPA research projects we posit that researchers have failed to name the mistrust inherent in many communities as historical trauma, nor have they taken a trauma-responsive approach to the creation and maintenance of CEPA projects. Our strong recommendation based on our experience with this project includes attending to the inherent trauma in communities. It is important to note that many communities in which historic trauma is of concern are also communities that cope daily with oppression,

poverty, racism, classism, and community violence. When social scientists fail to take trauma into consideration they risk re-traumatizing the very people they hope to help.

The SAMHSA principles of creating safety, building trustworthiness and trusting partnerships, collaborating, empowering, and identifying strengths as expressed in our data with the inclusion of attending to power differentials, may help to mitigate further trauma by research teams.

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### LIMITATIONS AND IMPLICATIONS

This case study reflects two questions related to a mutual CEPA project in which a team of researchers and community partners are participating. As such, the results are not generalizable per se. However, our finding that identification of areas of mistrust will help to inform the construct of trust for future measurement considerations is important. Further, the identification of the SAMHSA trauma principles as important best practices leads to practice implications for CEPA researchers and provides future research questions related to historical trauma of communities, along with the trauma caused by research within communities, and important practices to mitigate such trauma.

### Conclusion

This case study of one CEPA project to bring trauma responsive programming to an African American community led to the identification of a deeper definition of the construct of trust and best practices. These findings appear to mirror many of the SAMHSA trauma principles. Future research might consider studying the trust construct more closely and

identifying and studying trauma more closely in community-engaged participatory action research projects.

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## THREE JOURNEYS: ONE PROJECT

OLIVIA MCGEE-LOCKHART, KISHA TANDY, AND ANDREA COPELAND

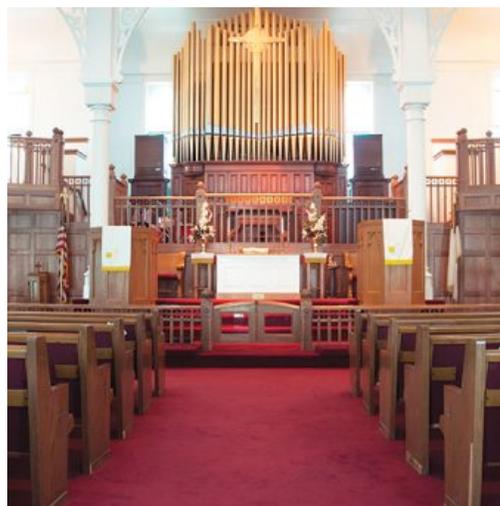
### ABSTRACT

The Bethel Project is about the history of Indianapolis' oldest Black church, archival records, preservation technologies, virtual experiences, and collaboration and co-creation among many different departments, heritage institutions and community members. This paper provides three perspectives on this project from individuals who've worked closely together over the past four years. This may seem like a long while to work on one project but for those whose research is community-based it seems about right.

Three unique voices will be presented with each telling their own narrative of what she thought when the project started and how her thinking has changed until now. Andrea Copeland is an associate professor in the School of Informatics and Computing whose research focuses specifically on public libraries, community collections, and engagement. Kisha Tandy is the associate curator of social history at the Indiana State Museum who researches African American history and culture. At the center of the project is Olivia McGee-Lockhart: Bethel AME Church of Indianapolis' Keeper of History, Indianapolis native, and an Indianapolis Public Schools educator for nearly four decades.

Working on this project produced many questions and was a learning experience. Who were the people who made up the congregation? What did they accomplish? Why is the physical structure important? Why fight to preserve the building? Why

preserve the paper collection? What do these records tell us about the neighborhood and the African American community in downtown Indianapolis? What led the congregation to the point of selling? How do you move forward? Everyone associated with this project will have various views, journeys if you will in response to the aforementioned questions but we can write with some assurance that we all learned new dates, new names, new circumstances as a result of this journey that had an impact on what we now believe.



*Photo 1. The altar in the Bethel AME Church*

### OLIVIA MCGEE-LOCKHART

Lockhart is a remarkable woman in so many ways. In over three-quarters of a century, she has witnessed much positive social progress but also in that time endured some discrimination and denial of equitable access to opportunities solely because of the color of her skin. One day I asked her, "do you ever feel anger regarding what your life could have been like if

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our social systems were just?" She replied, "No, I've always felt like I was right where I needed to be, doing what was needed to be done." That has certainly been the case with the Bethel project.

Until this project, she had not been in the news. Over the past four years, she's been interviewed by Amos Brown on his radio show, the *Indy Star*, the *Indianapolis Monthly*, Fox 59, and Wish TV. (See the reference section at the end of the article for publications and media related to this project.) Her love of the Bethel congregation, history, and this city inspired her to connect with new partners and allies outside of the church community to share Bethel's amazing story of strength and accomplishment. Given the historically significant African American community and landscape that existed before the IUPIU campus, Olivia is asked on occasion, "Are you sure it's okay to join with IUPUI to share our story?" She tells them that she believes intentions have changed and she senses a sincere desire on the part of IUPUI and Indianapolis' heritage institution partners to respect, remember and reflect on the contributions made by African Americans that occurred long before the campus arrived.

An interview with Lockhart conducted by Copeland will provide her perspectives on this project and how she came to a place where she could make that statement with confidence. Given the power and importance of her voice in this project, you are encouraged to view a short video of her talking with a reporter from the *Indy Star* (Lewis, 2016).

The excerpts provided below are from the interview with Copeland on August 24, 2018 at the Lincoln Square Diner in Indianapolis, Indiana.

### ***Getting to Know You***

- Andrea:* What did you think when you first met me?
- Olivia:* Don't make me laugh!
- Andrea:* You can be honest.
- Olivia:* Well, the fact that we just got through saying, it's been four years. I'm trying to remember. Tell me, where were we? When we met?
- Andrea:* We were in Spade Park Library, public lib- Rodney Freeman. We met at Rodney's. He had his Project-Back-Up group.
- Olivia:* Oh yeah.
- Andrea:* You brought in those amazing photos.
- Olivia:* Okay. Right.
- Andrea:* That was the first time I met you. The photos of women who were dressed as nurses, who were members of the Nurses Corps of Bethel.
- Olivia:* I was on the sidelines. I was watching, listening to all these people talk. It was an easy kind of thing, but I was not thinking about you individually, but I'm thinking, "I'm sitting here with all these librarians ... It was interesting, but I wasn't ready to jump into a whole lot of work at that time. So I backed off. It was like, "Okay, you're just one of the other librarians," ... to know what we'd be doing right now: that never crossed my mind.
- Olivia:* Miss Frances used to say to me, "Now, be careful about who you allow to see our papers and stuff like that." She said,

*"You know, we've got to be careful some folk can't tell our story like we tell it.*

*Some folks take our stuff and they run with it and get all the credit."*

*Andrea: She's not wrong. She speaks the truth.*

*Olivia: I was holding back, you know, just trying to see -- what was going on!*

*Andrea: I could tell.*

*Olivia: What else were you trying to do here. And it wasn't so much, it wasn't against you as an individual or anything like that. It was just the caution that Black folks have had to take all of their lives. And I said, "So, you have to" ... they talk so much about this at church, "Having discernment about people." After a while, you can just about figure that out. Of course, if you ever get crossed by anybody, then you say, "Okay, you close shop all together, you won't share a thing except among persons that you really know and trust." You have been a good girl. You've been fantastic. Because after you sat down when you came here to the Lincoln Square Diner, I said, "Oh, shoot." I wrote a little poem about you.*

*Andrea: You did? Oh my gosh! I gotta see this [poem](#).*

### **Shared Cultural Identity**

*Andrea: I have said that had there not been an African American archivist and an African American curator, I sincerely doubt that Olivia would have felt as comfortable in trusting the church's*

*history and their archive. I think having African Americans in those positions helps to establish trust in these institutions where there had been a lack of trust.*

*Olivia: Yes, right.*

*Andrea: Since the team members were African American, did that help you in terms of opening up this archive to the greater community?*

*Olivia: Oh, yes. Not even realizing that Rodney was moving on in a different direction, or at least no longer be present, enough happened with him and through him to venture out. Rodney Freeman was a direct link for considering any efforts toward sharing our treasure. Rodney, too, is a young, gifted African American -- a true guardian.*

*Andrea: Agreed.*

*Olivia: With what belongs to us.*

*Olivia: And then making an acquaintance, in addition to that, with genuine people, based on his recommendations ... It does make a difference. It really does. You know, it pulls so many commonalities together, when that happens.*

*Andrea: Was having Wilma Moore, a Black woman, and somebody with amazing archives credentials related to Black history. Did that help inspire trust? Is that what helped you trust an institution to represent the heritage and history of the church? Did that give you confidence?*

*Olivia:* Yes. Absolutely. She was saying, "Now Olivia. I can't tell you what to do, but ... you know this might be the best option to make sure the history of the church never gets lost." I said, "Yeah, I know, I know." She said, "Well, just think about it."

*Just talking about this now, I'm thinking about the difference between Wilma's age and mine.*

*Andrea:* Not much.

*Olivia:* No, it's not much. But it was enough for me to say, "Well, if we moved it back into history, when I was graduating from high school, Wilma was in whatever elementary grade somewhere along the line." I said, "Now, here it is in reverse, where she says, 'Okay, now, you have to get involved ... Come on. Let's get this done.'"

*Andrea:* Yeah.

*Olivia:* Wilma being of the same sex, of the same ethnic group, of the same everything, and then for me to having taught her youngest daughter just me our working relationship more binding.

*Andrea:* Yes.

*Olivia:* Yes, see, that was a triangle thing: a triangular sisterhood connect.

*Andrea:* Oh yeah, yeah.

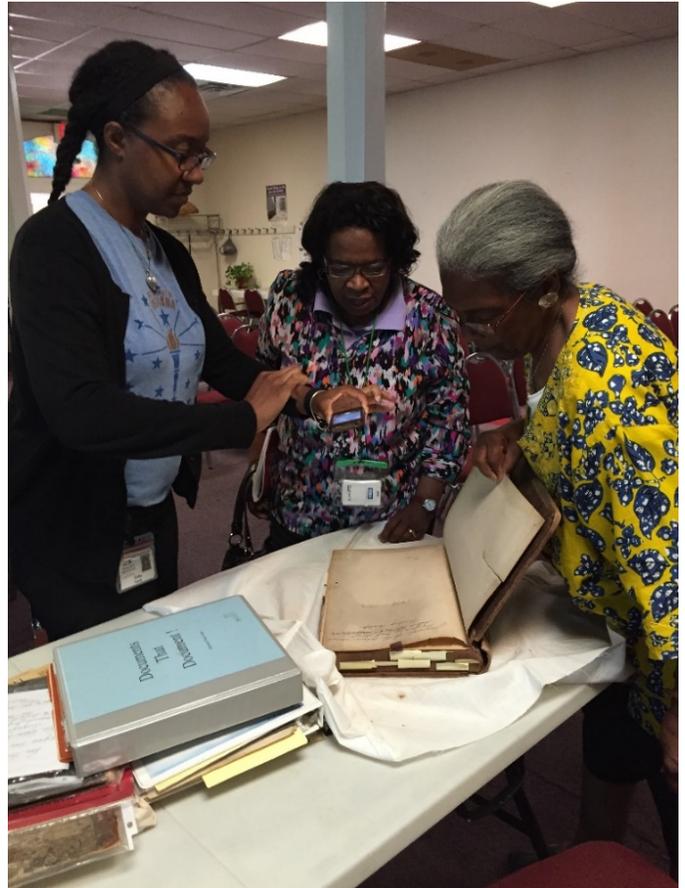
*Olivia:* You know?

*Andrea:* It took a lot.

*Olivia:* Yeah. Right.

*Andrea:* It took a lot.

*Olivia:* And when, what was it, Kisha had said, "One of my favorite photos is of you, Wilma, and I, looking at that journal," you know, that kind of thing.



*Photo 2. Kisha Tandy, Wilma L. Moore, Olivia McGee-Lockhart in the Fellowship Hall of the Bethel AME Church in the spring of 2016.*

*Andrea:* I love that photo.

*Olivia:* Wilma and I were sitting in the fellowship hall of the church. A couple boxes around and she's looking through them. We sat down and talked a little bit more. She said, "Now, you think about it." And I said, "Well ... " Now right now? I can't remember if I took a minute to think about it or a day, but I

said, "Okay." I said, "Now what do I have to do now?"

Prior to that day, Kisha and one of her interns had already started outlining, or at least listing all of the items in various boxes. Wilma said, "Okay, I'll make arrangements for these items to be picked up."

This project took place during a period of great transitions for the Bethel congregants. Given the repairs needed to the building, the displacement of African Americans from the neighborhoods surrounding the church, and a resulting dwindling and elderly congregation, the church building and property needed to be sold for the congregation to survive. This reality was not an easy one for the then-Pastor Louis Parham, who during all of this was fighting cancer. We had many conversations about this over lunch. Even though the survival of a building paled in comparison to the survival a congregation, he understood deeply that this was a painful loss to the African American historical and cultural landscape. Olivia was faced with making the decision to give (lose) the archive to the Indiana Historical Society during a time of when she and others were already experience a great sense of loss regarding their church building.



*"I said, 'Hm. I'm not giving everything.' So I said, 'Keep some of this stuff for the church, because we need to have something here, hands on, and visually, for persons who come to church.'"*

### **Who Keeps What? Where?**

**Olivia:** *It may have been, Paul, who came along with Wilma to pick up boxes from the church. It was in the sense somewhat of a relief. But at the same time, I said, "Hm. I'm not giving everything." So I said, "Keep some of this stuff for the church, because we need to have something here, hands on, and visually, for persons who come to church." They'll come to the church, first, before they visit the historical society. So I said, "If they think I'm releasing everything, they have another thing coming."*

**Andrea:** *They don't call you the keeper of history for nothing.*

**Olivia:** *That's right. Those things that I kept are in three-ring binders that says, "Kept for Us." I gave it that title. It is, as of right now, good that I held some things back. Since we're now in the new church, some of those photos have been framed. I went to Goodwill and got my frames, you know?*

**Andrea:** *Yeah.*

**Olivia:** *When folks step into the archive room, "Ooh, Ahh, Oh! There's so and so. Oh! I remember that!" So those are the kind of conversations they're having. And so many of what I have are duplicates that are at the historical society ... then there's some that they don't quite have, yet, so I've to figure out how to get some of those things to them.*

Andrea: *Well, there's always time.*

Olivia: *Oh, yes. There's plenty of time.*

Andrea: *It's a living community, a living archive. I don't think archivists are used to dealing with living, breathing organisms. They receive things when people are dead.*

Andrea: *We had this kind of intense conversation around where does this archive really belong? Does it really belong at the church itself, the AME Headquarters or at a local institution like the Indiana Historical Society?*

Andrea: *You were torn, because you could see all sides.*

Olivia: *Mm-hmm (affirmative).*

Andrea: *Now, given that-*

Olivia: *Where am I now on that? No, no, no. We've moved past that. IHS, the collection and the virtual experience. All become part of the local vernacular; we've been on the local news. None of that would have happened had we gone the AME route. But we, Bethel are still obligated to share with the connectional AME officer.*

Andrea: *Do you think there will be greater impact on the African American narrative, on our understanding of our own history, since the collection stayed in Indianapolis and became a resource to this community?*

Olivia: *Yes. Bethel as always been a vital part of Indianapolis history.*

Andrea: *So we made the right decision?*

Olivia: *Yes. I've grown a little bit in the past five years. Our decision was the best action taken. We, Bethel, once again, serve as a model for others. Bethel is in the position to encourage and support other African American landmarks and community histories.*

### ***The Teacher Becomes the Student***

Andrea: *So what's your biggest take away from working with me and Kisha?*

Olivia: *Have I learned anything from you guys?*

Andrea: *Yes, have you learned anything from us?*

Olivia: *Well yeah, because all the technology and stuff. I had no idea about all this stuff. Well, yes, hearing about it, because I'm just not familiar with how it works and all this. But I don't mind sitting back and listening and learning. I don't necessarily have to know how to do it. But I can appreciate the fact that the technology does and has put things in a different perspective and makes it easy to have access to so much. But out of everything, there's some good in it. Just to matriculate with young blood keeps, you young, too, at the same time. You and Kisha, you could have been one of my students.*

Andrea: *We could have been. Yes.*

Andrea: *Easily.*

*Olivia: For now, it's not role playing, it's just, right now, that's the only thing I can say, role reversal. That's it. That's what it is. I became the student and my students becomes the teacher. That's cool!*

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#### KISHA TANDY

In 1999, I had the opportunity to visit a recently renovated church building on the canal. The interior shined with new paint and upholstery. The building was Bethel African Methodist Episcopal Church. My Bethel journey first began in earnest when I met Mrs. Olivia McGee-Lockhart around 2002. I had visited the building as part of my new duties as a curator at the Indiana State Museum and working to collect artifacts, photographs and stories for the exhibits that would open in 2002. In 2012, Rodney Freeman, a fellow librarian and alum of Indiana Librarians Leading in Diversity fellows, contacted me about a project to scan materials, in particular photographs, from Bethel congregants. A simple request in the grand scheme of things.

Mr. Freeman also contacted Dr. Andrea Copeland, IUPUI School of Library and Information Sciences (now School of Informatics and Computing) and other librarians along the way. Mr. Freeman left the city in pursuit of professional opportunity shortly after the project began but Dr. Copeland and I continued to discuss the Bethel Project and preserving the archives. In one meeting, the Pastor, the late Louis Parham, shared a dated structural report. An architect reviewed the structure and found parts of the building to be deteriorating but stable. However, this report and financial hardship quickly changed the conversation

from preserving documents to saving a treasured building.



*This place has meaning and significance. Bethel is part of what makes history important to me, a building built by African Americans in the years following the end of slavery, that could stand for over one hundred and fifty years.*

It is important to note how we, Copeland, Lockhart and Tandy (there are many names that will not be mentioned in this essay), arrived to digitizing a collection. I was born and raised in Indianapolis, Indiana. This is home. This place has meaning and significance. Bethel is part of what makes history important to me, a building built by African Americans in the years following the end of slavery, that could stand for over one hundred and fifty years.

Through the discussions and efforts to save the building, one thing remained constant preserving what we could. The historical record of the congregation went beyond the members and served as a chronological record of a community and the annals of the African American community in Indianapolis. Its potential value to researchers both academic and general was significant. This worth as a resource to document the residents of Indianapolis and in particular the Black community in the near Westside of downtown Indianapolis is what led my desire to work with the Bethel Project. With the support of the Chief Curator & Research Officer and interpretation department as well as the then-CEO of the museum and most importantly the congregation, I worked in earnest to collect and deposit into repository an appreciated history. I along with Jamillah Gabriel, a

museum studies intern from IUPUI and then librarian at the Purdue Black Cultural Center, began processing what would become the Bethel A.M.E. Church (Indianapolis, IND.) Records 1922-2015 Collection (Moore, Blair, & Tandy, 2017).

Ms. Frances Connecticut Stout, an English and Spanish teacher at Indianapolis Crispus Attucks High School, served as the archivist and historian for Bethel AME before she died in 2004 at the age of 97. Ms. Stout passed on the archives, memories and a dedication to the history of Bethel to educator, Olivia Lockhart. Due to their painstaking efforts, documents dating from the 1800's are now available to interested scholars. When Jamillah and I arrived to review the collection, the documents were organized and boxed for easier access. We visited the church every Tuesday afternoon for a few hours.

One of my favorite memories was the handwritten notes with phrases like "HISTORY TO BE FILED AND DISPLAYED" "DO NOT DISTURB!" "THANK YOU!" and "Treasures from Bethel."

*From the wedding announcements to the pupil progress record to the listing for Black businesses in Indianapolis, these records shed light on the community.*



Photo 3. Boxes from the church archive



Photo 4. Manuscripts and church publications in the church archive.

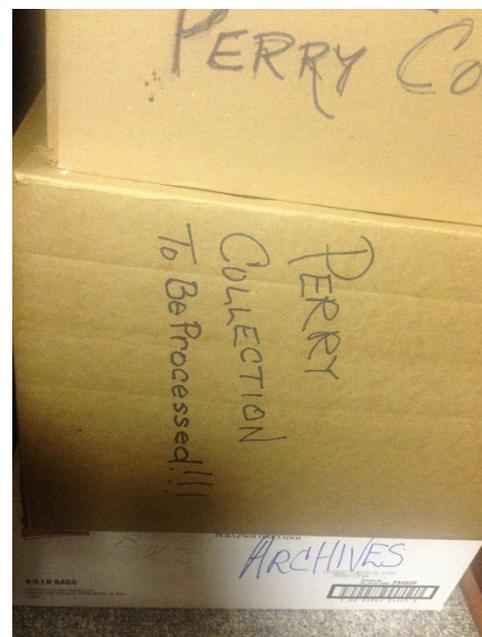


Photo 4. Boxes ready to be shipped the Indiana Historical Society archive

By the time that the archives went to the historical society in May 2016 to be completely processed and organized into folders for public use by archivist Wilma L. Moore and Lyndsey Blair, Ms. Gabriel had reviewed at least nine boxes of manuscripts, binders, bags, loose items, scrapbooks, packages, and photographs. The contents included substantial evidence of the events of the congregation, however, as a researcher; it was the individual, family and neighborhood records that caught my attention. From the wedding announcements to the pupil progress record to the listing for Black businesses in Indianapolis, these records shed light on the community. The Bethel archives are a community chronicle and for me the project was always about the institutions physical location as one of the last African American presences on the canal and role as a beacon of progress in the city as opposed to religion.

We lost two important people along this journey. Mrs. Wilma L. Gibbs Moore, longtime archivist at the Indiana Historical Society, community historian and mentor to many passed away on April 18, 2018. The Bethel Collection was one of the last collections that she processed. It was her goal to complete before leaving the society; she reached that goal. Louis Sidney Parham, Rev., the Pastor at Bethel during the transition from downtown to its current location on Zionsville Road, passed away on June 6.

Both were committed to ensuring Bethel's place in Indianapolis, Indiana and national history.

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#### ANDREA COPELAND

From the start of this project, I was unsure of how best to serve and to research at the same time. This project provided me the opportunity to explore,

on the ground, the connections and disconnections among communities, their archives and heritage institutions. Specifically looking for a framework that connects communities with the resources needed to preserve and make more accessible their histories and, in the process, create a more inclusive historical record for us all.

The amazing history of Bethel inspired changes to and motivated risk-taking in my research agenda. When this project started, I did not have tenure and my research was focused in a somewhat different direction, born-digital community archives rather than ones that exist in tangible formats. Further, community-based research projects are time intensive and I was aware that my clock was ticking, I needed to secure grant funding, to produce and to publish to satisfy institutional requirements for keeping my job. Additionally, I had to be quite careful that my publications were about the process of these connects and disconnects not the Bethel history, even though it was the motivating factor in my research direction. I'm not qualified in any way to tell or interpret it – either by disciplinary background or by lived experience. Writing about the history of Bethel would not establish the scholarly record needed in my discipline for a successful tenure dossier.



*Being mindful of my positionality throughout these public, scholarly and personal experiences, I believe was a critical component of the success of this project. By being intentional about my positionality, I was able to facilitate rather than hinder the development of co-creation and the building of equitable partnerships with community members.*

As a white woman from the east coast, my positionality on this project has always been an issue for me and quite possibly for the others, although no one has ever shared concerns. Personally, I was inspired by the Bethel story and I wanted to share it widely in whatever way the congregants felt comfortable. However, I did not want my enthusiasm and passion for having the Bethel voice heard to become the voice of this project. As the saying goes, “how can someone tell her own story, when you are standing on her throat.” There were several occasions where I spoke with the media over the course of the past four years and again I was faced with how to position myself in this project. Being mindful of my positionality throughout these public, scholarly and personal experiences, I believe was a critical component of the success of this project. By being intentional about my positionality, I was able to facilitate rather than hinder the development of co-creation and the building of equitable partnerships with community members.

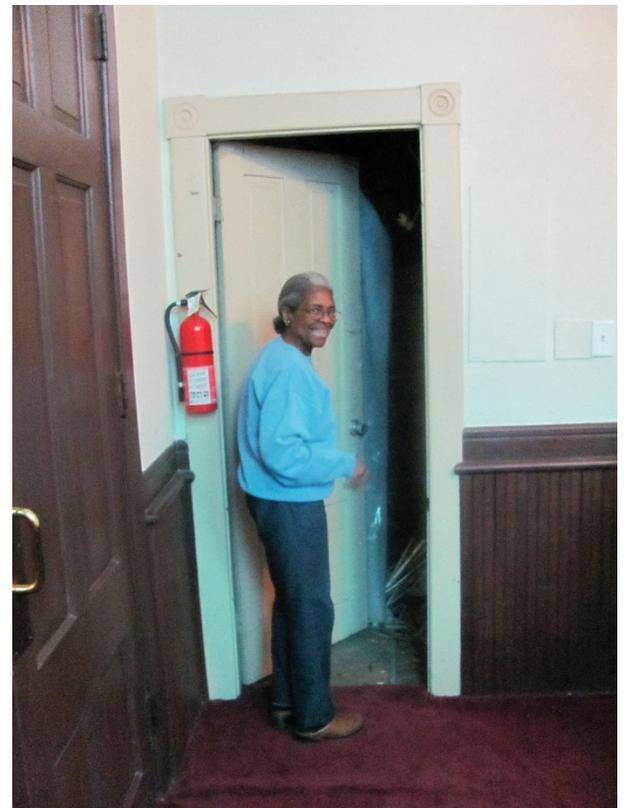
Intellectually, I began this project with a desire to gain a better understanding about how to build a more inclusive infrastructure to support the access and preservation of diverse histories. I focused early on the technical and institutional affordances and constraints. But as time progressed and with reflection, I’ve learned that while technology and institutional resources are important, any infrastructure of support has to be built on a diverse profession. Without diversifying the profession, our local and national histories will remain exclusive. If Wilma Moore and Kisha Tandy were not there to serve in their capacity as archival and museum professionals, none of this work would have been possible. Therefore, before we can address the

technical and organizational structures that support access to diverse archival collections, we need to build professions that reflect the great diversity of human experiences.

This journey has been full of emotions. At the start, I was in awe of the archive and Olivia.

The archive evidenced a powerful history of human strength and triumph: The Bethel AME Church, built in the shadow of slavery, housed congregants who contributed the economic and civic development of our city as they actively worked to improve the quality of life for the city’s African American citizens.

Olivia McGee-Lockhart, while she wrote a poem about me, I’m not sure I have the words to describe her justly. She is wisdom, strength, and compassion She is funny and loving. She is my friend.



*Photo 6. Olivia McGee-Lockhart opening the door to the church’s bell tower at 414 W Vermont Street*

With the realization of the impending sale of the church building, I became angry that the city didn't seem to want to save this national treasure. Where was this respect for those who had gone before us? Access to one's cultural heritage is a human right and the African American footprint from downtown was and is being steadily erased. This anger turned to sadness when the church was to be sold to become a hotel and would not be transformed into something for the community like an African American Heritage Center. Real tears and letters to Oprah. Not answered. Capitalism won. Hotels generate significant taxes for cash starved cities with mounting physical and social infrastructure needs.

*The archive evidenced a powerful history of human strength and triumph: The Bethel AME Church, built in the shadow of slavery, housed congregants who contributed the economic and civic development of our city as they actively worked to improve the quality of life for the city's African American citizens.*

Fortunately, the building will be preserved (with thanks to Indiana Landmarks) and repurposed.

With the forthcoming renovation of the church, a virtual sanctuary was built on a 3D imaging scan of the sanctuary. This work was done in partnership with my colleagues Zeb Wood and Albert William in Media Arts and Science. Virtual Bethel is a completely born-digital archive of the church building and with that I've come full circle to my initial interest in digital community archives.

My re/search for a framework that connects communities to heritage institutions to build a more

inclusive history has fundamentally changed because of this project. I now view diversification of the profession as the most critical element. Kisha Tandy and I are working with others in our community to increase the representation of persons of color in libraries and archives. The successes gained through the Bethel project towards the goal of creating a more inclusive history has created momentum towards future projects. Our first step was to create an endowed scholarship in honor of Wilma L. Moore. The purpose of this scholarship is to remove economic barriers from those individuals from underrepresented backgrounds that would otherwise want to join the heritage professions. We are just getting started and welcome your engagement with us.



*Photo 7. Bethel AME Church, located in downtown Indianapolis.*

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Virtual Bethel Project.  
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## SPEAKING UP, SPEAKING OUT: GRADUATE STUDENT VOICES

KEVIN HILLMAN AND JOSEPH FELDMAN

Kevin Hillman and Joseph Feldman are students in IUPUI's Urban Education Studies doctoral program. They responded to the editors' questions:

### Editors: What are your understandings of community engaged scholarship?

As doctoral students, our understanding is influenced and grounded by *collaborative engagement research* as discussed by Post et al. (2016). We referenced their work throughout our response because it helped us to articulate our thoughts. Much of the research literature can be “over the top” for beginning grad students. For example Post et al suggest,

*Collaborative engagement research is distinctive in its orientation for the following primary reasons: (a) the recognition that researchers are equally based in the community and in academia and that they are co-researchers who have their own knowledge and expertise base; and (b) the research process's deliberative approach, in that it aims to be fully democratic in an effort to address real-world problems. (pp. 79-80)*



Community-engaged scholarship can break down barriers between universities and communities, valuing the knowledge and assets of those present at the table. Viewing community members as experts strengthens the relationship, dispelling the notions of the ivory tower university researcher and the “helpless” community that needs to be saved. This helps in addressing and balancing power dynamics, creating a more equitable environment where community members have a voice in every step of the process. In turn, community members will feel empowered and less coerced, transitioning from the position of test subjects to collaborators. Post et al further state,

*Where collaborative engagement teaching and learning transcend the boundaries of the classroom, collaborative engagement research transcends the boundaries of traditional academic research. It involves shared and equitable decision-making that leads to equitable ownership for the research process, which is imperative for meaningful and relevant answers to*



*research questions. This, in turn, can lead to social change. (pp. 79-80)*

Addressing real-world problems through a community-engaged approach is important in combating the stratification that exists in our society. In order to be democratic in addressing these problems, the parties involved should be seen and treated as equal and valued. Being intentional about their presence and role creates an atmosphere for learning and change.

*Through the collaborative engagement research process, social and cultural change inherently take place. Social change and cultural change occur as people affected by the research problem become involved in the process because they, by virtue of their lived experience, have a greater knowledge of the problem as well as the possible solutions. Their involvement in the research is necessary so that they might also become part of the resulting change process. (Post et al, pp. 79-80)*

Influenced by our understanding of *collaborative engagement research*, we believe that community-engaged scholarship facilitates and informs partnership development and reciprocity between the university and community. These reciprocal relationships help to ensure that those involved have power over the decision making process, which facilitates an end result that is sustainable by the community.

*As community members move from subjects of the research to co-researchers and participate fully in the co-creation of knowledge, a resulting shift occurs in the existing hierarchal, academic-centric knowledge production system to more fully recognize the rights that co-investigators have to investigate and analyze their own lived experiences. In sum, collaborative*

*engagement research combines community-driven priorities, shared equitable decision-making, and social and cultural change with the co-creation of knowledge into a holistic, participatory, action-oriented research process. (Post et al, pp. 79-80)*

Community-engaged scholarship, as well as community-engaged research (CER), affords the opportunity to employ theoretical concepts into practice, praxis. Understanding praxis can be a challenge for graduate students, pushing our thinking beyond just “theory into practice” toward “theory into practice being transformative.” Through the transformational approach of praxis graduate students can begin to analyze and think more critically as to how we can make our systems and society socially just.

### **Editors: What do you need to be prepared to conduct CER?**

Students and faculty interested in community-engaged scholarship should approach it with a mindset that is conducive to this type of work. This is often done through intentional relationship building, which helps to engender trust between university and community. Future scholars need to realize that communities can and will identify the problems that are important to them and propose solutions to these problems. Therefore, scholars should not enter the research process from the stance of an expert who holds all of the knowledge and answers. Instead, there should be an openness to listening and learning from the community. Researchers valuing diverse perspectives and demonstrating a willingness to work alongside community members from various backgrounds will include populations whose voices have historically been silenced or excluded, such as linguistic and racially minoritized groups.

In addition to the *ways of thinking* described above, as doctoral students, we also need an understanding gleaned from experienced

community-engaged scholars. Not only do we need access to literature on the topic, but we also need access to faculty that actively partake in community-engaged scholarship in order to further develop our CER abilities and provide us with opportunities to identify how community-engaged concepts can be incorporated into our own research questions. We have come to understand that mentoring relationships with these faculty members are vital to doctoral students, since they can provide us with opportunities to participate in community-engaged research while receiving invaluable guidance and feedback. This would allow us to better understand the relationship between theory, practice and our responsibilities to community.

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## FORMING A MUTUALLY RESPECTFUL UNIVERSITY-COMMUNITY PARTNERSHIP THROUGH A “FAMILY AS FACULTY” PROJECT

CRISTINA SANTAMARÍA-GRAFF AND JOEL BOEHNER

### ABSTRACT

In this paper, we, a university special education professor and an executive director of a parent-to-parent non-profit organization, describe our collaborative partnership built on a common understanding that parents of children with disabilities are educational leaders. We address how we work collaboratively to locate and establish families as co-educators in an undergraduate special education course on families for pre-service special education teachers by using a Family as Faculty (FAF) approach. We use narrative inquiry as a methodology to detail shared moments and individual thinking about entering into this partnership. Through our narratives, we detail the ways in which we have worked together to construct a solid foundation for the first and subsequent FAF projects rooted in community-engaged participatory research. We highlight the ways in which our partnership began through establishing trust, respect, and clear, common goals. These mutually created goals are tied to specific outcomes that include: a) parent leadership in higher education settings, b) greater pre- and in-service special education teacher awareness of family rights and advocacy, and c) on-going structured commitments by both the university professor and the executive director to support each other's projects and organizations. Finally, processes and outcomes

centered around FAF are built on values such as reciprocity, mutual respect, and sustainability. Family as Faculty's success is ensured only to the degree that stakeholders are committed to these values and are honest with each other about their roles in FAF at any given moment.

*Keywords: university-community partnerships, Family as Faculty, collaboration, community-engagement, special education, disabilities, family engagement, reciprocity*

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## FORMING A MUTUALLY RESPECTFUL UNIVERSITY-COMMUNITY PARTNERSHIP THROUGH A “FAMILY AS FACULTY” PROJECT

This is a narrative of events relating the ongoing community-engaged, professional partnership between a university professor of special education and an executive director of a parent-to-parent non-profit organization. In relating our story, we hope to provide context for ways to establish and maintain a sustainable community partnership that is mutually beneficial for all stakeholders. We present this information as a narrative of our lived experiences, giving special weight to understandings about *partnership* that emerge from these tellings. We begin with who we are and our first correspondence and end with where we are now as we enter our third year of continued commitment to the families of children with disabilities whom we serve. We use narrative inquiry

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within this paper to tell our stories, but on a larger scale, embedded within the Family as Faculty project, the methodology used to enter into and sustain our partnership is rooted in community-engaged participatory research (described in a later section). Narrative inquiry as a storytelling tool is helpful in describing our experiences using a combination of first- and third-person voice. We use first-person singular to reflect upon our own stories, first-person plural to demonstrate our shared experiences, and third-person singular to distinguish our unique roles in this partnership. Though we structure our narrative through a linear progression of events, we also interweave critical self-reflections residing outside or on the periphery of actual events. These insights illuminate underlying metanarratives or self-reflection focused on power and privilege and the ways we grapple with our distinctive positionalities or identities in relation to one another and to the community members and families with whom we interact. For clarity, some of the terms used in this paper are unpacked in Figure 1.

Figure 1:  
*Concepts and Terminology Defined*

Equity	Within the context of partnership, equity is achieved when all stakeholders feel represented as full participants in the project, when power is fairly and evenly distributed, and when mutually created goals and intended outcomes are honored, acted upon, and/or realized.
Mutual respect	Within the context of partnership, mutual respect is viewing and treating the partner as an equal decision-maker and stakeholder. It is also the feeling of authentic trust that is engendered through gestures, words, and actions centered in a 2-way appreciation of one another's strengths and assets each person is bringing to the project.

Positionality	Within the context of partnership, positionality is one's identity as understood within social and political constructs. It takes into consideration identity markers such as race, class, gender, sexuality, and ability that position an individual's status differently depending upon the specific circumstances. For example, a community member with a dis/ability may have power and authority at a university-community meeting centered on equity issues and simultaneously may be marginalized by lack of access to the building at which the meeting is occurring.
Power	Power refers to the amount of status, authority, or decision-making ability one has within the specific circumstances of the partnership. It can be uneven or balanced; vertically-enforced or horizontally distributed.
Privilege	Privilege, in relation to power and positionality, is the advantage one has in a specific reality or set of circumstances. Within the context of partnership, privilege can favor one group over another, cause inequitable circumstances, fuel a sense of group entitlement, or reproduce damaging patterns related to colonizing practices.
Reciprocity	Within the context of partnership, reciprocity is an intentional choice and act between stakeholders of sharing time, energy, and resources with the other while receiving a proportionate return of service.
Sustainability	Within the context of partnership, sustainability is a mutually founded commitment with long-term implications. It requires honoring processes that may take an extended period of time.

Our stories narrate our experience of and involvement in Family as Faculty (FAF) approaches. *Family as Faculty* is a term to describe an approach to teaching or research in which family members take on leadership roles, teach others through their insider perspectives, and broaden understandings of those

who are working *with* or *for* their children (Heller & McKlindon, 1996; Johnson, Yoder, & Richardson-Nassif, 2006). These approaches originate from family-centered healthcare models and have been adapted in special education teacher education programs to influence and impact pre-service special education teachers' dispositional understandings of working and collaborating with parents/families of children with dis/abilities<sup>1</sup> (Forlin & Hopewell, 2006; Macy & Squires, 2009; Patterson, Webb, & Krudwig, 2009; Williams, 2012). Specifically, we are interested in ways that FAF approaches can center family leadership and knowledge in special education teacher education courses and programs while, at the same time, provide structured opportunities for family members to expand upon their roles as advocates for their children and for other families (Warren-Gordon & Santamaría Graff, 2018).

### **NARRATIVE INQUIRY**

To describe our partnership within the context of FAF we use narrative inquiry. Narrative inquiry is based on the premise that “stories are lived, and told, not separated from each person’s living and telling in time, place, and relationships” (Clandinin, Cave, & Berendonk, 2017, p. 91). It is a relatively new qualitative methodology that centers individuals’ stories as a way of making meaning of larger phenomena (Clandinin & Huber, 2010). Through storytelling, tensions can arise that shed light on specific challenges that are told,

<sup>1</sup> Disabilities with a slash (/) refers to the social construction of identity, rather than fixed, immutable traits. How meaning is attached to ability is, oftentimes, more disabling than the dis/ability itself due to the ways dominant mainstream society has normalized the conditions for ability and able-bodiedness (Davis, 1995; Davis 2013). In this paper, disability is



*Though this paper has in its title university-community partnerships what needs to be clear is that Family as Faculty – though (re)conceptualized and initiated at the university level – was never intended to be university-driven. The intention was always to use the resources at the university level to support and help facilitate community-engaged participatory approaches that were, to the greatest degree possible, community-driven.*

talked through, reflected upon, and examined (Clandinin & Rosiek, 2007). This method is particularly useful in analyzing the complexities of partnership in forming and building a collaborative relationship that is both unique to our personal, lived experience as well as informative for others outside of this inquiry who are engaged similarly.

We structure our narratives through a back-and-forth descriptive (re)telling of events that occurred between 2016 – 2018. To capture these events in written form, we pulled from a number of primary and secondary sources that included: a) notes from meetings we both attended, b) notes from informal conversations, c) materials from a conference presentation we were both involved in, and d) reflective writings about our partnership. Additionally, for this paper, we shared our writing in a Google document and were able to provide one another

written with a slash in specific references to children or students with dis/abilities.

feedback over the course of two months as we engaged in written correspondence about our partnership. Themes that emerged included the importance of mutual goals and values of respect, reciprocity, and sustainability. Underlying these goals and values were some tensions, namely how each of our roles in relation to one another and to the partnership brought up concerns around privilege and power. These goals, values and tensions are discussed and interwoven in subsequent sections.

**COMMUNITY-ENGAGED PARTICIPATORY RESEARCH**

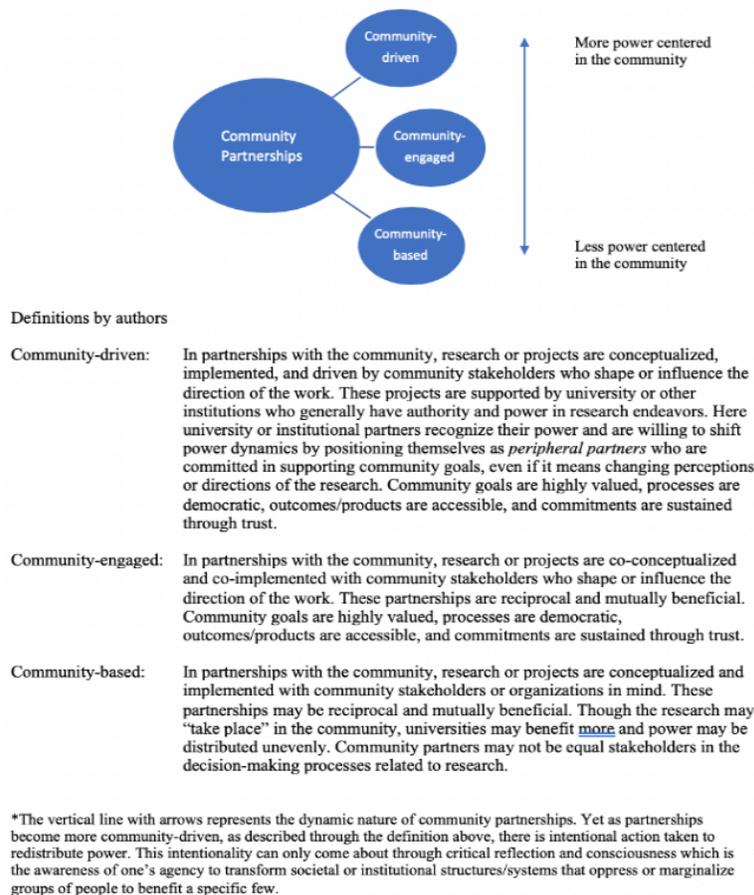
Although we use narrative inquiry as a tool to share our lived experiences, the underlying approach to how we enter into and sustain a mutually respectful partnership is grounded in community-engaged participatory research. Though this paper has in its title *university-community partnerships* what needs to be clear is that Family as Faculty – though (re)conceptualized and initiated at the university level – was never intended to be

university-driven. The intention was always to use the resources at the university level to support and help facilitate community-engaged participatory approaches that were, to the greatest degree possible, community-driven. Our definition of these approaches stems from the southern tradition of Participatory

Action Research (PAR) (Fals Borda, 1987, 2006; Freire, 1970/2000) and is reflective of what we determine to be “community-engaged” (See Figure 2).

“Community-engaged,” for us, is distinct from what we have defined as *community-based* and *community-driven*. All three terms, *community-based*, *community-engaged*, and *community-driven*, in our view, can be represented on

Figure 2  
Community Partnership Continuum & Terminology



a continuum toward more critical approaches to how we, as researchers and community stakeholders, ask, think about and examine the following questions:

- What is the purpose of the research?
- Who does the research benefit? Is it mutual? Reciprocal?

- Who holds the power? In other words, who is driving the research questions, research design, data collection, implementation, and dissemination of research outcomes?

### **WHO WE ARE**

In this section we begin by describing who we are, our backgrounds, and what brought us to our current work in a long-term, community-engaged partnership.

#### ***Cristina***

I am a female professor in special education at a university in the Midwest who has been an educator for over twenty years. I self-identify as a biracial Mexicana which, to me, means that I come from a mixed-race background. My father is Mexican and my mother comes from Italian/Irish heritages. For me it is critical to self-identify who I am in my work so that others understand how I foreground my biracial background in what I do professionally. Research-wise I have chosen to work with families of children with dis/abilities, particularly Latinx families. Many of the families with whom I work and collaborate with are immigrants (Santamaría Graff, McCain, Gomez-Vilchis, 2013; Santamaría Graff & Vazquez, 2014). Being forthright and transparent about my positionality as an able-bodied mother of non-disabled children and as a biracial, bilingual (but English-dominant), educated female in higher education is important in acknowledging the privilege that comes with each of these identity markers. More important, is the constant critical self-reflection I undergo in checking my own ego and power as I engage with community

partners who, oftentimes, are parents of children with dis/abilities.

#### ***Joel***

I am a male executive director of a parent-to-parent non-profit organization, IN\*SOURCE. I have served in this role for just over a year and have been with this organization for three years. While what most characterized my upbringing was my family's conservative evangelical Christian religiosity, what has come to most characterize my identity as an adult is how I identify in relation to my children. I am a white non-disabled foster/adoptive father to two African-American children with special needs. Understanding their stories before and after they entered my life shapes my understanding of privilege in an ongoing manner.

Professionally, I am the highest-ranking employee in an organization of about fifty employees nearly all of whom are parents of children with dis/abilities. IN\*SOURCE is a parent center with federal and state funding sources. Our founding is rooted in the disability rights movement and the activist efforts of the disability community to establish a place in public education for students with dis/abilities. Our work is based on and informed by power dynamics and privilege as it affects the disability community, particularly students with dis/abilities and their parents.

Leading a parent center demands a publicly expressed identity where personal experience informs and legitimizes professional judgment. I don't think I could do my work without frequent self-identification, yet my identity as a father drives my professional life

and is my defining passion. I am often the de facto or official parent representative in meetings of systemic importance where a parent's perspective is necessary or desired, and this representative role challenges me and informs my approach to collaborative efforts. The representative role that I play and that IN\*SOURCE plays in the scheme of special education in my home state challenges me to seek ways of more and more thoroughly equipping all families to advocate for their children. Without explicit attention on systemic inequities beyond disability such as opportunity gaps facing communities of color and non-English-speaking communities, for example, our role as a representative is problematized. My personal experience in a transracial family is the basis of my understanding of privilege and that perspective drives my professional judgment as a de facto or official parent representative.

### **CONTEXT OF OUR PARTNERSHIP**

#### ***Cristina***

Over two and a half years ago after I moved to a major metropolitan city in the Midwest to become a professor at a research institution, I decided I wanted to dive more deeply into community-engaged work with families of children with dis/abilities. To do this, I relied heavily on my previous experiences as a doctoral student in the Southwest United States and as an Assistant Professor in the Northwest. In both regions, I had the opportunity to work with Latinx families (Santamaría Graff, McCain, & Gomez-Vilchis, 2013). In the Southwest, however, I was able to work closely with a parent-to-parent organization that assisted me in recruiting Latina mothers of children with dis/abilities. I soon discovered through this work that

these Latina mother-advocates were experts about issues that impacted their children. I quickly learned that to *work with* these mothers meant I needed to be an active listener and learner who, in spite of my education, knew little about what it was to be a parent of a child with dis/abilities (Santamaría, 2009).

Having had this positive previous experience with the Southwest parent-to-parent organization, I decided, when I started working in the Midwest, to reach out to two parent-to-parent organizations. One was situated locally and the other's main office was in the northern part of the state about 150 miles away from where I was living and working. My first step was to research each organization's mission statements and to find out if their goals and values were in alignment with mine. Though both organizations responded positively to my initial emails, this narrative only describes the experience I've had with one of these organizations, specifically my interactions with IN\*SOURCE.

#### ***Joel***

When I first came to IN\*SOURCE, my job was to manage one of our grants. In this role I supervised as many as fourteen staff which included supporting personnel in a major Midwest metropolitan area. The grant I managed included deliverables around "outreach" efforts to historically underserved populations including families with incarcerated youth with dis/abilities, low income families, and non-English-speaking families. In order to support families whose primary language is Spanish, we employ staff who are bilingual in Spanish and English. Prior to any

awareness of FAF or relationship with Cristina, IN\*SOURCE bilingual staff had observed enough systemic shortcomings with respect to Spanish-speaking access to special education information that they had begun to work with IN\*SOURCE administration to raise further awareness of this problem. The solution that emerged from conversations with bilingual program specialists centered around the need for IN\*SOURCE to present the data and stirring anecdotes to our State Educational Agency (SEA) along with a request for a funding package that would support work training interpreters for special education.

I was personally affected by the stories our staff had accumulated through their work with Spanish-speaking families that involved unprofessional disclosures of private information, consequential technical details being misrepresented, conflicts of interest being unaddressed, and Local Educational Agencies (LEAs) able to abide by the letter of special education law without being equipped to know whether an interpreter is properly qualified for their important work. My work with bilingual staff to develop a solution that addressed the known issues and that the SEA would be able to support with funding brought me into a new place professionally. With the support of the Executive Director, IN\*SOURCE engaged the state office of special education around this concern culminating in a successful “pitch” to the state director of special education for support of this project as an additional node to our ongoing work with them.

As a statewide organization, IN\*SOURCE often is contacted by researchers who are pursuing studies that relate to disability and special education. We have varying degrees of involvement with scholars and institutions of higher education that range from participating in studies mutually designed with our feedback and access to families we work with in mind to the all too pervasive mass email with a link to a survey. If the study seemed particularly relevant, I would pursue the author requesting our support with some follow-up questions designed to get at their approach to working with families with special needs and even more basically whether they cared enough to answer my questions. I learned that almost always, the mass email was not intended to elicit substantial follow-up conversations. It is in this context that I learned of training requests from a professor of special education whose approach to working with our staff and her students particularly valued something that we too value--the importance of a parent’s perspective in their child’s special education. It was through staff involvement in a “training” capacity to Cristina’s students that led to a request for more formal, more integrated support of Cristina’s research emphasis, the FAF study. Cristina’s approach and methods were a welcome contrast to the much more common transactional approach.

### ***ESTABLISHING MUTUAL TRUST AND RESPECT***

In the following narratives, we discuss the first time we met. Our stories highlight the importance of entering into partnership with trust, respect, and clear, common goals. These goals center on family member leadership and ways that family members are

positioned in FAF projects to assist future teachers in their understanding of families as resourceful partners or allies. In this section, the value of mutual respect is integral in establishing a foundation for strong collaboration and communication.

### **Cristina**

My first email correspondence with Joel focused on my conceptualization of Family as Faculty (FAF) and the ways I believed IN\*SOURCE could be a key stakeholder in its organization and implementation. In the email, I introduced myself and provided IN\*SOURCE with a draft of the Internal Revenue Board (IRB) proposal in which I described the mixed methods study I intended to implement through a FAF approach. I hoped that sharing the proposal with Joel and other IN\*SOURCE members would engender trust. I provided them with the context for and purpose of the FAF study as well as give details about the ways I was positioning parents as teacher-leaders in my special education course. I wanted to demonstrate my commitment to the parents associated with their organization. I believed that a definitive plan with specific procedures and a timeline would provide IN\*SOURCE members with the opportunity to critique the project and give feedback.

In the email I sent to Joel and IN\*SOURCE, I not only sent the IRB draft proposal but also I specifically asked if IN\*SOURCE could provide me with access to families' emails so I could contact them to see if they would be interested in the FAF project. Joel shared the draft with the former IN\*SOURCE Executive Director and a few days later, after perusing

the document, they asked if they could meet with me face-to-face.

We met downtown in a hotel café where they were attending a state conference. Over coffee, both Joel and the former Executive Director seemed happy to meet with me and, at the same time, asked me pointed questions about the breadth and scope of my involvement with parents. Though asked with respect and politeness, Joel centered his questions carefully around specific protections I would be providing for parents who might be interested in participating in the study. I remember thinking how important it was for me to provide in-depth answers to his questions because he seemed to have concerns around how parents or family members may be exposed in public or academic settings. Both Joel and the Executive Director were clear that if they were to assist me in the recruitment of parents for my study, they needed to be assured parents were in good hands. In other words, I needed to demonstrate "good faith" by providing them with clearly written procedural steps, goals, and outcomes as documented in my proposal and throughout the project.

I remember describing the purpose of the FAF study and receiving an encouraging response by the Executive Director who said that our goals were "in alignment." What I believe he meant was that my intentional positioning of parents and families as experts of their children was central to IN\*SOURCE's goals as well. Specifically, it appeared he shared my view that families' innate and experiential knowledge of their children was an important component of their advocacy. The Executive Director and Joel extended

their support by offering to assist me in recruiting parents through their Listserv. I crafted a “recruitment” email asking for voluntary parent participation, submitted it to IRB for approval, and then sent it to IN\*SOURCE. The Executive Director and Joel approved of the language in the email and sent the email out to approximately 100 families affiliated with IN\*SOURCE. This gesture was significant because they sent the information from IN\*SOURCE’s official email and signaled to recipients that they approved of my study. Moreover, because parent/family recipients trusted IN\*SOURCE as an organization, they, in turn, *trusted* me because I was now directly affiliated with IN\*SOURCE.

## CONSIDERATION OF STEPS

Some of the ways that mutual trust and respect were established are listed in Figure 3 as delineated through specific steps. These “steps” are not formulaic nor are they always linear. Cristina’s story highlights the ways she initiated contact with IN\*SOURCE and the steps she considered before and during the initial meeting with Joel. Joel’s narrative below illustrates the careful consideration he took to ensure that IN\*SOURCE’s parents’ and families’ best interests were being accounted for before committing to the Family as Faculty project. Both perspectives are reflected in Figure 3’s “Steps” and may be helpful for those who are considering entering into university or higher education – community partnerships.

1. Know who you are and what you stand for. You should be able to articulate this orally or in writing succinctly.
2. Know the purpose and mission of your project/organization and be prepared to articulate this for your community or university partner or other stakeholders.
3. Do your homework. Before establishing contact, research the partner’s information. Whether it is a Curriculum Vita, an organization’s mission statement, or individuals’ biographies, find out if your work is in alignment with theirs.
4. Learn key players’ names and their positions before meeting with them, if possible.
5. Reach out in appropriate ways and through the proper channels. Establish parameters for communication. Demonstrate courtesy and respect in email and phone correspondence and in face-to-face interactions.
6. Be open and gracious when meeting and interacting with your partner. Allow one another to speak without interruptions and without set expectations. The process should flow with space for negotiation.
7. Allow expansion of your ideas. In line with number 6, a partnership should be given room to grow rather than feel forced, closed, or fixed.
8. Discuss alignment of one another’s purpose or mission. Here, transparency is key. Be upfront about number 2 with your (potential) partner and actively listen to their responses.
9. Find common ground and discuss mutual goals. Co-generated projects should yield mutuality – in other words – all parties involved should feel that they are benefiting from the experience.
10. Make a commitment, set timelines, and discuss responsibilities. These elements should be formalized and operationalized in writing for clarity, documentation, and accountability. Honoring responsibilities engenders trust and establishes mutual respect.

### *Joel*

Initial phone conversations about IN\*SOURCE helping launch FAF with Cristina instilled confidence in her approach to working with families. Broad mutual interest was established that included what was effectively an effort to establish parent perspective authoritatively in the curriculum of pre-service special education teachers at a major university. This was a gift, but Cristina’s careful positioning and awareness of power differentials did not make it feel forced as it had with other researchers who had taken time to answer my questions. Rather, I see the FAF launch as a

Figure 3:  
*Steps in Establishing Mutual Respect and Trust*

collaboration in every mutual sense of the word. From an IN\*SOURCE perspective, there was no easily discernible or realistic path toward realizing the opportunity to participate in the education of future special educators that Cristina was offering. Yet, this opportunity resonated so clearly with the persistent challenges around appropriate parent involvement within special education, which is one of the very reasons why organizations like IN\*SOURCE exist.

*For us, the commitment to partnership revolves around an authentic dedication to facilitating opportunities through which parent and family members can step into their leadership as experts of their children. This process of seeing oneself as a leader and expert may not occur overnight; it may not even occur in one semester.*

The broad mutual interest established with Cristina was fed by the thorough vetting of her requests for access to families we've worked with and endorsement of the FAF project by our organization. Trust was extended both ways during this process, and while I was most aware of and concerned about Cristina's intentions and process with her study, it was also apparent that she was investing valuable time and energy. As Cristina's commitment to these principles became increasingly evident, my desire to see her work thrive grew. While she was not a parent to children with dis/abilities, she was clearly in this for the long haul, and we wanted Cristina centrally involved in our organization's work beyond the FAF project. Cristina provided letters of support for the interpreter program

mentioned above and concurrently Cristina joined IN\*SOURCE's board of directors.

## CREATING MUTUAL GOALS

In this section, we begin by providing context for Family as Faculty's (FAF's) first iteration (2016 – 2017) to demonstrate the careful decisions made to guarantee that the partnership between Cristina, representing her university, and Joel, representing IN\*SOURCE, remained mutually beneficial. We also give specifics of the project to provide more background about ways FAF has been conceptualized to include parents as co-educators in university courses. We draw attention to Figure 4 which delineates Cristina's and Joel's initial goals they created individually as they each thought about FAF and its intended outcomes. Then, we describe how these individual goals became shared ones that eventually drove and continue driving other FAF projects.

Before the first Family as Faculty project began in fall 2016, Cristina, as stated earlier, contacted IN\*SOURCE and made a strong connection with Joel and the executive director. Cristina shared her FAF draft proposal with them. In it, were initial goals and intended outcomes she had created based on existing FAF educational literature. She wrote these for a small, internal grant she was applying for and was eventually awarded. She had initially contacted IN\*SOURCE during the application process because she was interested in partnering with a parent-to-parent community organization to implement the FAF study. The goals she wrote were centered on data collection procedures used to measure changes in both pre-

service teachers and parent co-educators over a 16-week period (See Figure 4).

Figure 4  
*Family as Faculty: Creating Mutual Goals & Their Intended Outcomes*

1. Cristina's Initial Goals	Intended Outcomes
a) To change pre-service special education teachers' views of families of children with disabilities from deficit- to asset-based.	To demonstrate a change in pre-service teachers' dispositions using a pre- and post-beliefs' survey and journal reflections.
b) To position family members of children with disabilities as leaders and co-educators in a special education course on families.	For parent co-educators to plan, organize, and teach specific classes in the course on families with the hope that they would experience a greater sense of self-efficacy and empowerment.
2. Joel's Initial Goals	Intended Outcomes
a) To assist parents in understanding their educational rights.	For parent co-educators to learn more about their rights under the special education law by teaching future special education teachers.
b) To give parents information about the special education process.	In line with (a), for parent co-educators to be able to articulate how processes described in state special education law pertain to their specific experiences.
c) To help parents and schools work together and develop positive relationships.	Through FAF, parents, in speaking with future special educators, will practice effective communication and interpersonal skills centered on parent/family-teacher collaboration.
d) To assist parents in becoming better advocates for their children.	Through FAF, parents will use their voice to tell their stories and feel more confident in their agency.
3. Mutual Goals Created	Intended Outcomes
a) To structure opportunities for parents/family members to step into leadership roles in higher education settings.	Through FAF, parents/family members will plan, organize, and teach classes on specific topics in a university special education course.
b) To organize specific activities through FAF for future special education teachers to develop an awareness of family rights and advocacy.	Classes led by parent co-educators will focus on topics of family rights and advocacy as presented through lived experience, case studies, and activities grounded in special education law.
c) For Cristina and Joel to maintain on-going structured commitments to support each other's projects and organizations.	Cristina demonstrates support by becoming a board member of IN*SOURCE. Joel commits to writing continuous letters of support. Both work together on grants, conference presentations, and manuscripts.

These goals and their intended outcomes impacted 22 pre-service teachers who were mostly white, middle-class, females and 8 parent participants. Of these eight, there were 7 females and 1 male. Of the females, there were 2 Latinas (1 from Nicaragua and 1 from Mexico) and one African American. In this first FAF project, the parents attended co-planning sessions in which they chose and organized content. Content centered on special education topics linked to course standards included, but were not limited to: collaboration, inclusive practices, disproportionality, ableism, medical treatments, communication with school administrators and teachers, and culture and language barriers. The course was structured so parents could present in pairs or triads. Four classes of 2 hour 40 minute periods in the 16-week course were dedicated to these parent-led class sessions. Parent as co-educators taught pre-service special education teachers specific course content from their insider lens and expertise of their child.

Before the implementation of the first FAF project, however, Joel asked Cristina questions about some of the parent presenters who were also parent advocates/trainers for IN\*SOURCE. He wanted to ensure that the parent presenters were supported by IN\*SOURCE in direct and tangible ways. For example, he provided specific parent presenters with printed copies of the state education law to use in FAF parent-led discussions for the pre-service teachers. He also gave access to specific PowerPoints parents could use to ground their information in law and policy. Through multiple conversations, Joel made clear some of IN\*SOURCE's main goals that he hoped to see

addressed through the FAF projects (See Figure 4). Cristina found these goals to be very important from an educator perspective. Over several conversations with Joel, she described how these goals could also be written for pre-service teachers and other educators. Future teachers, like parents, needed to know information about the special education process and how to work collaboratively with others to develop positive relationships. With these goals in mind, Cristina and Joel discussed ways their individual goals and intended outcomes could merge to create mutual ones. Mutual goals, for Cristina and Joel, meant an intentional integration of conceptual understandings and concrete outcomes that would benefit each of them in relation to their professional commitments. They developed three. The first two were structured through FAF parent/family-led sessions that focused on special education topics parents chose to teach. The last mutual goal was Cristina's and Joel's commitment to one another which entailed several ways that each of them would be supportive and accountable to each other's organization or projects (See Figure 4).

### ***MAKING SUSTAINABLE COMMITMENTS***

In community-engaged partnerships, sustainability is crucial in maintaining long-term commitments through which mutually established goals can be realized. Though short-term goals are necessary for taking first steps toward accomplishing concrete, timely actions, long-term goals require honoring processes that may take an extended period of time. For us, the commitment to partnership revolves around an authentic dedication to facilitating opportunities through which parent and family

members can step into their leadership as experts of their children. This process of seeing oneself as a leader and expert may not occur overnight; it may not even occur in one semester. For this reason, we think of Family as Faculty as a 5- or 10-year project in which there are many iterations. Even though certain funding mechanisms are structured to provide monies for 1-year increments, Cristina, in particular, conceptualizes each year as one part of a larger whole through which parents and family members progress toward leadership in higher educational spaces. Sustainability in the context of FAF means working with and learning from parents year after year as co-educators who enrich the overall project.

Sustainable, mutually founded commitments have been at the heart of our partnership. Here we take a moment to discuss the ways we have been consistently supportive of one another's projects. Specific questions that we have asked ourselves over the past three years are shared in Figure 5 to assist others who are interested in establishing long-term commitments with community or university partners.

Figure 5:  
*Sustainable Commitments: What Questions to Ask*

1. Have mutual goals been established, operationalized, and formalized (in some manner)?
2. Do these mutual goals have timelines attached? Are these timelines realistic? Are they fair to all stakeholders?
3. Has there been a discussion around what an enduring partnership around these goals may look like?
4. Do these mutual goals state who is responsible for implementing and carrying them out? Are the responsibilities equitably distributed?
5. Has there been a conversation around accountability? What does accountability mean for each person? What does accountability mean for implementation of and follow through of mutual goals?

6. Is there some type of memorandum of understanding (MOU) between you and your partner? Is it easily accessible? Is the language clear?
7. Does the MOU reflect a shared vision and mutual goals?
8. What structures or mechanisms have been put in place to ensure mutual goals are realized?
9. Where do meetings about accountability, long-term commitments, and mutual goals take place? How does location impact enduring partnerships?
10. Is there room for the commitments to evolve and transform as the project grows or changes?

In the academic year 2017 – 2018, Joel became the Executive Director of IN\*SOURCE. In his new leadership role, he has written comprehensive letters of support for Cristina. Cristina has been awarded several community-engaged grants and fellowships due in part to IN\*SOURCE's demonstrated commitment to the FAF projects. Further IN\*SOURCE has given in-kind matches to these grants consisting of administrative and staff support, material resources, and transportation costs. Continued funding has allowed Cristina to expand FAF and to continue working with parents affiliated with IN\*SOURCE. In fall 2017 graduate students, parents of children with dis/abilities, and community stakeholders affiliated with local parent-to-parent organizations collaborated together to organize and host an Inclusion Conference for over 130 participants. IN\*SOURCE was prominently featured in conference panels and family-led discussions.

The 2018 - 2019 FAF project that is currently underway consists of multiple stakeholder groups including: a) IN\*SOURCE and a local parent-to-parent organization; b) undergraduate pre-service special education teachers; c) graduate in-service teachers and

educators; d) undergraduate students acting as interpreters/translators from the Latino Studies Department; e) parent educators from previous FAF projects; and f) 18 Latinx family members of children with Down Syndrome and Autism. Extensive support from IN\*SOURCE has been necessary in securing funding and specific structural supports needed to implement this complex study involving over 70 stakeholders. One main purpose of this third iteration of FAF is to support Latinx families through ongoing family-driven workshops. Latinx parent participants are either Spanish/English bilingual or monolingual Spanish speakers learning English as a new language. This year's project focuses on family-driven mini-action plans through which these parents, with the support of students, create short- and long-term goals to address challenges their children with dis/abilities are experiencing in schools. IN\*SOURCE, under Joel's leadership, has connected Cristina to several bilingual parent advocates who are instrumental to the overall planning and implementation of this project.

In turn, Cristina has demonstrated specific commitments to IN\*SOURCE described in the next section that contribute to the organization's overall stability and sustainability. For example, she has given extensive time and energy to IN\*SOURCE's organization to ensure its long-term, fiscal solvency by writing letters of support, co-writing grants with Joel, and connecting IN\*SOURCE with university-based centers to enhance its reputation as an equity-centered organization. Further, she has established and maintained strong relationships with IN\*SOURCE's

board members and staff and continues to co-teach with parents affiliated directly with this organization.

### **ATTENDING TO RECIPROCITY**

Reciprocity is an intentional choice and act between stakeholders of giving time, energy, and resources to the other while receiving a proportionate “return” of service. Reciprocity, to us, should not be measured and scrutinized solely in strict, quantitative terms. For example, if we *give* 6 hours of volunteer time to our partner we should not expect them to *return* an exact equivalent as measured in the same form. From the outside, this input/output mechanism of measuring effort may appear “equal” but, in practice, it can feel forced and disingenuous. We conceptualize this “mechanism” as a fulcrum as shown in Figure 6, whereby a balanced partnership can only be maintained if the effort exerted is equivalent to the load or responsibility carried.

Reciprocity in a community partnership should be a dynamic process in which negotiation between stakeholders is conducted respectfully, whereby

mutually defined and beneficial goals are the center of all discussions. Perhaps the equivalent “effort” of 6 hours shows up in a different manner, for example, in

providing “free” recruitment for the partner’s project at a state conference. Time, energy, and resources should be given and received within a continuous flow that makes sense to the everyday activities and choices being made to sustain a healthy and equitable partnership.

Additionally, intent,

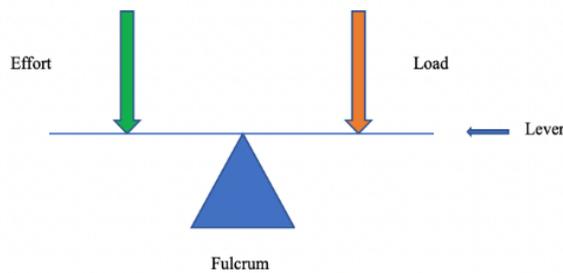
integrity, and accountability are core, underlying elements of reciprocity that drive meaningful and authentic relationships. Simply stated, if we, as community partners, can say with 100% confidence that “we have each other’s backs” and “we can count on one another” then we know internally that the relationships are sustainable and balanced.

### **Reciprocity to Parents in FAF**

In all FAF projects, Cristina has been able to provide monetary compensation to parent participants to demonstrate she values their expertise as professionals who are contributing to the overall FAF research. When Cristina shared the initial FAF

Figure 6

*Reciprocal Relationships: What to Consider*



In this picture, a fulcrum is featured as a way to represent reciprocal relationships. The fulcrum is the pivot point around which a lever turns or, in the case of community partnerships, the center of a situation or activity. The lever is the mechanism demonstrating equilibrium. In partnerships, a lever may be the perception individuals have of how power is distributed. If distributed evenly, the “lever” will teeter steadily, horizontally. If uneven, there may be the perception that a certain person is carrying much authority but may not be pulling his/her/their weight. In other words, in a balanced community partnership the effort exerted to create and maintain an equal or equitable relationship is equivalent to the load or responsibility carried. For example, when there is balance among and between stakeholders (e.g., university faculty and community members) power is equitably shared and each person experiences fairness in and a democratic approach to decision-making as well as mutually beneficial processes and outcomes. The effort given and the load carried for one group of stakeholders is equitable to the other group or groups of stakeholders depending upon the goals of the partnership.

proposal with Joel in 2016, one of the points of conversation was payment and its distribution. Cristina explained that paying the parent co-educators was an important gesture to show she deeply respected their knowledge, time, and curricular and instructional contributions. Cristina was adamant that, in spite of certain parents assuring her that they “didn’t need the money in order to participate,” she wanted to show she recognized the importance of their participation in the course. Paying them for their expert input and time was an act of reciprocity. Moreover, the parents trusted Cristina with their lived experiences. They willingly shared their stories with pre-service special education teachers. In turn, Cristina demonstrated to parents that their expertise was just as, if not more, important. She did this by replacing “traditional” course content with parents’ first-hand narratives. Joel was appreciative of these actions and stated how important it was to value parents’ contributions as experts of their children in FAF projects.

### ***Reciprocity in Partnerships***

Specific to our partnership, there have been several moments we want to highlight that are tangible acts of reciprocity. During the first iteration of the FAF project after Joel had sent out the email to assist Cristina in recruiting parents, he asked her for a letter of support for a grant he was writing for a language interpreter program mentioned earlier. This program was designed to prepare special education interpreters to “build cultural bridges” within their schools to better facilitate special education case conferences with schools and families. Cristina felt qualified to recommend this program because of her bilingual

special education background. Fortuitously, IN\*SOURCE was awarded funding to implement this program. In line with reciprocity being given and received “within a continuous flow that makes sense,” (Joel, email correspondence) we benefited from assisting one another in meeting individual goals that contributed to supporting families in our respective projects.

Another act of “reciprocity” was Cristina’s board member application submission to IN\*SOURCE. She wrote a comprehensive cover letter detailing the ways she could contribute directly to ADVOCATE’s mission: “to provide parents, families, individuals & service providers in the state of Indiana the information & training necessary to help assure effective educational programs & appropriate services for individuals with disabilities.” The former Executive Director and the IN\*SOURCE Board of Directors voted on and accepted her application. Since 2016, Cristina has been serving on IN\*SOURCE’s board and, since 2017, has acted as Secretary.

Finally, we presented together at a regional conference held in Las Vegas for parent training and information centers interested in unique opportunities for partnerships to benefit families. Our presentation focused on the FAF project and our collaboration as university-community member partners. In addition, we recently wrote and submitted a Department of Education Grant for a Statewide Family Engagement Center. Though we were not awarded this grant, we collaborated with several other stakeholders including a federally-funded, Equity Assistance Center.

## ADDRESSING POWER DYNAMICS

In this section, it is helpful to refer to Figures 2 and 6 to understand the balance and distribution of power in university-community partnerships. Here Cristina and Joel extend their understandings of mutual respect and reciprocity by bringing up specific issues related to power. For Cristina, the discussion is focused on tensions emerging from community-engaged work originating from dominant, Eurocentric university structures and applied to community settings. Joel speaks to the inherent dichotomy of “running a business” versus helping families. However, he centers his narrative on ways that power can be shared in order to attend to both the *business* of IN\*SOURCE and its *mission*, the latter being focused on parent advocacy.

### Cristina

Power dynamics must be accounted for in all community-engaged relationships, specifically university-community partnerships. Though I cannot speak for all service-learning or community-based projects originating out of universities, I can describe my own evolving understandings of power as I reflect on the ways I’ve needed to problematize the university’s role in my own FAF projects. There are major tensions in my work with families as I integrate community-engaged activities within a “service-learning” course. Here, service-learning is defined as, “An instructional approach that is credit bearing and linking curriculum goals with intentional learning within the community” (Delano-Oriaran, 2015, p. 38). By intentionally situating FAF approaches in my courses, I become accountable to university constructs

that limit the amount of time allotted for FAF projects. In other words: *Is it really possible to do authentic community-engaged projects with families and students when I only have 16-week chunks of time to build and develop relationships?*

Another tension is constructing genuine ways to assess students. Because of university norms, I need to evaluate students’ performance and learning through grades. In community-engaged work, “grading” students on the process of building important student-family partnerships seems contrary to the purpose of my work. I want relationships to develop authentically. When students “do community-engaged work” to demonstrate course expectations to “get the good grade” then the energy they bring to their “engagement” is rooted in obligation rather than in genuine acts of caring, consideration, empathy, respect, and trust. Conversely, when students are open to learning about and from community partners as a means to expand their own understandings and to fully embrace the collaboration process through dialogic interactions, then, I believe, authentic beginnings for *engagement* are possible.

As an instructor who intentionally situates FAF approaches as pedagogical tools for learning, I need to be extremely aware of uneven power dynamics (Cummins, 2009). Embedded within these dynamics between students and community stakeholders is the potentiality for “service” to be *done for* communities perceived to be in need of help or “damaged” in some way (Koster, Baccar, & Lemelin, 2012; Tuck, 2009). Knowing that traditional service-learning is an institutional practice historically connected to

dominant Eurocentric values is an important part of conscious awareness in engaging with communities (Leeuw, S. D., Cameron, E. S., & Greenwood, M. L., 2012). When service-learning projects are not centered in social justice and equity, they become extensions of Eurocentric, colonizing practices (Mitchell, 2008, 2014). If equity and social justice are not considered in community-engaged work originating in or from the university then “the work” can potentially harm the community stakeholders for whom it was designed.

Even with pure intention to expose my students to community-engaged work co-constructed with stakeholders, I know these experiences designed for university-level courses may not be enough to disrupt deficit-driven beliefs of parents and families. Further, what keeps me up at night is thinking about whether or not working within university course parameters allows for true reciprocity with community stakeholders. Is the work I am doing truly beneficial for the parents, families and community partners with whom I collaborate? Even when I intentionally institute measures to center stakeholders’ voices in my work, is the work equitable on *all* levels or do some individuals feel excluded or marginalized? Though I embed several opportunities to collect data from stakeholders in my FAF studies about how and if they believe they are benefiting from the FAF projects, sometimes I wonder if these opportunities reach deep enough to unearth the complexities of their answers.

### **Joel**

While IN\*SOURCE is a 501c3, for many practical purposes we are a business. We have

employees, a website and a 1-800 number, operate with contracts and invoices, have hours of operation, company laptops, reimbursement protocols, and so on. While IN\*SOURCE is concerned with efficiency and fiscal sustainability, we do not turn dollars into products or services in order to make a profit. Rather, we turn dollars into products and services in order to help families. Any mutually beneficial relationship needs to account for that governing purpose. Grant and contract stipulations also inform what mutual benefit means to IN\*SOURCE. Tellingly grant and contract funded work is often referred to as a “project” and often functions as a mediating expression of all that might be done toward fulfilling IN\*SOURCE’s mission and what there are resources to do. Realizing a mutually beneficial partnership may help get to project deliverables more efficiently, which from the “business” aspect of being a nonprofit is, of course, helpful. All the better, however, if a mutually realized benefit can do what you do not have any business or project capacity for yet is fully aligned with mission. While the FAF did help with project deliverables, the latter is what FAF really represented for IN\*SOURCE.

### **CONCLUSIONS: WHAT’S NEXT?**

At the heart of our work is the understanding that families of children with dis/abilities are strong advocates for their children who deserve respect and integrity from educational professionals in decisions impacting their child. We interpret Section 300.300(a)(2)(iii) of the *Individuals with Disabilities Education and Improvement Act* (IDEIA) to mean that parents *are* equal stakeholders and should be given every opportunity to voice their concerns, contribute

to their child’s specific school-related goals and objectives, be actively and seriously listened to for their unique insights, and have equitable access to power structures that inform their child’s academic and educational trajectory.

address areas these families have identified and want to pursue that, ultimately, will benefit their children and others with dis/abilities.

**FURTHER EXPLORATIONS**

Through our mutually respectful partnership, we are creating innovative pathways for families to participate as leaders and knowledge-makers in special education teacher preparation courses. We understand that *in partnership* our work with families is enhanced as we consider options that we had not conceived of before or were unable to enact without one another’s support. As we look to the future, we are interested in expanding Family as Faculty and other programs that center families’ voice in educational spaces. We are committed to opening more doors for historically minoritized families to engage in and influence programs at the local and state level, in the classrooms, and at higher education institutions. In practice, this engagement means listening to families from diverse cultural, linguistic, racial and ethnic backgrounds and collaborating with them to shape future iterations of programs like FAF. By doing so we hope to genuinely

While we describe a successful instance of a mutually respectful university-community partnership, we believe further research and exploration of this topic is warranted within the field of special education and beyond. The underlying values of equity including mutual respect, reciprocity, and sustainability inform this partnership, are relevant to other fields of study, and need to be more fully realized within special education. In Figure 7 we provide some concrete examples of how we are thinking about applying these values to our future collaborative work as well as how these values may be considered in others’ community-engaged projects.

Future inquiries might also interact with the substantial mutual benefit for both partners in that the approach by Cristina was iterative but not transactional and focused but not brief. Simply, a mutually respectful approach toward a community partner takes time but pays off, and indeed this and other successful university-community partnerships

Figure 7  
Future Application of Mutual Respect, Reciprocity, and Sustainability

	In FAF Projects	In Community-Engaged Work
<b>VALUES</b>		
<ul style="list-style-type: none"> <li>Mutual Respect</li> </ul>	<p>We will continue to find common ground that attends to shared goals. We will focus on shared goals 2 and 3 in Figure 4. In the next iteration of FAF, Latinx immigrant parents will be positioned as co-educators and teach about their understandings of a) home country vs. U.S. schooling practices, b) differing cultural perceptions of disability, and c) asset-based resources used in the home that can positively impact their child’s learning in school.</p>	<p>In your partnership with an organization or group, attend to the questions in Figure 4. Sit down with your partner and decide where your shared goals intersect. You may consider creating a Venn diagram, writing down individual goals and seeing if any individual goals are common to both parties.</p> 
<ul style="list-style-type: none"> <li>Reciprocity</li> </ul>	<p>We will keep checking in with one another to assess balance of power and responsibilities as we move into the fourth iteration of FAF. Because we are thinking about writing a parent-engagement grant, it is important that we distribute our tasks conscientiously so that one person is not doing the bulk of the writing.</p>	<p>In your partnership, use the diagram of the fulcrum (Figure 6) to consider both effort and load. Write down one another’s responsibilities to see if there is equitable balance. If there are uneven power dynamics, talk about them using a visual model to help show the imbalances. Then redistribute responsibilities where needed for fairness and equity.</p> 
<ul style="list-style-type: none"> <li>Sustainability</li> </ul>	<p>We will keep our long-term commitment to the FAF project through its projected iterations. Meeting at least 2-3 times/year to discuss timelines in meeting our shared goals is crucial. Reassessing timelines and goals is also an important step to ensuring maintained reciprocity, mutual respect, and an enduring relationship.</p>	<p>In your partnership, use Figure 5’s questions to shape how your shared goals will be realized. Sustainable commitments can produce outcomes that reach deeply and are meaningful to those involved or impacted. Part of sustainability is connecting shared goals with specific outcomes (see Figure 4) linked to concrete timelines. Use shared calendars or documents that will hold every person accountable to her/his/their responsibilities. These timelines and responsibilities should be accessible to everyone.</p> 

undergirded by equity ideas must make pragmatic sense in order to persist. What other insights can be gleaned by examining the intersection of equity and practicality? And how can this examination inform and transform spaces for genuine, sustainable partnerships?



Students and parents work together to build the tallest, free-standing structure with the materials provided.



Students and parents are working together on mini-action plans centered on family-driven goals.

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## GRASSROOTS MATERNAL CHILD HEALTH LEADERSHIP CURRICULUM

LINDSEY SKINNER, DEBORAH STIFFLER, NANCY SWIGONSKI, KARA CASAVAN, ASHLEY IRBY, LARONA DIXON, AND JACK TURMAN JR.

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### ABSTRACT

In the United States, Indiana ranks 43<sup>rd</sup> for its infant mortality rate. Twenty-nine of the 988 Indiana ZIP codes account for 27% of infant deaths. There is a need to train and mentor community members in these high risk ZIP codes to lead local maternal and child health (MCH) efforts that address the priorities of community members related to poor birth outcomes. A comprehensive grassroots MCH leadership curriculum is needed for this training process. We developed a curriculum designed to train community members in Indiana's high-risk ZIP codes to be grassroots maternal child health leaders (GMCHL). A team of public health faculty, clinicians, social service practitioners and community leaders developed the initial curriculum. Community feedback sessions that included grassroots community members, local clinicians and social service providers and non-profit leaders were conducted to get feedback on curriculum content. This feedback was incorporated to create the resulting grassroots MCH leadership training program. This curriculum provides a framework that can be used and adjusted to meet the needs of diverse communities across our nation to train residents to emerge as local MCH leaders that advocate for healthy pregnancies for all.

*Keywords:* social determinants of health, infant mortality, community development, policy advocacy, women's empowerment

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### INTRODUCTION

The measurement of infant mortality (IM) (death before an infant's first birthday) is used throughout the world as a key indicator of a nation's health and well-being (CDC, 2018). Among the United States, Indiana ranks 43<sup>rd</sup> for its infant mortality rate (CDC, 2018). Twenty-nine of the 988 Indiana ZIP codes account for over one quarter (27%) of infant deaths (Indiana State Department of Health [ISDH], 2017). Current approaches to address this problem include home visiting services, healthcare policy changes, increasing awareness among healthcare providers and interventions targeting individual health behaviors. Community-based grassroots efforts to raise the awareness and action of citizenry to address this vital public health problem and advocate with a community-centered voice is lacking. We are addressing this need by developing a curriculum, grounded in the Social Ecological Model (SEM) of Health Promotion (Bronfenbrenner, 1994), to train grassroots maternal and child health leaders (GMCHL) to lead community-based efforts to reduce infant mortality.



Addressing societal factors by equipping GMCHL to be health and social change agents is crucial to creating and sustaining a culture that promotes neighborhood health. Previous studies demonstrate that fostering community leaders for community-based health promotion efforts resulted in program sustainability, incorporation of health promotion elements into non-health sector community institutions and mediated the creation of multisector teams in the community to address health problems (Goodman & Steckler, 1987/88; Orlandi, 1986; Shediak-Rizkallah & Bone, 1998). Our approach builds on the previous work of others by incorporating the lifecourse theory (Lu & Halfon, 2003), a place- and community-based approach (Gabbe et al., 2017; Pies, Barr, Strouse, & Kotelchuck, 2016) and bringing the community in as its own specific discipline (Reynolds et al., 2015; Smith, Tiwari, & Lommerse, 2014). This manuscript presents the process of developing and testing this curriculum for training GMCHL. A detailed MCH leadership training curriculum for grassroots community leaders is missing from the literature. The curriculum we developed can be applied to community development activities in a diverse range of neighborhoods that are struggling with persistent adverse birth outcomes.

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## MATERIALS AND METHODS

### *Curriculum Overview*

Our curriculum is grounded in transformative andragogy (Knowles, 1973), which is one of the foundations of modern adult learning theory (Merriam, 2001). Transformative andragogy proposes that adults learn differently than children based on

four assumptions: changes in self-concept; the role of experience; readiness to learn; and orientation to learning. We incorporated the distinguishing characteristics of adult learning (Goad, 1982; Hanson, 1981) into each module. As the curriculum builds through each module, it promotes a learning process where each participant is actively involved and responsible for his/her learning. Time and activities are given during each session for the GMCHL to reflect on their previous experiences and relate to what they are learning. The curriculum uses images and quotes to evoke emotional responses from the GMCHL and data to appeal to their intellectual learning. The goal is to combine the knowledge and expertise of the facilitator with that of the GMCHL, thus creating new knowledge for optimal community development work (Smith, Tiwari & Lommerse, 2014). Learning objectives were created using Bloom, Engelhart, Furst, Hill, and Krathwohl (1956) taxonomy. Learning objectives were designed to correlate with the MCH Leadership Competencies developed by the MCH Leadership Training Conference (2009).

Every attempt is made to present the information at a level that is easily understandable as 14.7% of adults lack basic literacy skills and 13.6% lack below basic literacy skills (National Center for Education Statistics, 2003). For GMCHL to be empowered as agents of change to improve MCH health outcomes, they need to be equipped with terminologies used at the public health, medical, and policy making levels. To this end, we define and use terminology that is used in the aforementioned sectors. As words or terms are identified that are unknown or confusing during the curriculum, we

create a vocabulary list for the GMCHL and work with them during mentoring sessions on the correct use of these terms. In addition, we will ask the GMCHL to provide lists of terms/phrases that are used to describe MCH conditions experienced in their community. Together we will develop health communication strategies to optimize the dissemination of MCH information in the community.

The original draft of the curriculum was developed by a team consisting of: public health faculty, practicing nurses, physicians, social service providers, government public health workers, and local MCH non-profit leaders. The curriculum is divided into four sequential modules. All training and mentoring occurs in community sites that are easily accessible for participants. The knowledge content of the curriculum is centered around the following themes: leadership development and community health promotion, understanding adverse birth outcomes, health equity, and community and policy development. The initial training focused on these themes lasts four months. The curriculum allows for flexibility in scheduling and the GMCHL determine how and when they complete the sessions. During the initial four months, the GMCHL will also be trained in the following skills to help them build their leadership capacity.

*Photovoice.* The Photovoice method is a CBPR method used for the development and implementation of community health assessments and program planning. Photovoice was successfully used to educate community leaders and policy makers about MCH issues in their neighborhoods (Wang & Burris, 1997).

Each GMCHL will be trained in the Photovoice method and provided a digital camera to document strengths and concerns of their community. Trained program staff will facilitate discussion of the photos utilizing the following questions: what do you see here, what is happening here, how does this relate to your life and the lives in the neighborhood, why does this situation, concern, or strength exist, and what can we do about this?

*Storytelling.* GMCHL will complete multiple storytelling workshops led by collaborators from the Department of Anthropology. This process helps the GMCHL develop skills in telling their personal story and the story of their neighborhood. The training sessions will cover the fundamentals of good stories, interview tips, writing exercises, and an opportunity for the GMCHL to draft their own story.

*Policy Advocacy.* Our partner, the Indiana Institute for Working Families provided curriculum to teach the GMCHL skills in policy development and advocacy. Following training, they will help GMCHL form partnerships with their local representatives to begin policy advocacy for MCH promotion.

*EvaluLead.* The EvaluLead model will be used to guide and evaluate community priorities. This evaluation tool was developed by a partnership of the Public Health Institute, the W.K. Kellogg Foundation and the US Agency for International Development (Grove et al., 2005). The tool utilizes an open-systems approach for guiding and evaluating community leadership development based on values, norms and performance factors, and results in leadership goals at community, organizational and individual levels.

The goal is that after the four months, the GMCHL will have the foundation to begin their work while being continuously mentored.

### ***Soliciting Curriculum Feedback***

To ensure that our curriculum is comprehensive, we solicited input from 26 community members that represent a wide range of age, race/ethnicity, work expertise (grassroots citizens passionate about MCH, local health and social service providers, local government public health workers, non-profit leaders) and cultural backgrounds. In these sessions, we presented a summary of our initiative, themes from the four curricular modules, and key objectives and highlights from each module. A questionnaire was used for evaluation that included the following: name three things you learned from the information presented, what should we do better with this curriculum, how can grassroots leadership development impact the health of your neighborhood, what part of the curriculum did you find to be the most helpful, what part of the curriculum did you find to be the least helpful, how did the information presented change you, and has the information presented changed how you view the relationship between the characteristics of your community and the health of women, children, and families living in your community? Following the discussion of the questionnaire, an open discussion was held to solicit feedback driven by the participants. In addition to these community sessions, we received extensive feedback on the entire curriculum from: a child psychiatrist with a specialization in maternal and infant attachment, the lead case manager of Healthy

Start for Marion County, and staff from the Indiana Institute for Working Families, the Urban League of Indianapolis and the Indiana Rural Health Association. A thematic analysis (Braun & Clark, 2006) was performed to synthesize the feedback from all of the community members. Changes were integrated into the curriculum.

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## **RESULTS**

Our results are organized by the four curricular modules, inclusive of feedback regarding each module, a detailed presentation of the learning objectives, correlation to MCH competencies (MCH Leadership Competencies Workgroup, 2009), knowledge and skill building activities and associated learning activities for each curriculum session.

### ***Module 1: Leadership in a Maternal Child Health Context***

Many reviewers expressed the importance of recruiting community members to be the main facilitators of building the capacity of the neighborhood to support healthy birth outcomes. Other feedback included the need to conduct a strengths asset analysis of GMCHL to help them understand their personal strengths from which to build their leadership. The overwhelming majority of reviewers expressed the great need for this MCH training approach that emphasizes skill building and action to complement the current work in Indiana. Using this feedback and the work of our team resulted in the curriculum details of module 1 (Table 1).

### ***Module 2: Adverse Birth Outcomes***

Most reviewers expressed their great surprise at the persistent IM problem in communities across Indiana, especially those reviewers who resided or worked in several of the high-risk ZIP codes. In module two, the context of pregnancy is introduced to describe how the health of a woman before she becomes pregnant can determine how healthy her pregnancy will be. Some reviewers expressed the need to include information on interconception, family planning, depression [specifically the differences between depression, postpartum depression, and baby blues] and domestic violence. Other reviewers discussed the importance of teaching the GMCHL health communication strategies to disseminate the information they will learn to members of the community. Some reviewers expressed concern that the GMCHL would lack the ability to understand statistics such as IM, preterm birth, and low-birth-rate calculations. Using this feedback and the work of our team resulted in the curriculum details of module 2 (Table 2).

### ***Module 3: Equity for All Babies***

Feedback for module three included the significance of sharing data on birth disparities and inequities in communities, defining disparity, equality, and equity, and sharing disparities in birth outcomes for people in Indiana based on race and geographic location. Two curriculum reviewers did not agree with sharing a table that showed similarities in birth outcomes in three high-risk Indiana ZIP codes with Iraq, Syria, and Libya as they were concerned the data were not accurate since it came from other countries. The same reviewers also did not agree with sharing

statistics that showed African-American infants are two to three times more likely to die than their white peers. Their concern was that this did not properly highlight the work being done currently to reduce this disparity. However, the majority of reviewers discussed how important it is to share data with the GMCHL regarding all forms of birth disparities. The majority of reviewers also found it to be powerful to show that some of the high-risk ZIP codes in Indiana have similar or worse IM compared to our war-torn or politically unstable countries. Reviewers found it very helpful to discuss the impact of chronic stress on biological systems associated with pregnancy. They believed that this would be very helpful in validating the beliefs about stress observed throughout local communities. Using this feedback and the work of our team resulted in the curriculum details of module 3 (Table 3).

### ***Module 4: Power of Community Engagement***

The multi-sector reviewers found the use of storytelling and Photovoice to be powerful tools to capture the voice and story of the community. There was great consensus that the community realities surrounding IM are not prioritized in our state and that there is a paucity of community action approaches to complement health care approaches. Feedback was given concerning the type of questions the GMCHL would answer during Photovoice, the amount of time they would have to take the photos, and the Photovoice training process. During this session the GMCHL also get introduced to using the EvaluLead tool to make their community leadership plan. Using this feedback and the work of our team resulted in the curriculum details of module 4 (Table 4).

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## DISCUSSION

While developing this curriculum we received a wide range of feedback to ensure the curricular content is inclusive of all necessary topics. It was evident in receiving feedback from our multi-sector partners, that developing MCH community leaders is needed to build the capacity of the community to support positive MCH outcomes. It was widely acknowledged that building their skills (i.e. Photovoice, storytelling, policy development, EvaluLead) will equip them from just having knowledge to being able to act on the knowledge. Likewise, it was pointed out that GMCHL would foster new knowledge of healthcare providers and policy makers, thus helping them better perform their duties. It was widely acknowledged that community members are not usually incorporated into decision making discussions that impact MCH practices and policies for their community. Leaders who are from and/or based in their community better understand the challenges and strengths of their community. This allows for a better community needs assessment, priority setting, and identification of necessary solutions that ultimately leads to community development that better supports community members and their birth outcomes (Harper-Hannigan et al., 2017). One challenge we faced in developing this curriculum and its review process was accessing grassroots community members who could help in its development and review process. We often were presented with community organization leaders to provide feedback, but not grassroots community members who have direct or indirect experience with adverse birth outcomes. To overcome this, we worked in partnership

with the Indianapolis Urban League to connect with community members who are participating in some of their programs. Our Urban League partner greatly supported this effort. She emphasized the lack of knowledge among citizens regarding infant mortality and the persistent disparities associated with this problem. She and the individuals she connected us with were vital in providing feedback regarding the use of data in the curriculum and the need for community leaders training.

The main objective of the training curriculum is to provide GMCHL with the foundation necessary to begin their community efforts. These GMCHL will represent community as an equally important discipline in Indiana IM reduction strategies (Smith et al., 2014), filling the gap of grassroots community participation in decision making that influences local MCH outcomes. Our leadership development model is linked to the Smith, Tiwari & Lommerse (2014) community development framework, which posits that decision-making, empowerment, and participation are all necessary and continuous processes for community development and that "...community-based capacity building is both a prerequisite and an outcome of community development." Through this framework, the social capital of the GMCHL will be further developed, thereby increasing their civic engagement, trust and reciprocity of fundamental information exchange between community members (Bourdieu, 1986). Building community capacity in neighborhoods at risk for poor outcomes will result in an improvement to community members' abilities to cope with adversity and limitations, foster a sense of place (McMurray & Clendon, 2011) and help lead the

physical, social, economic or environmental transformation (Smith et al., 2014) of their neighborhood to support improved birth outcomes.

It is widely recognized that access to data and its collective analysis by community members, researchers and clinicians is vital to the success of a community-based effort at improving health or social outcomes (Israel, Shulz, Parker, & Becker, 1998). Often community members do not have access to data that pertain to their communities, thus further isolating them from making informed decisions about their community needs. Throughout feedback sessions we learned that community members as well as health and social service professionals were not aware of the IM issues facing Indiana communities. Our training program will provide GMCHL with data that promote their basic understanding of Indiana's adverse birth outcomes, their risk factors, and birth disparities impacting U.S., Indiana and local communities. With this foundational understanding, GMCHL will emerge as community experts who are skilled participants and decision makers in multi-sectorial MCH discussions.

Clinical interventions alone cannot reduce infant mortality because birth outcomes, like overall health, are the product of one's environment, opportunities and experiences (Collins, Wambach, David, & Rankin, 2009). Building a community's health promotion capacity is essential to any coordinated

effort aimed at improving and sustaining health outcomes (LaBonte, Woodard, Chad, & Laverack, 2002). As evidenced by the gap in the literature, and feedback received from a wide array of individuals passionate about improving birth outcomes across Indiana, our priority to develop and mentor ZIP-code based GMCHL is not only unique but needed. We implemented a process to develop a curriculum that is adaptable to any community and addresses the many factors needed to be a successful GMCHL. As we begin to implement this by training community members, we will continuously seek their feedback on curriculum content and delivery to make sure we are optimizing their learning experience and future participant's learning experiences.

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#### DECLARATION OF INTEREST STATEMENT

The authors do not have any conflicts of interest.

Table 1:

## Module 1 Components

Learning Objectives: where applicable can accommodate MCH Learning Competencies (2009)	Knowledge (k), Skills (s), and Activity (a) components
1. Describe the role that community leaders play in maternal and child health development.	Individuals must be considered within their social environment (k).
2. Define community capacity building and the importance in improving local maternal and child health issues.	Characteristics of community-based health promotion programs (k). Importance of community leaders (k). Need healthy neighborhoods for healthy pregnancies, infants, and families (k)
3. Define leadership development in the context of community capacity building (MCH competency 2).	Define leadership (k). Command and Control, Servant, and Transformational leadership styles (k).
4. Demonstrate ability to identify personal leadership skills (MCH competency 2).	Self-reflection's importance in leadership (k). Recognize inherent leadership qualities as well as those that need to be cultivated (s). Leadership style activity (a).
5. Complete and analyze a personal strengths inventory to gain insight into innate personal leadership qualities (MCH competency 2).	Formulate self-reflection leadership skills (s). Strengths inventory of leadership skills (a).
6. Recognize optimal health promotion programming requires action at the individual, interpersonal, organizational, community, and public policy levels.	Neighborhood is the agent for change (k). SEM of Health Promotion (Bronfenbrenner, 1994) (k).
7. Differentiate policy issues for women at various points in the lifespan.	Women's health across the lifespan (k). Policy concerns during child, teen, adult, and older adult years (k)
8. Provide examples of the relationship between healthy communities and healthy pregnancies.	GMCHL provide examples from personal experience or learning that demonstrate the connection between healthy neighborhoods and pregnancies (a).
9. Discuss intergenerational differences in life experiences and how this can shape different perspectives and conversations with community members.	Traditionalist, Baby Boomer, Generation Xer, and Millennial generations (k). Highlight historical events that happened during different generations (k). Introduce common values held by each generation (k). Introduce the idea that our life experiences shape who we are, how we view the world, and communicate (k).

Table 2:

## Module 2 Components

Learning Objectives: where applicable can accommodate MCH Learning Competencies (2009)	Knowledge (k), Skills (s), and Activity (a) components
1. Define infant mortality, preterm birth and low birth weight (MCH competency 4).	Learn current CDC definitions of IM, preterm birth, and low-birth-weight (k).
2. Discuss risk factors for adverse birth outcomes.	Premature rupture of membranes, intrauterine infections, genetic abnormalities, multiple pregnancies/fertility treatments, birth spacing, maternal age, history of preterm birth, chronic stress, drugs of abuse, and domestic violence (k).
3. Compare/contrast the context of pregnancy for women in the USA and Indiana.	Learn current March of Dimes and NIMH data given on national and IN rates of obesity, depression, late or no prenatal care, smoking and binge alcohol use for women ages 18-44. (k). Discuss similarities/differences in data (a).
4. Differentiate depression, postpartum depression and baby blues.	Learn current NIMH and CDC definitions of depression, postpartum depression and baby blues (k). Discuss similarities/differences (a).
5. State what to do if someone is severely depressed or suicidal.	Share National Suicide Prevention Lifeline and treatment options (k). Discuss what to do in crisis (a).
6. Describe difficulties preterm infants can have later in life if they survive infancy.	Cerebral palsy, blindness, hearing loss, and learning, breathing, or feeding problems (k). Differences in infant brain at 31 and 40 weeks (k).
7. Explain the importance of maternal-infant attachment and why communities should support this bond.	Foundational for physical, cognitive, and emotional development and provides benefits for mothers, infants, children, families, and communities (k). Poor attachment can cause behavioral disturbances, poor peer relationship, feeding difficulties, and emotional regulation problems (k). Communities must support healthy maternal-infant attachment (k).
8. Contrast unsafe infant sleeping with safe infant sleeping.	1/16 infant deaths in Indiana are due to unsafe infant sleeping that are 100% preventable (SUIDs not SIDS) (k). AAP's (2016) ABCDE's of safe sleep (k). Discuss safe and unsafe infant sleep images (a).
9. Identify infant sleeping myths.	Four myths: they will choke lying on their back, they will catch a chill, I bond best sleeping with my baby, and it looks like a prison (k). Discuss other myths they have heard and how they might refute them (a).
10. Distinguish differences in how infant mortality, preterm birth, and low-birth weight rates are calculated.	Teach current CDC calculations of IM, preterm birth, low-birth-weight (k).
11. Compare/Contrast differences in infant mortality, preterm birth, and low-birth weight rates at the national, state, county, and local levels.	Learn current March of Dimes infant mortality, preterm birth, and low-birth-weight data for U.S., Indiana, the county of the GMCHL and the ZIP code of the GMCHL (k).
12. Identify Indiana priorities for reducing infant mortality.	Unsafe infant sleeping and premature birth (k).
13. Identify Indiana priorities in accessing services.	Prenatal care, WIC, mental health care, transportation, physical activity, and smoking reduction (k). Discuss where people in their community go for these services (a).
14. Rehearse a sample presentation wherein you have to teach the local community members about infant mortality, preterm birth, low birth weight, and their associated causes and consequences. (MCH competency 4).	Principles of health communication (k). Develop skills in presenting data and information to lay audiences (s). Develop skills in public speaking (s). Present to the facilitator and other GMCHL (a).

Table 3:

## Module 3 Components

Learning Objectives: where applicable can accommodate MCH Learning Competencies (2009)	Knowledge (k), Skills (s), and Activity (a) components
1. Discuss the range of disparities in health outcomes and discuss how health equity is applied to address this. (MCH competency 2).	Use Whitehead (1991) definition of disparity, equality, and equity (k).
2. Contrast race and ethnicity.	Learn definitions of race and ethnicity (k). Discuss their thoughts on race and/or ethnicity (a).
3. Differentiate birth outcomes in the USA, Indiana, and globally within the context of disparities.	Comparative analysis of birth outcomes across race/ethnicity, immigrants, global community (k).
4. Discuss the different types of birth disparities in their community.	Highlight ZIP-code specific birth disparities for their community (k).
5. Contrast differences between acute and chronic stress.	Compare/contrast acute, chronic, minor, and major types of stress (k). Show the effects of chronic minor and major and acute major stress on the body's hormonal, cardiovascular, and immunological systems (k). Provide examples of chronic minor and major and acute major stress's effect on pregnancy and birth outcomes (k).
6. Complete a personal adverse childhood experiences (ACES) survey to increase awareness of the range of life experiences that contribute to chronic stress.	Recognize how incidents that happen to us as children shape our lives later on (k). Continuation of the self-reflection process. Looking internally to see how their experiences have shaped their lives (s). ACES activity (a)
7. Explain how chronic stress is related to birth disparities and differences in maternal and child health outcomes for different communities and groups of people.	Discuss how chronic stress reduces an individual's ability to make healthy choices especially regarding smoking, diet, exercise, alcohol, or illicit drug use (k). Changes in the neuroendocrine, vascular, and immune-inflammatory pathways can impact a mother's pregnancy leading to adverse birth outcomes (k).
8. State ways to reduce chronic stress.	Identify stress reduction techniques (k). Discuss advice they would give others to reduce stress (a).
9. Develop a list of community resources that can be used to promote equitable birth outcomes (MCH competency 3).	Create a list of community resources and assets that can address barriers to MCH promotion (a).

Table 4:

## Module 4 Components

Learning Objectives: where applicable can accommodate MCH Learning Competencies (2009)	Knowledge (k), Skills (s), and Activity (a) components
1. Outline one's role as a grassroots maternal and child health leader to build the capacity of their community to improve birth outcomes and maternal and child health.	Define aim as building community capacity to support healthy women, infants, and families (k). Community members must identify the problems, solutions, and action plans (k). This empowers the community and improves the individuals' health status, behaviors, and coping (k). Share community-based model (k).
2. Apply knowledge of the social ecological model in suggesting ways to improve maternal and child health in their community.	Re-introduce SEM model (k). Develop skills in identifying MCH in the different levels of the SEM (s). Have GMCHL identify ways to improve MCH health in each level of the SEM (a).
3. Develop appreciation of being a mindful leader.	Discuss importance of being mindful as a leader (k).
4. Practice mindfulness exercise and describe how to incorporate this into daily activities.	Mindfulness exercise (k). Develop skills in being a mindful leader (s). Mindfulness activity (a).
5. Summarize importance of storytelling as it pertains to maternal and child health.	Storytelling can be used to make a point or convey a message and to facilitate discussions (k). Being a good leader means listening to others' stories (k).
6. Develop, in an impromptu session, a personal story that highlights the need for taking actions to improve birth outcomes (MCH competency 5).	Developing storytelling skills (s). Present a story (a).
7. Describe goals and basic practice of Photovoice.	Describe process of Photovoice (k).
8. Discuss the use of Photovoice to improve birth outcomes in your community.	Discuss 4 guiding questions of Photovoice: who makes up families in your neighborhood, document "mom's story" with 3 pregnant women and 3 mothers, what are sleeping environments of babies in your neighborhood, and what is your role as a change agent in the community (k, a).
9. Describe basic process of policy development (MCH competency 12).	The following information is provided by Indiana Institute for Working Families: The composition of the Indiana House of Representatives and the Senate, registering to vote, identifying IN lawmakers, how a bill becomes a law in Indiana, and how to approach their lawmaker (k, s, a).
10. Differentiate policy issues for women at various points in the lifespan.	Childhood: preschool, brain development, immunizations, and family support (k). Teen years: prevention of STD's, pregnancy, and smoking, drugs of abuse, and alcohol use (k). Adulthood: interconception, preventative health services, child raising, quality childcare, and parental support (k). Old adulthood: raising grandchildren and managing chronic diseases (k). Discuss different policy issues for women across the lifespan that are not included (a).
11. Identify a policy to improve women's health and a personal strategy to advance this policy (MCH competency 12).	Help them develop skills in making a policy action plan (s). Identify a policy that they would like to advance to promote MCH (a).

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## A MIXED-METHODS, COMMUNITY-BASED STUDY TO IDENTIFY PREDICTORS OF DEPRESSION IN LATINO ADOLESCENTS BY GENDER

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### ABSTRACT

Latino adolescent depressive symptoms are a growing national problem. In this mixed-method, community-based participatory research study we quantitatively examined predictors of depression known to impact adolescent mental health that are amenable to interventions. Concurrently, we qualitatively assessed parents' perceptions of mental health problems in children, their causes and potential solutions. The data from parents ( $n = 108$ ) was obtained in focus groups led in Spanish, and the data from the majority of adolescents ( $n = 86$ ) was obtained in English language surveys. Among the adolescents there was an even representation of males (47.7%) and females (52.3%),  $M_{\text{age}} = 15.24$  ( $SD = 1.97$ ). Nearly half (47.7%) of the adolescents were experiencing minor depression and one in ten (10.5%) were experiencing major depression according to their scores on the 9-item Patient Health Questionnaire (PHQ-9).

Adolescent participants reported low acculturative stress, average social support, and high mastery, as well as highly functional families. Males reported higher self-mastery than females and lower acculturative stress. Predictors of depression differed by gender. For males, self-mastery predicted lower depressive symptoms; for females acculturative stress

predicted higher depressive symptoms. The focus groups with parents supported and expanded quantitative findings. The parents demonstrated a keen awareness of depression in teens and their own contributions to the problem, including their efforts to maintain their culture of origin, which may contribute to their teens' acculturative stress. Parents also reported difficulties knowing what steps to take and finding resources. The additional dimension of parental voice is often missing from studies of adolescents, and here it clarified many of the issues identified in the teens. These findings suggest the need to focus on mental health in this population, potentially developing differential interventions by gender and taking a family systems approach.

Keyword: Depression, acculturative stress, self-mastery, Latino Adolescents, gender.

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### INTRODUCTION

In the United States, more than four-in-ten Latinos can be found in 10 metropolitan areas, six of which are located in California and Texas (Brown & Lopez, 2013). However, the Latino population has been establishing roots in other communities across the country. From the year 2000 to 2011, among the 60



metropolitan areas with the largest growth in Latino population, Indianapolis, Indiana saw the highest increase at 197% - this represents a growth from 33,290 to 84,466 in that decade alone (Brown & Lopez, 2013). Many of those that arrived in Indiana during those years settled in the state and started families. Among the then 426,000 individuals who identified as Latino in the whole state, 32% were foreign born, and 76% were of Mexican origin, 8% Puerto Rican, 6% Central American, 2% Cuban/Dominican, 2% South American, and 6% Other (Strange, 2013). The average age of the foreign born subgroup was 36, and the average age of the US born was 16 (Pew Research Center, 2014). These Latino parents are now facing the challenges of raising adolescents in a culture and environment different from their own, and far from extended family support. In these newer migration destinations for the Latino population, Latino parents cannot depend on the resources and connections present in communities with long-established Latino populations, and are more likely to have unmet needs, especially parenting support. This is a problem given the mental health needs identified in Indiana teens, and Latino teens in particular.

Specifically, compared to the US as a whole (11.9%), a higher percentage of Indiana youth (14.6%) experienced a major depressive episode in 2014 (SAMHSA, 2015). A 2015 report from the Youth Risk Behavior Survey (YRBS) identified higher rates of suicide attempts in Latino youth (15.5%) in the previous year compared to their non-Hispanic White peers (8.7%) (CDC, 2015). These data point to a serious problem for Latino youth, one that VD, the community partner, and SB and her team, the academic partners,

decided to explore jointly given their shared interests in the wellbeing of this population.



*Latino parents cannot depend on the resources and connections present in communities with long-established Latino populations, and are more likely to have unmet needs, especially parenting support. This is a problem given the mental health needs identified in Indiana teens, and Latino teens in particular.*

We sought to identify predictors of depression in Latino youth, as a first step in developing community-based prevention programs. We examined intrapersonal factors (acculturative stress, mastery) and interpersonal factors (social support, family functioning) known to impact adolescent mental health in general and to be amenable to interventions. Acculturative stress may contribute to depressive symptoms among the teens who are themselves immigrants or have immigrant parents (Lawton & Gerdes, 2014; Lorenzo-Blanco, Unger, Baezconde-Garbanai, Ritt-Olson, & Soto, 2012; Roche & Kuperminc, 2012). Acculturative stress is the stress experienced as individuals go through the process of acculturation and adjustment between their native cultural values and customs and the mainstream American customs and cultural values (Lawton & Gerdes, 2014; Stein, Gonzalez & Huq, 2012). For these teens, acculturation to the US may happen more quickly than for their parents, potentially causing problems at home (Cox Jr., Zapata Roblyer, Merten, Shreffler & Schwerdtfeger, 2013; Lawton & Gerdes, 2014).

Teens experiencing acculturative stress may be at risk for depression; yet a well-functioning family, as well as self-mastery and social support, may be protective (Kuperminc, Wilkins, Roche & Alvarez-Jimenez, 2009; Lorenzo-Blanco et al., 2012). A family that is strong and cohesive will not only protect against stress and depression, but may be less likely to contribute to stress, especially acculturative stress (Dillon, De La Rosa & Ibañez, 2013). Teens high in self-mastery are more likely to see stressors as temporary events that they will be able to overcome, and are less likely to experience depression. Social support is instrumental to mental health and protective against depression for youth (Rueger, Malecki, Pyun, Aycock & Coyle, 2016). Low peer, family and school social support are associated with suicidal ideation and attempts in youth (Miller, Esposito-Smythers & Leichtweis, 2015).

During adolescence especially, females face higher risk for depressive symptoms than males overall (Mojtabai, Olfson & Han, 2016). Moreover, adolescent Latina females are more likely to suffer from more severe depressive symptoms than their male counterparts, and are more likely to attempt suicide than any other race and ethnicity (Lorenzo-Blanco et al., 2012), thus gender is an important factor to investigate when considering the mental health outcomes of Latino adolescents (Lorenzo-Blanco et al., 2012).

Therefore, in the present study we examined depressive symptoms among Latino teens in an emerging Latino community, focusing on gender differences, acculturative stress, and protective factors, such as family support. We assessed parents because

parental perceptions are key to understanding youth mental health issues (Miller, Esposito-Smythers & Leichtweis, 2015).

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## METHODS

### **COMMUNITY-BASED PARTICIPATORY RESEARCH (CBPR)**

The present study was conducted using a Community-Based Participatory Research (CBPR) approach. CBPR “equitably involves all partners ... with a research topic of importance to the community with the aim of combining knowledge and action for social change to improve community health and eliminate health disparities” (Wallerstein & Duran, 2010, p. S40).

We employed several key principles of community-based research as described by Israel and colleagues (1998). First, we developed the study collaboratively after discussing the challenges that Indiana Latinos face. Once the study was developed, the entire team built upon the strengths of the community partner in terms of knowledge about the community and their existing cadre of community contacts for recruitment purposes. Throughout the duration of the study, both the community partner and the academic partners were actively engaged and included in all phases of research. Both the community partner and academic partners conceptualized and wrote this manuscript.

The study described here was the first collaboration of this community-university partnership. The academic partners (SB, KC & TW) shared with IMHC their interest in focusing on Latino youth mental health after exploring statistics regarding this health disparity. The Indiana Minority Health

Coalition (IMHC) facilitated the connection with the Latino Health Organization. Once we were introduced, we began to jointly explore the literature and decide on the focus and methodology of the study, which was funded by IMHC.

### **DESIGN**

The study employed a concurrent mixed-methods research design with different participants for each method of data collection. Quantitative data were obtained from adolescent participants via several survey instruments, while at the same time complementary qualitative data were collected from parents in focus group sessions. These adolescent and parent study sessions were held simultaneously. The academic partners and the community partner were involved in data collection.

### **RECRUITMENT**

Following university IRB approval, the community partner initiated recruitment. Self-identified Latino adolescents and their parent(s) living in the Indianapolis metropolitan area were eligible to participate. Phone calls were made and/or letters were sent to clients of the community partner with adolescent children, requesting that only one adolescent per family participate, chosen by the parent. The community partner also sent flyers and letters to community centers or churches where she has pre-existing ties and approval. Families who learned about the study through the flyers or letters and were interested in participating called the community partner and signed up for the study. Eight meetings were planned and held in community locations in two counties, one urban, one suburban,

over a time period of four months. Each session lasted 60-90 minutes.

### **CONSENT AND ASSENT**

The study was thoroughly explained in Spanish to parents and adolescents. Opportunity was given to all potential participants to ask questions. A study information sheet was available for their convenience. It was made clear to both parents and adolescents that the responses that each gave would be treated as confidential and anonymous by the study team. A process of implied or passive assent/consent was employed; attendees who did not wish to participate following the study explanation were given the opportunity to leave the event. At this point, parents and adolescents were separated into different rooms in the facility to conduct the separate assessments. To participate, at least one parent and one teen per family had to voluntarily consent to be part of the study; however, in some cases both parents participated in the focus groups.

### **STUDY PROCEDURES**

#### *Adolescents*

No identifying information was collected from any participant, primarily to encourage adolescents to answer honestly without worry that their parents may discover how they answered. The researchers offered to each *adolescent* participant 1) written surveys in English or Spanish, whichever they preferred, or 2) the option to have the survey questions read out loud (privately) in the case that there were any participants who had trouble reading or writing. Eight (4 girls and 4 boys) completed surveys in Spanish; none asked to have the surveys read to them. They were informed that they could ask any questions if needed, and also

stop if they felt tired or uncomfortable. On average, it took approximately 60-75 minutes to complete the questionnaires and participants received a \$10 gift card for their time. KC managed the adolescent data collection with the help of research assistants.

#### *Parents*

At the same time the adolescents were completing their questionnaires, *parents* participated in a focus group session. More than one parent per child could, and sometimes did, participate. Members of the group were asked a variety of questions in Spanish to explore their perspectives on the overall study theme of stress and sadness among Latino adolescents.

Parents were asked to think of adolescents in general, including their own children and their children's friends, to reduce fear of personal disclosure. Questions included:

- 1) How much stress do you think adolescents are under, and why?
- 2) What does this stress look like in adolescents? (eg.: he/she cries frequently, sleeps too much, is not hungry, does not socialize)
- 3) What do you think is causing stress in adolescents?
- 4) What might parents do that causes more stress to their adolescent child?
- 5) What can parents do to help their adolescent child deal with stress?
- 6) How sad do you think adolescents are in general, and why?

- 7) How worried are you about the behavior of adolescents in their daily life environment, and why?
- 8) What specifically are adolescent children doing that worries you, and why?
- 9) How much do you think the new culture is related to the stress in Latino adolescent children, and why?

These focus group discussions were co-led in Spanish-only by SB and VD. The choice of Spanish-only was based on the community partner's knowledge that adults in the Latino community she serves are mostly limited English proficient. She informed parents of the language of the focus groups when she recruited them. Mean number of parents per focus group was 13.5 (median = 13), with a low of 11 parents in one of the groups and a high of 15 parents in two of the groups. Parents were told that they could stop participation at any time if they felt uncomfortable, and none were required to answer any of the questions. No identifying information or demographics were collected from parents on advice from the community partner (VD), to encourage participation, increase their comfort level with participation, and confirm the anonymous nature of participation. With participants' consent, the discussions were audio-recorded for subsequent transcription. Upon conclusion of each focus group, each parent received a \$10 gift card as a token for participation.

#### ***MEASURES (FOR ADOLESCENTS)***

*Demographics.* The demographic form included age, gender, immigrant status (immigrant, first, or second generation), language most spoken

with friends, language most spoken with family, and proportion of Latino friends.

*Depression.* To measure depression levels, the PHQ-9 (Kroenke & Spitzer, 2002) was utilized. The PHQ-9 is a 9-item instrument that measures different manifestations of depressive symptoms and has been validated in several languages, including Spanish. The answers selected (on a 4-point scale) range from 0 = *Not At All* to 3 = *Nearly Every Day*. Sample items include: "little interest or pleasure in doing things," "feeling down, depressed, or hopeless," and "feeling tired or having little energy." Scores range from 0 to 27 when computing raw scores. There are also cut-offs for depressive severity diagnostic categories. Scores from 0 to 4 suggest minimal or no depression, 5 to 9 suggest mild depression, 10 to 14 suggest moderate depression, 15 to 19 suggest moderately severe depression, and scores from 20 to 27 suggest severe depression. In the literature, the PHQ-9 has been shown to be reliable. In a study of Hispanic American women, the reliability was  $\alpha = .84$  in the sample who chose the English version and  $\alpha = .85$  in the sample who chose the Spanish version (Merz, Malcarne, Roesch, Riley, & Sadler, 2011). Reliability in the present sample was  $\alpha = .87$  for the English version.

*Acculturative Stress.* The Social, Attitudinal, Familial, and Environmental (SAFE) scale (Mena, Padilla & Maldonado, 1987) was utilized to measure acculturative stress. The SAFE scale is a 24-item survey rated on a 5-point scale from 1 = *Not Stressful* to 5 = *Extremely Stressful*. Sample items include: "It bothers me that family members I am close to do not understand my new values," "It bothers me that I cannot be with my extended family," and "I don't feel

at home in this country." A 'does not apply' response option was also available, with a score of 0. Thus, possible scores ranged from 0 to 120. In the literature, the SAFE scale has been shown to be reliable with  $\alpha = .89$  (Mena et al, 1987). VD, SB and MR translated the SAFE into Spanish. Reliability in the present sample was  $\alpha = .90$  for the English version.

*Social Support.* The Child and Adolescent Social Support Scale (CASSS) (Malecki, Demaray & Elliot, 2000) was utilized to measure perceived support from family and school. The CASSS consists of 60 items that may be broken down into five subscales of 12 items rated on a 6-point scale from 1 = *Never* to 6 = *Always*. Subscales measure perceived social support from parents, teachers, class, school, and close friends. The full scale ranged from 60 to 360, with each subscale ranging from 12 to 72. Sample items include: "My close friends understand my feelings," "My teachers make sure I have what I need for school," and "My parents show they are proud of me." In the literature, the CASSS has been shown to be reliable with  $\alpha = .96$  (Malecki & Demaray, 2003). We used the full scale in the present study to preserve statistical power and to capture the totality of available support from all sources. VD, SB and MR translated the CASSS into Spanish. Reliability in the present sample was  $\alpha = .97$  for the English version.

*Self-Mastery.* In order to measure self-mastery, Pearlin and Schooler's (1978) Self-Mastery Scale was utilized. The Self-Mastery Scale is 7 total items that are scored on a 5-point scale from 1 = *Strongly Disagree* to 5 = *Strongly Agree*. Scores had possible ranges from 7 to 35. Sample items include: "I have little control over the things that happen to me," "I often feel helpless in

dealing with the problems of my life,” and “What happens to me in the future mostly depends on me.” In the literature, the Self-Mastery Scale has been shown to be reliable with  $\alpha = .74$ -.75 (Scheier, Carver, & Bridges, 1994). Reliability for the Spanish version has been reported at  $\alpha = .74$  (Rini, Wadhwa & Sandman, 1999). Reliability in the present sample was  $\alpha = .80$  for the English version.

*Family Functioning.* The Family APGAR (Smilkstein, 1978) was utilized to measure perceived family functioning. The Family APGAR consists of 5 items that are scored on a 5-point scale ranging from 1 = *Always* to 5 = *Never*. Scores had possible ranges from 0 to 10. Sample items include: “I am satisfied with the way my family and I share time together,” “I am satisfied that my family accepts and supports my wishes to take on new activities or directions,” and “I am satisfied that I can turn to my family for help when something is troubling me.” In the literature, the Family APGAR has shown to be reliable with  $\alpha = .77$  (Gómez & Ponce, 2010). The Spanish version has shown reliability of  $\alpha = .84$  (Bellon-Saameno, Delgado-Sanchez, Luna del Castillo, & Lardelli-Claret, 1996). Reliability in the present sample was  $\alpha = .86$  for the English version.

### **DATA ANALYSIS PLAN**

After each collection session, surveys were taken back to the academic team’s office where the results were securely entered into statistical software (IBM® SPSS® Statistics). Our first step was to describe the sample and the variables of interest, and determine relations among them. For this purpose, descriptive and bivariate analyses were completed for each collected measure. Our second step was to determine

what factors may explain depression and whether these differed by gender. For this purpose, regression analyses were used to examine predictors of depression and multivariate analyses of variance to compare males and females. A power-analysis for the regressions with G\*Power, alpha = .05, power = .80, four predictors indicated a needed sample size of 84 (Faul, Erdfelder, Buchner & Lang, 2009).

Focus groups were analyzed following a thematic approach (Boyatzis, 1998). Audiotaped focus group discussions were transcribed and translated verbatim by one of the authors (MR). Independently, MR and SB identified themes, and then met to discuss the themes and reach agreement on the set of themes to be used. They each then coded the transcripts according to the themes. Once the transcripts were coded, VD and KC verified the results. Cross-comparisons of focus group results for consistency with findings from adolescent surveys are detailed below.

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## **RESULTS**

### **DEMOGRAPHICS**

Our study sample consisted of 86 Latino adolescents ( $M_{age} = 15.24$ ,  $SD = 1.97$ ), and 108 parents. Demographics were not collected from parents participating in focus groups at the recommendation of the community partner to increase participation and facilitate disclosure. The responses from adolescents show that all but 3 parents were foreign-born (see Table 1). Among the adolescent participants, there was even representation of males (47.7%) and females (52.3%). See Table 1 for additional adolescent demographic information by gender; Chi-square

analyses showed no differences by gender in any of these demographic variables.

Proxy measures of acculturation among the demographics, such as language spoken outside the home (*English* was between 82.2% and 91.1% of the sample in the present study) and choice of friends (*Mostly or All Hispanic*, between 57.7% and 68.3%), suggest that overall, this sample of adolescents was already acculturated. This is noteworthy given that most of the adolescents were foreign-born (68.9% for females, and 56.1% for males).

Table 1: Demographic information by gender

	Females (n=45)	Males (n=41)
<b>Age</b>	Mean=15.20 (SD=2.19)	Mean=15.29 (SD=1.72)
<b>Immigrant status <sup>1</sup></b>		
I was born outside US	68.9%	56.1%
I was born inside US	28.9%	39%
My parents and I were born in US	2.2%	4.9%
<b>Ethnicity of friends <sup>2</sup></b>		
Mostly Hispanic	53.3%	61%
Mostly not Hispanic	35.6%	24.4%
All Hispanic	4.4%	7.3%
All not Hispanic	6.7%	7.3%
<b>Language for survey</b>		
English	91.1%	90.2%
Spanish	8.9%	9.8%
<b>Language with friends</b>		
English	82.2%	90.2%
Spanish	17.8%	9.8%
<b>Language with family</b>		
English	4.4%	4.9%
Spanish	95.6%	95.1%

Notes:

<sup>1</sup>Coded as born in US vs. Not for analyses

<sup>2</sup>Coded as all or most Hispanic or Not for analyses

No statistically significant differences by gender on any of these variables.

### DESCRIPTIVE AND BIVARIATE ANALYSIS

Means and standard deviations for study variables by gender can be found in Table 2. When examining cut-off scores for the PHQ-9, nearly half (47.7%) were experiencing minor depression and 10.5% were experiencing major depression. As a group, participants reported low acculturative stress, average social support and high mastery; they also reported highly functional families. Boys and girls differed in self-mastery,  $F(1,84) = 6.89, p = .011$ , with boys scoring higher than girls. They also differed in acculturative stress,  $F(1,84) = 6.68, p = .010$ , with girls scoring higher than boys.

Table 2: Correlations and Means (SD) among Study Variables by Gender

#### FEMALES

	PHQ-9	SAFE	CASS	MAST	APGAR
PHQ-9 Depression (raw score)	♦	.679**	-.306*	-.302*	-.268
SAFE – Acculturative Stress		♦	-.281	-.459**	-.399**
CASSSS – Social Support			♦	.069	.247
MAS – Self-Mastery				♦	.061
APGA – Family Functioning					♦
Mean	7.8	37.33	129	24.26	7.58
SD	5.48	20.28	20.54	4.68	2.32
Minimum	0	2	71	14	1
Maximum	25	80	180	32	10

MALES

	PHQ-9	SAFE	CASS	MAST	APGAR
PHQ-9 Depression (raw score)	♦	.485**	-.430**	-.646**	-.498**
SAFE - Acculturative Stress		♦	-.250	-.671**	-.273
CASSSS - Social Support			♦	.416**	.697**
MAS - Self-Mastery				♦	.397*
APGA - Family Functioning					♦
Mean	5.29	27.51	123.01	27.07	7.29
SD	5.91	14.07	22.66	5.27	3.08
Minimum	0	4	60	16	0
Maximum	21	61	183	35	10

Note. \* $p < .05$ ; \*\* $p < .01$   
 Statistically significantly different means by gender: self-mastery ( $p = .01$ ) and acculturative stress ( $p = .010$ )

Pearson correlations among variables are shown in Table 2, separated by gender. In general, correlations were low to moderate for all variables; however, it is noteworthy that correlations among some variables differed in strength by gender. In order to determine whether the differences in correlations were statistically significant, we used Fisher r-to-z transformation. With this approach we found that the correlations between depression and self-mastery were statistically significantly different by gender ( $z = 2.04, p = .04$ ), as were the correlations between social support and family functioning ( $z = -2.72, p = .007$ ).

We also examined demographic variables and their relationship to depression. Age was moderately correlated to depression ( $r = .32, p = .003$ ); closer examination showed scores in depression ranged from a low of  $M = 3.44$  ( $SD = 1.02$ ) at age 12, to a high of  $M = 12.78$  ( $SD = 2.59$ ) at age 18, with fluctuating scores

across ages. One-way analyses of variance examined differences in depression by gender, immigration status, and ethnicity of friends. Females reported higher scores in depression than males,  $F(1,84) = 4.172, p = .044$ . When we examined males and females by severity of depression based on cut-off scores, females were more likely to be at least minimally depressed than males (73.3% compared to 41.5%; see Table 3). There was no difference in PHQ-9 scores between those born in the US and those born outside the US, nor among those whose friends are mostly or all Hispanic or not ( $p > .05$ ).

Table 3: PHQ-9 Depression Diagnostic Categories by Gender

Diagnostic Category	Female n (%)	Male n (%)
Minimal or no depression (score ranges 0-4)	12 (26.7)	24 (58.5)
Mild depression (score ranges 5-9)	19 (42.2)	8 (19.5)
Moderate depression (score ranges 10-14)	9 (20)	5 (12.2)
Moderately severe (score ranges 15-19)	4 (8.9)	2 (4.9)
Severe depression (score ranges 20-27)	1 (2.2)	2 (4.9)

**MAIN QUANTITATIVE ANALYSES**

In order to examine the combined relationship of all predictor variables with depression, we ran regression analyses. Separate regression analyses were run examining predictors of depression for each gender to examine strengths of association and prediction values between groups. For both males and females, depressive symptoms (total PHQ-9 scores), the dependent variable, were regressed onto the various predictors: acculturative stress (SAFE), social support (CASSSS Total Scores), self-mastery, and family functioning (Family APGAR). The regression for females was statistically significant,  $F(4,40) = 9.09, p <$

.01. The full model explained a total of 42.4% of the variance in depression. Only acculturative stress showed enough strength to enter the regression equation ( $\beta = .656, p < .001$ ), with higher stress predicting higher depression. The regression for males was also statistically significant,  $F(4,36) = 8.69, p < .01$ . The full model explained a total of 49.1% of the variance in depression. Only self-mastery showed enough strength to enter the regression equation ( $\beta = -.467, p = .010$ ), with lower mastery predicting higher depression. These findings suggest that although all predictors as a whole played a role in male and female depression, there was one specific variable in each group (stress for females and self-mastery for males) that stood out.

### **QUALITATIVE FINDINGS FROM PARENT FOCUS GROUP**

Five major themes emerged from the eight focus group with parents ( $n = 108$ ). These were:

- 1) Parents' awareness and worry about depression in their children
- 2) Parents' awareness that their own behaviors and emotions impact their children
- 3) Parents' lack of resources to deal with stress in the family
- 4) Minority/immigrant status is both a cause of depression and a barrier to solutions
- 5) Conflicts between parents and teens are caused by cultural adaptation differences.

#### THEME 1:

This first theme addressed the focus of the present study, i.e. the depressive symptoms in Latino teens. Parents were asked several questions about this topic, and were informed that this was the focus of the

study. It is therefore not surprising that describing teens' depressive symptoms was a major component of parent responses. The teens' externalizing and internalizing behavior made it clear to parents that something problematic was happening. Some of the comments of parents that indicated problematic changes in behavior included:

*"They do not want to talk, so one can tell that something is going on whether it be in school, with friends, at home."*

*"She was so depressed she would go into the closet and cover herself with a blanket, and that scared me."*

*"They get into a bad mood. They also demonstrate it with anger...you can tell by their facial expressions...it worries me a lot."*

*"...my son will isolate himself, lock himself in his room—he does not want to come out."*

*"With the story of the girl [the cutting], I wanted to mention it to my children because I worry a lot. ..."*

#### THEME 2:

Throughout the focus group meetings, parents showed insight into their own contributions to their children's mental health. These were demonstrated by comments such as:

*"We do not always express it, but sometimes the teens will hear us talking about our economic situation, about not being able to pay the rent, to buy food."*

*"Sometimes there are conflicts between a couple...a lack of money and family problems so they find out and I think that is a cause of great stress for them."*

*“We are living in an age where the Latino is persecuted because of the migratory situation. So if the parents are feeling affected, it is to be expected that the adolescents feel it as well.”*

*“...sometimes parents make it so that the kids are embarrassed of their background. So we cannot do that because they do not know what or who they are, if they are from here or from there, although they were born here.”*

#### THEME 3:

However, in spite of recognizing the problem and potential causes, parents often reported feeling helpless to find solutions because of various limitations.

Some of the parents' limitations were financial:

*“There are support centers but those are not accessible. ... sometimes our income is not enough to send our teens to a good psychologist or support group.”*

*“...I do not have any other family here to help me take care of them or to give me advice on how to help them. This is difficult for me.”*

Other times the limitations were related to free time:

*“...he does not confide because he says, ‘You work too much and come home tired and if I tell you my problems...’”*

*“So if they are happy and want to do things but I am not, I am stressed with work and bills, all that, I cannot give them the quality of time that they need. So they become stressed and lock themselves in their room, separate themselves from us.”*

Mostly parents reported limitations in terms of not knowing what to do:

*“As a parent, one feels powerless/helpless. They are at that age where one does not know what to do...we do not want to make them feel worse.”*

*“One does not know how to talk to the girls ...what do I do to take her out of that place to make her understand that I need to be with her and she needs to be with me? I have not been able to achieve that, I do not know how.”*  
*“They do not know how to communicate with us and we do not know how to be with them. ... I do not know how to go about doing that.”*

#### THEME 4:

Parents reported that minority/immigrant status was a barrier because of language and cultural differences, interpersonal problems, or legal issues.

Examples include:

*“...the culture influences them as well because migrating to another country as an adolescent is difficult because they want to go out but it is hard because it is another language.”*

*“[The Latino adolescents] do not identify with the [American teens] because of the language and the school and they do not identify with us because we are in a new country and we do not have our culture, our people.”*

*“My son has talked to me about how he has heard how teens make fun of students that have arrived from other countries so that causes stress.”*

*“...we do not have documents; they cannot get driver's licenses, all that perturbs them. So all that causes them to constantly think about all*

*those stresses and how we are going to pay for college when we do not have a social security number to be able to keep studying..."*

#### THEME 5:

In this theme parents address the effects on the family of the process of adaptation to the new culture.



*The pain some parents experience as they see their children become Americanized may cause strain in the family. Although parents report understanding the need for their children to integrate, they expressed difficulty with the process.*

Parents evidenced pain at watching their children adapt and possibly lose their culture of origin, and at times understanding that this may be a necessary step for adaptation. Comments included:

*"I impress upon her that she can be American because she was born here but she has our culture. So I have always told her that she has to embrace her culture. That she has Hispanic parents, that she looks Hispanic, that she does not look American, so she has to know that it is her culture, it is her roots and that she should not forget that."*

*"We as parents are never going to lose our culture. But we also need to understand that they are living in another culture. So for them, many times it is difficult. It provokes stress. So sometimes there is no identification with them because we teach them one thing, but they live in a different culture. And sometimes as parents we close ourselves off; we are also at fault for that."*

*"Even in the language, they come home talking in English and one tells them to speak Spanish because it would be terrible to be a Mexican that does not speak Spanish."*

### **TRIANGULATION OF QUANTITATIVE AND QUALITATIVE FINDINGS**

We found that the focus groups with parents informed and explained the quantitative data from the youth surveys. Our quantitative findings identified various levels of depressive symptoms in the adolescents. These were described by parents as a variety of behaviors, both internalizing and externalizing, in Theme 1.

Furthermore, the quantitative findings suggested that factors within the family contributed to depressive symptoms. Specifically, our assessment of family functioning using the Family APGAR scale, and of social support with the CASSS correlated with depression in boys. The CASSS, but not the Family APGAR, correlated with depression in girls. Theme 2 from the focus groups, where parents recognized that some of their behaviors and emotions contributed to the depressed mood in their children, clarified what sorts of couple and family issues might be leading to the observed correlations.

Theme 4, where parents reported language and cultural differences, interpersonal problems, and legal issues related to minority status, may partially inform why acculturative stress, as measured with the SAFE, correlated with depression among teens. Acculturative stress is the stress experienced as one adapts to a new culture, and the issues identified by parents might be

interrupting the teens' integration, or making it more challenging.

Theme 5 may be the most interesting and informative for future interventions. In this theme, parents address the effects of acculturation on the family. Parents explain how the process of acculturation and its associated stress (SAFE) relate to family functioning (APGAR). In the quantitative analyses, among females, family functioning correlated with acculturative stress, which was the only statistically significant variable in the regression predicting depression scores in girls. Among boys, family functioning correlated, at similar strength, with mastery, which was the only statistically significant variable predicting depression scores in boys. The pain some parents experience as they see their children become Americanized may cause strain in the family. Although parents report understanding the need for their children to integrate, they expressed difficulty with the process.

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## DISCUSSION

The results from the quantitative data gathered from the adolescents are consistent with the findings from other studies. In the present study Latino adolescent females reported higher rates of depression than their male counterparts, which matches extant literature (Lorenzo-Blanco et al., 2012; García, Manongdo & Ozechowski, 2014). Importantly, we found different predictors of depression among males and females, with girls' depression predicted by higher acculturative stress, and boys' by lower self-mastery. Social support from friends, family and school, and self-mastery correlated with lower depression for girls,

but in the presence of higher acculturative stress, did not reach significance in the regression, suggesting that the negative impact of acculturative stress was stronger than the positive impact of social support and self-mastery. For boys, higher social support from friends, family and school, lower acculturative stress, and higher family functioning correlated with depression, but in the presence of self-mastery did not reach significance in the regression, suggesting that the positive impact of self-mastery was stronger than the positive impact of social support and family functioning and the negative impact of acculturative stress.

Latino cultural norms show large differences in how parents raise Latino girls and boys. Traditional Latino cultural norms set expectations that female outside-the-home activities will be more restricted than males' (Lui, 2015; Roche et al, 2018) and that within the home they will perform household activities and be submissive to the rest of the family (Cupito, Stein & Gonzalez, 2014). These norms differ from the cultural norms in the US, which do not make such marked differences by gender (Raffaelli & Ontai, 2004). It may not be surprising then that immigrant girls acculturate at a faster rate than their male counterparts, possibly attracted to the greater freedom experienced by adolescent girls in the US (Céspedes & Huey, 2008; Lorenzo-Blanco et. al, 2012), a freedom that immigrant boys are not denied within their own culture. Unfortunately, this process threatens adolescent girls' mental health (Cupito, Stein & Gonzalez, 2014). Furthermore, parents who arrive in the US may be struck by the cultural differences in behavior, dress, and freedom for girls. These

differences may cause them to enforce their own cultural norms even more strictly than they would otherwise. These different cultural norms and rates of acculturation may explain why acculturative stress was the most powerful predictor of depression among the girls.

For boys, who in our sample did not experience as much acculturative stress as girls, the experience of adapting to the new culture may not be as impactful. Instead, the confidence and ability to deal successfully with stressors plays a more salient role. Self-mastery has been consistently found to protect from depression in adolescents (Gilster, 2014; Watkins, Hudson, Caldwell, Siefert & Jackson, 2011). It is important to note that self-mastery correlated with depressive symptoms at the bivariate level for the girls in our sample as well. Programs that increase self-mastery may help Latino teens, especially first or second generation or those whose parents have yet to acculturate.

Although the focus groups asked parents about teens in general and did not match the parental reports with the children's data, the mixed methods findings suggest other factors that relate to depression as well. Family functioning is invariably impacted by the experience of immigration and adaptation to a new country and culture (Lawton & Gerdes, 2014). In the focus groups held with the Latino immigrant parents, conflict related to cultural differences they experience with their children was often reported. As parents strived to maintain their cultural identity, their children seemed to strive to assimilate, or at least this was what parents perceived. Parents perceived danger in this, as they saw their culture and its values as

sources of strength for themselves and potentially for their children. As the children acculturate, they may not readily adopt, or may even reject, family traditional cultural values, causing even more family conflict and less family cohesion (Lorenzo-Blanco et al., 2012; Lui, 2015). Efforts to solidify family relations in Latino families may reduce family conflict. *Familismo*, a Latino cultural value of loyalty, respect and obedience to family, is protective of mental health in youth and may be diminished during the process of acculturation (Stein, Gonzalez, Cupito, Kiang & Supple, 2015). Interventions aimed at parents that explain the process of integration as an adaptive one may help them maintain familismo while at the same time allowing their children to integrate effectively into their new culture.

This decrease in family functioning may be especially difficult for girls. Although family functioning was not related to depression in girls, it was related to acculturative stress suggesting a potential indirect effect of family functioning for girls. Latino girls' acculturation may be accompanied by the deterioration of family cohesion and functioning due to the loss of Latino cultural values believed to discourage family conflict (Lorenzo-Blanco et. al, 2012). Because Latino adolescent females have greater sensitivity to interpersonal difficulties than their male counterparts, they may have more difficulty with family conflict, which places them at higher risk for depression (Lorenzo-Blanco et. al, 2012).

Our findings also highlight the importance of social support from various sources for these teenagers. Support from friends, family, teachers and school, the universe of relations for teenagers, were related to

lower depressive symptoms in both girls and boys. These findings are not surprising, as the relation between social support and mental health is well understood, and has been previously examined among Latino teens in general (Gonzales, Fabrett & Knight, 2009; Kuperminc, Wilkins, Roche & Alvarez-Jimenez, 2009; Potochnick, Perreira & Fuligni, 2012) and immigrant Latino youth (Blanco-Vega, Castro-Olivo & Merrell, 2008). These findings do, however, suggest further avenues for addressing depressive symptoms in this population. These include strengthening the available support systems and finding new avenues to address the growing concerns over these teens' mental health.



*Because of their challenges with language and cultural adaptation, parents felt helpless when faced with mental health problems in their children, and unable to find professional help in their community.*

Strengthening teens' social support systems become especially important when considered in light of the main findings from the parent focus groups. Theme 4 from the focus groups presents both an explanation for the frustrations of parents and a course of action if interventions are to be tailored to parents or to changes in policies at the local, state, or national level. Because of their challenges with language and cultural adaptation, parents felt helpless when faced with mental health problems in their children, and unable to find professional help in their community. Although at several of the focus groups parents

demonstrated interest in seeking help from mental health professionals, this was not always the case. Difficulties with getting Latino parents to seek mental health care for their children is well documented in the literature (McCord, Draucker & Bigatti, 2018; Stafford, Aalsma, Bigatti, Oruche & Draucker, 2019). This combination of reports from parents and extant literature suggest they are not likely to provide their teens with professional help unless it comes to them in the form of community-serving organizations that focus on mental health. Therefore, strengthening the available support systems, and finding new ones, is one way in which we can address the growing concerns over these teens' mental health; these support systems should include mental health professionals culturally competent to work with this population.

Our unique mixed methods approach, collecting quantitative data from adolescents and qualitative data from parents, was a strength of the study. It allowed for triangulation of data, and demonstrated that what happens within the home, what their parents perceive and how they behave, are important to understand adolescent depression and adaptation. The additional dimension of parental voice is often missing from studies of adolescents, and in the study reported here clarified many of the issues identified in the teens. It suggests a family-focused approach to interventions directed at this problem. Such an approach includes family therapy, parental training, and other approaches that consider the family unit as important when addressing problems in children and adolescents (Carr, 2014). There is evidence that this approach may be more effective than focusing on the individual child. A recent study of

family-focused therapy for depression in children, with a sample that was 15% Latino, found that it resulted in better depression outcomes for the children and more satisfaction among families in all demographics included (Thompson, Sugar, Langer & Asarnow, 2017).

The study presented here was a cross sectional, correlational, CBPR study, and as such, had inherent limitations. No conclusions can be drawn regarding causation among the variables. It is possible that depressive symptoms in the teens lead to problems in the variables we identified as predictors. It is also possible parental behaviors are caused by teen depression, and not the other way around. Although the triangulation of the teen's data with parental reports suggested explanations of one by the other, neither parents nor teens were privy to the others' data. Therefore, our conclusions are speculative and need to be confirmed in future research. Only studies that follow families over time, preferably upon arrival to the US or even earlier, would clarify causation. Of course, such studies are difficult with newly-immigrated and low-income populations. Our survey instruments as well as our focus group questions sought to determine mostly *what* was happening, much more than *why* or *how* it was happening. This was purposeful, as it was a first step in understanding the needs of the community.

Furthermore, our study was focused mainly on the teens, their parents, and their immediate surroundings. The experiences these families may have with the larger community within Indiana and at the national level were not explored. Future research that explores the impact of national immigration policies and the increased discrimination occurring toward this

population needs to be conducted. Research focused on parents suggests high psychological distress associated with immigration actions and national news (Roche, Vaquera, White & Rivera, 2018). Convenience sampling most likely resulted in a biased sample, especially given that our community partner conducted the recruitment. However, in CBPR research it is the needs of the partner's constituents that are the focus of the collaboration, presenting both a limitation and strength of this type of research. These limitations related to CBPR, however, are counterbalanced by the importance of, and the ability to, reach a sample that seldom is represented in research.

In spite of these limitations, the quantitative data from the adolescents in the present study helps to understand factors associated with depression in Latino youth, and the qualitative data with parents clarified many of the dynamics between Latino teens and their parents during the difficult and uneven process of acculturation in these families. It suggests further avenues for research into this important problem and informs potential interventions at both the individual, family and community level.

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