Community-engaged Asset Mapping with Latinx Immigrant Families of Youth with Disabilities

Yolanda Suarez-Balcazar[a], Amy Early[a,] Damiela Miranda,[b] Hannah Marquez[a], Ashley Maldonado[a], and Manuel Garcia Ramirez[b]

[a] University of Illinois at Chicago, 1919 West Taylor, Chicago, IL 60612, United States.
[b] University of Seville, Department of Psychology, Camilo Jose Cela, s/n, Sevilla 41018, Spain.

This study was conducted at the University of Illinois at Chicago.
*Corresponding author: Yolanda Suarez-Balcazar
University of Illinois at Chicago (UIC)
College of Applied Health Sciences, Department of Occupational Therapy
1919 W Taylor St. Chicago, IL 60612, United States.

*Yolanda Suarez-Balcazar, is a Professor and Head of the Department of Occupational Therapy, Affiliate Faculty in the Department of Psychology and Department of Disability and Human Development. (ysuarez@uic.edu)
Amy Early, OTD, OTR/L, is an Occupational Therapist, graduate of the University of Illinois at Chicago. (arearly16@gmail.com)
Daniela Miranda, is a graduate student in the Department of Psychology, at the University of Seville, Seville, Spain. She conducted a research placement at UIC while the study described here was being conducted. (danimiranda@us.es)
Hannah Marquez, is a doctoral student in the department of occupational therapy at UIC. (hkweke2@uic.edu)
Ashley Maldonado, is a doctoral student in the department of occupational therapy at UIC. (amaldo24@uic.edu)
Manuel Garcia Ramirez, is a Professor in the Department of Psychology, at the University of Seville, Seville, Spain. (magarcia@us.es)

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Author Note

Abstract

Asset mapping is a participatory methodology that engages community members in identifying services and settings that promote health and wellbeing. This study aimed to identify community assets from the perspective of Latinx immigrant families with youth with disabilities. Latinx immigrant families ($n = 21$) participated in the mapping, followed by a reflection session and an open forum ($n = 30$). The findings revealed that families identified faith-based organizations and social service agencies as some of the main assets in their communities, while they identified mental health services as the most needed. The results also showed that participants preferred to utilize services and resources that are within walking distance of their homes, provide safe spaces, treat them well, offer bilingual services, do not require documentation, and are affordable. This study has important implications for community scholars and practitioners interested in implementing asset-based methodologies that focus on participants as experts of their own realities and agents of change and that promote advocacy and empowerment actions.

Keywords: Latinx immigrants, asset mapping, disability, participatory research

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The health status of Latinx immigrant families, in particular those with children and youth with disabilities, is a public health concern due to their limited access to quality health and social services and to the large numbers of uninsured Latinxs (Balcazar, et al., 2020; Ruiz et al., 2016). It is well established that the Latinx population has limited access to culturally and linguistically relevant community services (Escobedo et al., 2019). Independent of socio-economic status or documentation requirements to access health services (via the Affordable Care Act), poorer health among this population has been linked to perceived discrimination in health care services, a lack of culturally relevant services, communication barriers, and limited access to and affordability of healthcare services (Chen et al., 2016). Disparities in general health and in access to health services are further magnified among Latinx children and youth with disabilities and their families (Rimmer et. al., 2011).

Research evidence consistently indicates that Latinxs in the United States lack regular health providers and often seek alternative and accessible resources to respond to their physical and mental health needs (Alcala et al., 2016). Latinxs frequently rely on one another's knowledge and skills to support their own wellbeing (Adames & Chavez-Duenas, 2017; Authors et al., 2020). The use of informal resources illustrates both a need within the Latinx community as well as this community's capacity to respond to stress and find support from within. Additionally, the political climate and attitudes toward immigration in the U. S. between 2017-2020 created a hostile environment for the Latinx population, leading to fear of punitive immigration policies, anxiety over possible separation from loved ones, and more frequent experiences of discrimination (Langhout et al., 2018). This increased social and emotional burden resulted in an increase in mental health stress and trauma, further pressuring families to

seek support from non-traditional sources (Gulbas & Zayas, 2017; Author, 2020). These burdens are even more pronounced among Latinx families with youth with disabilities, as they face twice the stigma and adversity in accessing resources given the intersectionality of their ethnicity and disability status (Cohen, 2013; Magaña et al.,2016; Authors et. al., 2018). Yet, there is a scarcity of information on the services and support systems available to Latinx families with youth with disabilities and on the use of strength-based approaches to explore the resources available to them.

Purpose of the Present Study

The aim of the present study was to identify the community assets, in the form of services and settings, that support the health and wellbeing of Latinx families caring for youth with disabilities via implementation of a community-engaged asset mapping methodology. Specific research questions included: (a) What are the highest rated community assets in the form of services and settings? (b) What are the most desired community services? (c) What are the characteristics of the community services and settings identified as assets? (d) What are the concerns and barriers to community services and settings? (e) What are the community services and settings used outside participants' neighborhoods? These research questions are addressed in this mixed-methods community-engaged asset mapping methodology grounded in a conceptual framework of empowerment and advocacy.

Community-engaged asset mapping engages residents in identifying resources and services that promote health and wellbeing through a participatory-action research approach and an interactive and dynamic visual process (Kretzmann & McKnight, 2005). This process facilitates the identification of strengths and assets as defined by the community itself, in contrast to traditional deficit-based approaches that define the needs of underserved neighborhoods from

the top down (McKnight & Kretzmann, 1990). The visual aid of the map displays the physical

relationships of underserved communities to assets, resources, and settings that support health

and wellbeing, highlighting connections between community resources and building on pre-

existing assets, while focusing on residents as citizens and agents of change rather than passive

service recipients (Mathie & Cunningham, 2003).

Conceptual Framework

A community-engaged asset mapping methodology is grounded in a conceptual

framework of community development that focuses on empowering communities through

advocacy and by identifying strengths (Wolff et al, 2016). The process is designed to empower

residents to develop self-advocacy skills by expanding on the strengths identified and

brainstorming actions to address needs. Communities forced to live on the margins of society

often develop their own dynamics and strategies to address unjust circumstances, since dominant

forms of care are not culturally relevant, not bilingual, or not otherwise sensitive to their realities

(Miranda et al., 2019). Traditional deficit approaches look at communities from a dominant lens

that undermine the relationships between residents and community assets and settings that have a

real social value to them, and as such are underappreciated throughout mainstream care systems.

Within a community development framework, participants engage in the process of making their

own decisions about community assets, explaining why they are identified as such and

identifying the action steps they want to take (Zimmerman, 2000). Identifying assets promotes

empowerment and advocacy as it considers community residents experts of their own realities

and is a process that builds residents' capacity to advocate for their health and wellbeing.

Asset mapping implies a critical evaluation component where residents have a space to

share their experiences and identify the supports and barriers in their community. Similar to

other visual participatory research methods, asset mapping facilitates critical dialogue and conversations about community resources through a visual and dynamic process followed by reflection (Foster-Fishman et al., 2010). This process helps residents build collective knowledge and identify their priorities for improving their health and wellbeing while challenging the negative narratives about residents that drive how resources are allocated within their community.

To date, only a few asset mapping studies have included Latinx immigrants (see Cutts et. al., 2016). To our knowledge, no applications of asset mapping have included parents of youth with disabilities nor aimed to understand community assets in the form of services and settings. Therefore, we adapted the community asset mapping method implemented by Miranda et al. (2019) in collaboration with a marginalized Roma community in Spain.

Method

Background and Setting

Prior to initiating the community asset mapping project, the authors of this manuscript developed and implemented the Healthy Lifestyles Program (*Familias Saludables*) in collaboration with community leaders and a community agency serving individuals with developmental and intellectual disabilities and their families (see Authors, 2018; Author 2020). The agency is located in a predominantly Latinx neighborhood of Chicago with a population of over 33,000 residents, 71% of whom are Latinx (Chicago Health Atlas, 2019). In this area, 14% of the households are at the poverty line (Chicago Health Atlas, 2019). The healthy lifestyles intervention, described elsewhere (Authors, et al., 2016; Authors, 2018), was offered at the community agency to Latinx families with youth with disabilities and followed a community-based participatory approach including ongoing development in collaboration with the

community. The Heathy Lifestyles community program was approved by the authors' University Institutional Review Board. The Healthy Lifestyles Program included exercise, health education, a family goal setting component, as well as frequent social learning group discussions and meaningful conversations, during which families discussed and inquired about local community services that could meet their needs (Author, 2020). One of the topics that emerged from a conversation was the need to identify assets—settings and services--in the community that could support residents' needs. In response, the investigators offered participants the opportunity to engage in a community asset mapping process during one of the program sessions. Institutional Review Board approval was obtained for the implementation of the asset mapping, and it was conducted at the partner agency following the signing of a supplemental consent form by those participants willing to allow data to be collected by the team. A $10 transportation stipend per family and refreshments were offered during the mapping session.

Participants

Twenty-one Latinx families participated in the asset mapping. An adult was the primary participant from each family, with periodic input from their children (with or without a disability). The sample included nineteen women and two men. One participant was an adult with a physical disability, another was a grandmother caring for a child with a disability, and the others were parents of youth and young adults with intellectual and developmental disabilities and mental disabilities. Some of the families were caring for youth on the autism spectrum (ranging from high functioning to non-verbal), others were caring for youth with developmental disabilities requiring intensive assistance with daily activities, while still other families were caring for children with a primary diagnosis of anxiety or Post-Traumatic Stress Disorder. All participants identified as Latinx immigrants (first generation) from a variety of countries of

origin, with the majority immigrating from Mexico. All participants spoke Spanish throughout

the mapping activity, subsequent reflection session, and open forum.

Community Asset Mapping Methodology

We adapted the asset mapping methodology for participants' culture and literacy levels

and divided the research process into five steps. During the preparation step, in conversations

with families and with their feedback, the investigators developed a set of 4 x 5" visual service

mapping cards for the participants representing the services and settings of interest. Previous

research supports the usefulness of visual and interactive materials when working with residents

with low literacy and/or limited English proficiency (Cutts et al., 2016).

The visual service mapping cards reflected the broader project's primary focus on

promoting healthy lifestyles by representing both formal and informal services one might use to

support health and wellness. The investigators selected the services and settings represented

based on participants' input as well as inter-researcher consensus; five team members

independently created lists of the most commonly identified potential services and supports

throughout the social learning conversations, and these lists were compared. Each set of cards

named a specific community services and settings (visual picture and name) including: (a)

primary healthcare doctor; (b) rehabilitation service (e.g., occupational, physical, or speech

therapy); (c) dentist; (d) mental health service; (e) sport or recreation facility; (f) community-

based organization; (g) park; (h) school or education setting; (i) church/religious service; and (j)

home. A blank card was also available for participants to map services and resources of their

choice that may have been overlooked or missed amongst the other cards. The cards provided

space to indicate the type of service typically received at each service or setting, the most

common mode of transportation participants used to get to and from the service or setting

(walking, public transit, or private vehicle), frequency of use (number of times per week, month, or year), and level of satisfaction rated on a scale of faces showing varying levels of happiness (ranging from very dissatisfied to dissatisfied, satisfied, and very satisfied), paired with Spanish descriptions. The scale of faces corresponds to scores ranging from 1 to 4. Each set of visual service mapping cards was color-coded to match the home neighborhood of each participant, in order to allow investigators to identify when a card was placed outside the participant's home neighborhood.

The researchers also prepared seven poster boards, five of which illustrated the communities participants had previously reported as their neighborhoods of residence. Each neighborhood poster board included familiar neighborhood landmarks and main intersections that would be easily identifiable for participants to facilitate accurate placing of the visual service mapping cards. Neighborhoods were color-coded in correspondence to the colored borders of the visual service mapping cards to facilitate organization of information throughout the data collection and analysis process. The researchers created a sixth board to represent services participants might receive outside of the five communities illustrated, and a seventh board titled "desired services" where participants could map services they were not currently receiving but needed or desired access to.

In the second step, participants came together at the agency, received an orientation to the asset mapping activity and materials from the principal investigator, and were given the opportunity to opt out of participation if desired. Participants were asked to select a home card that corresponded to the color of their neighborhood of residence and place it on the appropriate poster board. We did not ask for any other confidential demographic information nor the exact address of participants' homes. Participants then examined the visual service mapping cards,

completed the cards representing the services and settings they were currently using, marked their responses on each card (type of service, mode of transportation to get to the service, satisfaction with service, and frequency of use) and placed the cards on the poster board of the neighborhood in which they received that service. They were encouraged to complete cards representing services and settings that both they personally and other members of their immediate family used or needed, including the child with a disability. Participants were offered as many additional cards as desired to represent perceived services or assets that were not included in the set of visual service mapping cards or to map multiple locations of the same service (e.g., two different churches attended). If participants were not receiving a specific service but needed or desired that service, they placed a card on the "desired services" board. At the end of the mapping activity, investigators collected any mapping cards representing services that participants reported as "unused."

Immediately following the asset mapping activity, participants engaged in a brief reflection session for the third step. To allow for greater participation, we divided the participants into two reflection groups which followed the same protocol. Participants shared perspectives on the overall asset mapping process as well as their thoughts on the various services and resources they had identified. They were also encouraged to observe the different poster boards to see where everyone else had placed their cards and to exchange ideas and resources. The researchers asked families the following questions: (a) What services and settings in the community are available to you that support your family's health and wellbeing and that of your child with a disability? (b) Are you satisfied with these services and settings? Why or why not? (c) What services and settings do you wish you had available for yourself or for your child with a disability? (d) What would you like to see change in the services and settings near you? (e) What

can you do or where can you go to maintain your family's wellness? Two graduate students took

notes during each of the reflection sessions.

The fourth step involved data entry and analysis. The visual service mapping cards and

poster boards were carefully observed and photographed to identify patterns, such as which

communities had the most cards, and then the cards were removed from the poster boards and

their information was transferred and coded into an Excel spreadsheet. Two independent

researchers coded the mapping cards and compared the resulting data files, with 98.2% interrater

agreement. The information extracted from the cards included neighborhood (color of the card),

type of service or setting, common transportation mode, level of satisfaction, and frequency of

use. Discrepancies in card interpretation were discussed between the researchers until a

resolution was reached. These discrepancies were mostly about reading the marks made by the

participants on the cards.

Data were then labeled and classified according to service or setting identified, type

(formal versus informal), and location (inside home neighborhood, outside home neighborhood,

unused service, missing/desired service). Informal services and settings included parks,

recreation centers, churches, community agencies, and schools. Formal services included

rehabilitation facilities, doctors, dentists, and mental health services (services received outside of

the church). Community agencies and schools were categorized as informal services due to the

diversity of services they offered, as well as their free/low-cost nature. This categorization was

also based on the opportunities these settings offered to build intangible support systems by

connecting parents with each other, facilitating family gatherings and events, or hosting

community festivals. Local churches were identified as informal because the services they

provided were not necessarily ongoing, and they were often provided by university students,

paraprofessionals, and/or were settings that prompted informal networking, support, and personal connections. We do acknowledge that formal services are provided in settings classified here as informal. But in this study, the researchers were trying to examine the informal activities and services provided within formal settings, according to participants' input. Furthermore, these classifications were created based on previous literature demonstrating increased reliance on informal services among Latinxs and variations in service usage for Latinxs and low-income populations based on location and proximity to home (Martinez & Rhodes, 2020).

Total numbers of services used, unused, and desired were calculated, along with the percentage of formal and informal services reported per location. Average satisfaction scores were calculated for each service. Correlation between transportation method reported and overall service usage (number of participants who reported using the service) was calculated in SPSS using Spearman's rank correlation coefficient (rho). This was appropriate because our transportation data was both nominal and nonparametric.

Finally, the researchers transferred the data on exact service locations into Google Maps to share with participants during the fifth step. The identified resources were located by address or name as provided by participants and pinned on Google Maps to generate a visual aid for the follow-up open forum, knowledge transfer, and data interpretation. The researchers also pinned the available but un-utilized services for comparison.

The fifth step consisted of an open forum to share and discuss the results of the mapping with the families. About 30 Latinx parents of youth with disabilities attended the open forum, including both participants who completed the mapping activity and a few more who had heard about the project through social connections. At the forum, the researchers presented the summary results to participants. The researchers then displayed the Google Maps visual aids,

beginning with a map of the medical and dental services used in the two neighborhoods where participants primarily resided and any additional medical and dental services available that participants were not currently using. The second map presented a grouping of two of the most desired services (mental health services and youth programs). These maps enabled participants to play a pivotal role in data interpretation. The group moderator then led participants in a discussion on the following three questions: (a) What do you like about the resources in the community and services you are currently utilizing and resources available to you that support your family's health and wellbeing, including that of your child with a disability? (b) What are some of your concerns regarding existing resources and services when you consider accessibility for yourself or your child with a disability? (c) What services would you like to have that you don't have access to? Following the open forum group discussion, the researchers conducted a qualitative analysis of the group transcripts. Qualitative comments were transcribed verbatim and translated using back-to-back translation techniques (Grunwald & Goldfarb, 2006).

Data Analysis

To analyze qualitative data an analytic approach was utilized. Two bilingual members of the team with experience in analyzing qualitative data were involved in the analysis. Both independent coders identified relevant themes about each community service and setting mentioned and listed on the cards. Based on a team discussion of the transcript and an early review of these themes, a decision was made to use a deductive analytic approach (Braune & Clarke, 2006) whereby data were categorized into themes based on the research questions of the study and the questions posted to participants during the reflection session after the mapping and open forum. A codebook was developed which included type of service or setting, satisfaction with services and settings, characteristics of services and settings identified as assets, concerns

and barriers to utilizing community services and settings, and services and settings desired and/or utilized outside the participant's neighborhood. Two researchers individually analyzed the transcripts according to this codebook. Descriptive coding was followed in accordance with the research questions identified a priori. Interrater reliability was established by comparing the two coders' themes for consistency. The comparison revealed 95% agreement between the two coded transcripts. Both coders were familiar with the study and the mapping methodology. The coded transcript was given to a third-party coder, who then coded the data and discussed the codes and themes with the other two coders.

Methodological integrity as the basis for trustworthiness was enhanced by following principles of fidelity and utility (Levitt et al., 2017). Fidelity principles put in practice included using two independent coders to analyze the data, engaging multiple investigators, checking data results and seeking feedback from participants during the open forum, and grounding the data results with rich quotes and examples from participants (Levitt et al., 2017). Utility principles put in practice in this study included checking with participants on the meaning of the early data, retuning to participants for additional data during the open forum, and aligning the research questions to the research data (Levitt et al., 2017; Thomas, 2006). During the open forum, the researchers presented to participants a synthesis of the main results that emerged, asking participants to add to or comment on the synthesis and whether the results presented captured their reflections entirely, in order to check for accuracy.

Results

Both quantitative and qualitative data are presented here based on the asset mapping methodology, the group reflection that followed, and the open forum held two weeks later. Advocacy and empowerment actions by participants are also reported. As expected, and as

alluded to in the literature, a service or resource identified as an asset by some participants was occasionally identified as a concern by others, except faith-based settings. We present the results according to the research questions, with the quantitative findings first, followed by the qualitative results.

Quantitative Findings

Community assets in the form of services and settings: Utilization and satisfaction. Using the cards provided, participants mapped a total of 149 cards, including 98 classified as informal and 51 as formal, for an average of 7.0 cards per family. Most informal assets were utilized on a weekly basis, while formal assets were typically utilized yearly. As shown in Table 1, participants identified local parks as the most widely used community settings, followed by churches/settings of worship and doctors. Participants were generally satisfied with services they were receiving, with average satisfaction scores ranging between 3 and 4 for all services. Participants reported the lowest average satisfaction with parks (3.41) and the highest average satisfaction with community agencies and churches (3.69 and 3.63, respectively). Services and programming received at the church were coded as "church" services regardless of their nature. Likewise, services received at the school setting were coded as "school" regardless of the nature of the service.

Most Desired Community Services. Mental health services were mapped as the least used service. Participants mapped dental services as the most commonly desired/needed, followed by mental health services, rehabilitation services, and "other" services, in particular programs for youth with disabilities. These references to most desired services were outside of those they were already receiving at churches (e.g., mental health) and schools (e.g., rehabilitation services).

Geographical Location and Utilization of Services and Settings. There was a noticeable difference between formal and informal services with regard to geographical location. Fifty-eight percent of informal services were received inside participants' home neighborhoods, while only 17.3% of formal services were similarly located. According to Spearman's rank correlation analysis, transportation via walking was significantly positively related to service usage (r 0.81, p 0.01). Higher rates of reported transportation to a service via walking were commonly associated with higher rates of service usage. No correlation was found between service usage and transportation via driving or public transit. Participants mapped 17.6% and 28.6% of informal and formal services, respectively, as unused, and reported lacking (by categorizing as a "desired service") only 2.4% of the informal services mapped, compared with 14.3% of formal services. The data showed that a high number of participants were seeking medical and dental services outside their neighborhoods, and that participants were not using rehabilitation (outside of the school setting) and mental health services (outside of the mental health services offered at church), in particular for their youth with disabilities.

Qualitative Findings

Participants engaged in interpretation of the above quantitative findings both during the reflection session immediately following the asset mapping and at the open forum where the researchers presented the results and led participants in a discussion. The findings reported below are a synthesis of these two separate discussions. Themes about the services and settings that emerged out of the analyses are presented utilizing quotes from participants. All data has been de-identified of names and locations to protect confidentiality.

Assets of Community Services Utilized and Settings Frequented. Participants reported the highest average satisfaction with community agencies. In the reflection session, numerous

participants reported receiving needed services from the community agency partner in this study.

These services included a monthly family craft night, home-visit respite services for caregivers

of youth with disabilities, group homes for young adults with intellectual disabilities, job

training, and the Saturday intervention program provided by the research team. Participants

expressed that the services received from community agencies were meeting many of their needs

as families with youth with disabilities, as these services were bilingual in Spanish and English,

sensitive to the Latinx culture, and treated their youth with disabilities well and made them feel

proud of who they were. Participants mentioned in particular two local agencies, one being the

community partner agency where the study took place. As one participant said, "There are only a

couple of agencies in this area that offer services for people with disabilities, including youth,

and understand the Hispanic culture."

Participants also identified faith-based settings such as churches as a major asset and

source of satisfaction, thanks to the variety of services they provided to the community. Two

local churches in particular were mentioned. Several participants mentioned the benefits they

received from local churches, including free immigration services and legal counsel, food

assistance programs, domestic violence services and couples' therapy, health services provided

by medical students, mental health services, religious education, recreation and socialization,

leadership development, and programs inclusive of children with disabilities. They also

mentioned receiving all this programming in their native Spanish.

One participant stated,

"In [name of church] we have the support of the medical students from [local university],

and they come every 3 or every 6 months and they have services for diabetes, high blood

pressure, cholesterol, and that is something useful for all Hispanics who don't have

medical cards and if they find that you have an illness, they will take you to [medical center]."

Another participant added: "At my church they have a program and that is where all of the children with disabilities go and it is very good [in reference to preparing for First Communion and other programming], they accept and treat well children with disabilities." Another participant said, "The churches are providing supports for the community such as consultation about immigration and [access to] lawyers.*"*

Several participants particularly mentioned the value of the social opportunities, legal assistance, space for spiritual and mental wellbeing, and various other supports provided by churches in light of the current immigration policies and their fear of authorities. "At [name of church] they help me heal. I can cry there and everything. I can vent there. They support all my needs and those of my family. I feel safe."

Medical services outside of the health services provided at churches were another asset. Participants rated medical services as satisfactory when they felt the clinics and doctors were providing thorough check-ups, treating them respectfully, offering affordable care, and conscientiously attending to their health needs. One participant reported: "If my doctor sees something irregular she tells me, 'Go to the laboratory.' I like the attention of the providers. These people are always respectful of their patients. They always try to make you feel good." Another participant alluded to liking her healthcare provider because they offered affordable prices for people without insurance.

Participants identified dental services as a fourth asset. Some discussed satisfaction with their dental provider because of the provider's care and respect for children with disabilities. One mother stated,

"I like my dental service very much. When I started taking my children to [street name], I did not like how they treated them. I changed to [dentist office name] and it is a very great service. Above all, they treated my son with a disability very well there and my daughter. They have very good service."

Another participant supported the previous statement, saying, "I put the dentist [mapping card] because I love how they treat my children, including my child with a disability. I've gone too—I've gone to where I take them, and everything is in great condition, very clean. It is very nice." A few families also expressed satisfaction with finding dental care providers who were bilingual and who knew how to treat well and relate to children with disabilities.

Concerns about Community Services and Settings. Parks received mixed reviews from participants. Although some families identified the proximity or existence of a local park as a community asset, they quickly identified this asset as an area of major concern as well. Participants expressed satisfaction with the play spaces and walking paths at the local parks, yet reported significant safety concerns. Many recounted instances of gang activity making the park inaccessible despite its presence as an important community landmark and gathering space for many cultural and recreational events. These concerns are reflected in one mother's statement:

"I like that the park is close to where I live, but I am unsatisfied because there are many gangs around the park, a lot of shootings. It is not very safe to be in the park anymore.… We have things for our kids, but the reality is that it is not safe.… I say this because my son was recently shot in the arm. He was shot here.… So, now it's best to say, 'Don't go to the park, not anymore.' Since he was shot, he now needs rehabilitation services and he is very traumatized to even go outside."

As this participant expressed her view, several others nodded in agreement. Other participants followed this conversation by identifying a nearby recreational facility that they believed was being used by gangs as a place to sell drugs. All participants expressed concern about letting their kids play outdoors due to this unsafe situation.

Participants also identified dental care as both a strength and a concern, reporting distance as a barrier to dental service accessibility. One participant explained she does not often use dental care for her family: "It is far because I have to take 2 trains and 2 buses, but I like it [dental service]." Other concerns included cleanliness and the dentists' patience and lack of understanding of youth with a disability. One participant reported,

> "I used to take my kids to a dentist near [street name]. I didn't like how they treated my kids. The lady would treat them badly because my kids have the problem of wanting to throw up when they do their [teeth] cleaning.... And then she told my daughter [with a disability], 'If you don't behave then I'm not sure what is going to happen,' and that is not how you talk to a child. It's almost like they would try to scare her. My children didn't want to go back anymore."

Other Participants also reported dissatisfaction with inadequate quality of dental care:

> "When I went to the one here by [street name], I would go in with my daughter [with a disability] and in 5 minutes she was done. And when I took her to another [dentist office name] the condition in her mouth was very bad. So, I noticed that they weren't doing their job there, instead they would just take the money from the government and they wouldn't do their job as they should."

Participants reported dissatisfaction with some healthcare services due to cultural insensitivity to home remedies as well as scheduling conflicts. They also expressed difficulty

finding Spanish-speaking doctors and doctors that treat them well. One participant explained: "They don't schedule you at the time you are available, when you want or can come in, sometimes they don't treat you with respect. They don't care about you or listen to what you have to say." Others alluded to barriers such as distance, lack of private transportation, and having to make a long trip on public transit with a child with a disability.

Finally, participants expressed dissatisfaction with the limited availability of recreational facilities and sports programs for children and adolescents, in particular for those with a disability. Many of the participants reported dissatisfaction with the youth programs due to distance, scheduling conflicts, limited space, lack of supervision by program staff, and safety concerns due to the presence of gangs and drugs. One participant stated:

> "I would like to have [programming for youth with disabilities] for my children because when they return from school they don't have much to do. For example, I have my son with a disability in a program right now … but I have to go all the way to the north side to find something for him to do, I go up to the north side because there are no programs close to my neighborhood. It is a program that prepares them for high school."

Another participant added: "What happens is that the few recreational programs for youth are filled very quickly and they don't have many spots open [for children with disabilities].… It seems like every year they have the same people. There is no way of getting in. Something needs to change." Another participant supported the above statement: "As someone who lives further away, it's a bit more difficult to enroll my kid with a disability [in programs] because of my work hours."

Services Outside Participants' Neighborhoods. Themes in the secondary data arose from the open forum in response to questions concerning why participants do or do not use

certain services and what services they did not have access to and would like to have. The data

revealed that multiple participants received formal health services outside of their

neighborhoods. Participants reported seeking services outside of their neighborhoods due to a

lack of services within close proximity, the high cost of services in their area, or a lack of access

to services due to documentation status or insurance. One participant stated, "I seek healthcare

and counseling services outside my community because there aren't any near us. Mainly, they

ask you if you have health insurance and when you say, 'No I don't,' then they deny services to

you." Another participant added, "There are many places that don't see people without legal

documents."

       Desired Community Services. Participants noted both mental health and rehabilitation

services as services they did not frequently use, yet several identified these services as desired, in

particular for their child with a disability. Participants agreed that mental health services were

particularly needed for both themselves and their children, yet were inaccessible. They reported a

lack of mental health services that met their needs for Spanish-speaking providers, affordability,

service provision without insurance, and proximity. As a result, participants reported utilizing

informal mental, emotional, and social support services offered at local churches and obtaining

support from their own social network. One participant shared,

       "My daughter [with a disability] needs counseling services, but I can't find an affordable

       option for her, so I take her to the church. At my church they don't ask for

       documentation, they speak Spanish, and [they] offer many services that my family needs,

       and besides other families there support you as well."

       Participants reported rarely using rehabilitation services (e.g., physical therapy,

occupational therapy, vocational rehabilitation, speech therapy) outside of the school setting for

their child with a disability, instead supplementing their health and wellness with home remedies or community healers. One participant said, *"When we can't find services, we go to the healer, they will give you a massage and herbs. I say that because … 90% of the population is Mexican or Mexican descendant families. So, in our culture, we go to the healer."* Others relied on only school-based rehabilitation services for their children with disabilities. Yet some families alluded to their child needing additional rehabilitation services. A major barrier participants faced when accessing rehabilitation services was their lack of insurance coverage. One participant reported not using therapeutic rehabilitation outside of the school setting for their child with a disability, despite the doctor recommending such services: "Mainly because you ask your insurance for those services and if the person doesn't have them [covered under insurance], they don't give it to them. They aren't within reach for the person."

In summary, most participants identified two local churches as well as particular community agencies as the most important assets in the community. It is also important to note that during the mapping session, most participants expressed high levels of satisfaction with the local agency where the program was taking place and considered this particular agency a significant asset to the community. Participants mentioned liking these services and settings (the churches and community agency) in part because they were meeting their needs and those of their child with a disability, the services were in Spanish, people treated them with respect, and the services were nearby. Participants expressed mixed feelings about the local parks, healthcare services, and dental services. Most of the dissatisfaction regarding these services and locations involved concerns about safety, quality of treatment (not being treated with respect), lack of acceptance of their child with a disability, and cleanliness. They also alluded to not being satisfied with some services because the providers didn't listen or show that they care, didn't

offer programs in Spanish, lacked flexibility in scheduling appointments, and were not affordable.

Advocacy and Empowerment Actions

The results were shared with the agency staff (some of whom attended the open forum) and with a state representative in a town hall meeting. The town hall meeting was organized by the agency and advertised to the community. On their own initiative, study participants saw this as an opportunity to advocate for services and share the results of the mapping study with the state representative. About 40 parents and caregivers of youth and young adults with a disability attended the town hall meeting. The university researchers attended the town hall meeting to support the participants, but did not participate in order to respect participants' desire to share their voices with the state representative. The state representative listened to the families and assured them she was going to work with the community to address some of the safety issues. Families asked the state representative to take steps to address increasing safety concerns at the local parks and the lack of programming for youth with disabilities in the community. However, she did not make any commitment to advocate for more resources for the community. Twelve months after the town hall meeting, no action steps had been taken by the state representative to address the concerns of the participants. Unfortunately, populations that have a history of marginalization are often ignored by those in positions of power (see Author, 2020).

Community-engaged asset mapping can aid with neighborhood planning, local advocacy, and systems change. After the town hall meeting, families enhanced support mechanisms among themselves by exchanging phone numbers, creating a walking group in the community, and introducing new families to the local church; some families also became more actively involved in their community. The community partner agency established stronger connections with the

local churches identified by families as major assets. Furthermore, based on this study and the

concerns and needs that arose, one of the research assistants for this project developed a

directory of local services for families. Given that multiple program participants identified

mental health services as strongly desired yet inaccessible, she investigated local mental health

and community services that were affordable, bilingual/bicultural, and had experience serving

Latinx families with youth with disabilities, and compiled a directory of 27 mental health service

providers. This directory was then distributed to the program participants and to various

community agencies.

Discussion

There is limited research on the perspective of Latinx immigrant families with youth with

disabilities on the community services and settings available to them, the factors that characterize

assets, and the barriers to services. The Latinx parents of youth with disabilities who participated

in this study relied more heavily on informal than formal services for supporting their health and

wellbeing. This aligns with previous literature on Latinxs and their tendencies to seek informal

or nontraditional health services (Alcala et al., 2016). The results indicated that programming at

community service agencies and faith-based organizations plays a fundamental role in

responding to the needs of Latinx families with youth with disabilities.

Participants identified a couple of local churches as the most important informal asset due

to the variety of services they offered. In their view, the churches offered legal, counseling,

emotional, tangible, and social support; educational programming; and leadership and advocacy

opportunities, in addition to offering programming for youth with disabilities. Previous research

has noted the role of churches in supporting community residents (Adames & Chavez-Dueñas,

2017).

We also found a positive correlation between services accessed via walking and usage, indicating that participating Latinx parents and caregivers of youth with disabilities were more likely to utilize a service if it was within walking distance of their home. This may indicate that services within walking distance are easier to navigate with children with disabilities, as well as that residents are more likely to be familiar with and know about services within their neighborhoods. Other factors that contribute to the greater usage of such services may include not owning a car, having limited resources to pay for transportation, and/or not feeling comfortable navigating neighborhoods other than their own.

Latinx parents and caregivers identified factors that influenced their use of medical and dental services including the cultural sensitivity of providers, legal documentation requirements, affordability, language, being listened to, and respectful treatment of children with disabilities. According to participants, these factors either encouraged or deterred them from using services. These aspects, along with service proximity, can explain why Latinx families with youth with disabilities utilize the alternative routes of informal health services within their neighborhood, such as churches. A few participants who did not know about the supports provided by the local churches immediately took note of the address and contact information, and others offered to introduce them to the church and go along with them.

Participants also raised some concerns about the assets identified. Many expressed fear of violence in public spaces such as local parks due to gang activity. These results are troublesome as parks are traditionally considered healthy spaces for community engagement and physical and recreational activity (Bedimo-Rung et al., 2005). Participants expressed that violence often deterred them from visiting neighborhood parks. Paradoxically, participants still identified parks as one of the most used settings. This may be because of the parks' proximity to home and

participants not having many other options for open green space. These elements may explain

why nearby faith-based organizations and community agencies were a safe space for these

Latinx families. Our results reflect the capacity of community agencies and faith-based

organizations to become empowering community and safe spaces to learn one's rights and to

receive spiritual comfort and social capital (Adames & Chavez-Dueñas, 2017; Derose et al.,

2019; Maton, 2008; Villatoro et al., 2016). The finding that these are entry points for accessing

services is useful to inform future community collaborations with Latinx immigrant parents.

Limitations of This Study and Future Research

This study has some limitations, including a small convenience sample of participants,

the lack of additional demographic data about participants that could have been collected during

the reflection and open forum sessions, and the limited services and settings included in the

visual cards. The latter limitation may have provided a narrow view of the community assets and

strengths. Future research is warranted. The fact that participants were recruited through the

community agency sponsoring the project may have biased the results in terms of the type of

participants recruited and the agency being identified as an asset. This particular agency is one of

the few in the area that provide services for people with disabilities and their families, that

emphasizes on Latinxs, and that have personnel who are bilingual in Spanish. So the results may

be biased towards participants who were already engaged with the agency and were satisfied

with their services. While agency staff were not present during the asset mapping process, they

were present during the open forum, so it is also possible to assume that participants may have

seen the need or felt compelled to identify this agency as an asset.

Future research should focus on a wider sample from diverse community organizations,

and should explore a more diverse set of community services and settings. Surprisingly,

participants did not mention community services or settings related to immigration, aside from

the services provided at the church. Future research should explore in more depth the quality of

services and programming at churches, addressing questions of who provides such services and

what factors make such services culturally sensitive.

This study also has implications for policy and for empowering Latinx families of

children with disabilities. Community stakeholders and policy makers need to advocate for safe

public places so that youth with disabilities and their families can participate in their

communities, play, and thrive. They should also advocate for culturally relevant and bilingual

mental health services. In addition, researchers and practitioners alike should develop

partnerships with local churches and social agencies to reach out to the Latinx community.

Finally, community scholars and practitioners should promote the implementation of asset-based

methodologies that facilitate empowerment and decision making among participants (e.g.,

identifying community assets from their own perspective, advocating for desired services,

organizing walking groups, and connecting one another to local resources).

Conclusions

Engaging Latinx immigrant parents and caregivers of youth with disabilities in

community asset mapping is an innovative method to conceptualize neighborhoods. It increases

collective efficacy to advocate for needed services and to optimize the use of legitimized settings

(in this study, churches and community agencies). Engaging in research through sharing

experiences to co-produce knowledge is in line with social innovation methods to address

complex problems that are the product of political, economic, and social injustices (Murray et al.,

2010). The active and meaningful participation of community residents in the research process

helps mitigate power imbalances and elevates the voices of people who have been kept on the margins of society (Author, 2020).

Understanding the relationship of Latinx immigrant families of youth with disabilities to their identified context—the community services and settings they value—through asset mapping can provide knowledge to improve local health and wellbeing. However, the social aspect of this methodology can be a potential limitation due to the silencing impact of fear of disclosure related to the risk of immigration enforcement, common among Latinx immigrant families. Thus, it is necessary to ensure the confidentiality of participants' spaces in this type of research. To conclude, in this community-engaged asset mapping study, Latinx immigrant parents of youth with disabilities identified churches and local community agencies as integral to maintaining their health and wellness. Participants reported respectful treatment, bilingual care providers, cleanliness, location within their community, and absence of a documentation requirement as factors that make healthcare services assets to them. Participants also reported a significant need for dental services, mental health services, rehabilitation services, and youth programs.

The participatory community-engaged asset mapping methodology utilized allowed for a safe space for participants' voices to be heard and validated. We contributed new knowledge regarding the sources of support for Latinx immigrant families with youth and young adults with disabilities as well as their concerns. Future research should explore how such methodologies can be utilized to empower families to promote their own wellbeing. Overall, this study makes an important contribution to the literature by demonstrating the utility of an asset mapping methodology, identifying community assets from the perspective of Latinx immigrant families, and elevating the voices of Latinx families with children with disabilities.

References

Adames, H. Y., & Chavez-Dueñas, N. Y. (2017). *Cultural foundations and interventions in*

    Latino/a mental health: History, theory and within group differences. New York, NY,

    US: Routledge/Taylor & Francis Group. https://doi.org/10.4324/9781315724058

Alcalá, H. E., Albert, S. L., Trabanino, S. K., Garcia, R., Glik, D. C., Prelip, M. L., & Ortega, A.

    N. (2016). Access to and use of health care services among Latinos in East Los Angeles

    and Boyle Heights. *Family & Community Health, 39*(1), 62-71.

    https:doi.org/10.1097/FCH.0000000000000090

Balcazar, F., Magana, S., Suarez-Balcazar, Y. (2020). Disability among the Latinx population in

    the USA: Epidemiology and empowerment interventions. In A. Martinez, S.D. Rhodes

    (Eds). *New and Emerging Issues in Latinx Health.* (pp 127-144). Switzerland, Springer.

Bedimo-Rung, A. L., Mowen, A. J., & Cohen, D. A. (2005). The significance of parks to

    physical activity and public health: A conceptual model. *American Journal of Preventive*

    Medicine, 28(2), 159-168. https://doi.org/10.1016/j.amepre.2004.10.024

Braune & Clarke, 2006. Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology.

    Qualitative Research in Psychology, 3(2), 77–101.
    https://doi.org/10.1191/1478088706qp063oa

Chen, J., Vargas-Bustamante, A., Mortensen, K., & Ortega, A. N. (2016). Racial and ethnic

    disparities in health care access and utilization under the affordable care act. *Medical*

    Care, 54(2), 140-146. https://doi.org/10.1097/MLR.0000000000000467

Chicago Health Atlas. (2019). Access health data for Chicago and your community. Retrieved

    May 28, 2021 from: https://www.chicagohealthatlas.org

Cohen, S. R. (2013). Advocacy for the "abandonados": Harnessing cultural beliefs for Latino

families and their children with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities, 10*(1), 71-78. https://doi.org/10.1111/jppi.12021

Cutts, T., Langdon, S., Meza, F. R., Hochwalt, B., Pichardo-Geisinger, R., Sowell, B., Chapman, J., Dorton, L. B., Kennett, B., & Jones, M. T. (2016). Community health asset mapping partnership engages Hispanic/Latino health seekers and providers. *North Carolina Medical Journal, 77*(3), 160-167. https://doi.org/10.18043/ncm.77.3.160

Derose, K. P., Williams, M. V., Branch, C. A., Flórez, K. R., Hawes-Dawson, J., Mata, M. A., Oden, C. W., & Wong, E. C. (2019). A community-partnered approach to developing church-based interventions to reduce health disparities among African-Americans and Latinos. *Journal of Racial and Ethnic Health Disparities, 6*(2), 254-264. https://doi.org/10.1007/s40615-018-0520-z

Escobedo, P., Gonzalez, K. D., Kuhlberg, J., Calanche, M. 'Lou,' Baezconde-Garbanati, L., Contreras, R., & Bluthenthal, R. (2019). Community Needs Assessment among Latino Families in an Urban Public Housing Development. *Hispanic Journal of Behavioral Sciences*, *41*(3), 344–362. https://doi.org/10.1177/0739986319845103

Foster-Fishman, P. G., Law, K. M., Lichty, L. F., & Aoun, C. (2010). Youth ReACT for social change: A method for youth participatory action research. *American Journal of Community Psychology, 46*(1), 67-83. https://doi.org/10.1007/s10464-010-9316-y

Gulbas, L. E., & Zayas, L. H. (2017). Exploring the effects of U.S. immigration enforcement on the well-being of citizen children in Mexican immigrant families. *RSF: The Russell Sage Foundation Journal of the Social Sciences, 3*(4), 53-69. https://doi.org/10.7758/rsf.2017.3.4.04

Grunwald, D., & Goldfarb, N. M. (2006). Back translation for quality control of informed

Consent forms. *Journal of Clinical Research Best Practices*, 2 (2).

www.translationdirectory.com/article1043.htm.

Kretzmann, J. P. & McKnight, J. L. (2005). Discovering community power: A guide to

mobilizing local assets and your organization's capacity. Battle Creek, MI: W. K.

Kellogg Foundation. https://resources.depaul.edu/abcd-

institute/publications/publications-by-topic/Documents/kelloggabcd.pdf

Langhout, R., Buckingham, S. L., Oberoi, A. K., Chavez, N. R., Rusch, D., Esposito, F., &

Suarez-Balcazar, Y. (2018). Statement on the effects of deportation and forced separation

on immigrants, their families, and communities. A policy statement by the Society for

Community Research and Action: Division 27 of the American Psychological

Association. *American Journal of Community Psychology, 62*(1-2), 3-12.

https://doi.org/10.1002/ajcp.12256.

Levitt, S. M., Motulsky, S. L., Wert, F. J., & Morrow, S. L. (2017). Recommendations for

designing and reviewing qualitative research in psychology: Promoting methodological

integrity. *Qualitative Psychology*, *4,* 1, 2-22.

Magaña, S., Parish, S., Morales, M. A., Li, H., & Fujiura, G. (2016). Racial and ethnic health

disparities among people with intellectual and developmental disabilities. *Intellectual and

Developmental Disabilities, 54*(3), 161-172. https://doi.org10.1352/1934-9556-54.3.161

Mathie, A., & Cunningham, G. (2003). From clients to citizens: Asset-based community

development as a strategy for community-driven development. *Development in

Practice, 13*(5), 474-486. https://doi.org/10.1080/0961452032000125857

Martinez, A. D., & Rhodes, S. (2020). *New and Emerging Issues in Latinx Health.* Switzerland,

Springer.

Maton, K. I. (2008). Empowering community settings: Agents of individual development,

      community betterment, and positive social change. *American Journal of Community*

      Psychology, 41(1-2), 4-21. https://doi.org/10.1007/s10464-007-9148-6

McKnight, J. L., Kretzmann, J., Northwestern University (Evanston, Ill.). Center for Urban

      Affairs and Policy Research, & Neighborhood Innovations Network. (1990). *Mapping*

      community capacity. Evanston, Ill: Center for Urban Affairs and Policy Research,

      Northwestern University. https://mn.gov/mnddc/parallels2/pdf/90s/90/90-MCC-

      McKnight_Kretzmann.pdf

Miranda, D., Garcia-Ramirez, M., Balcazar, F., & Suarez-Balcazar, Y. (2019). A community-

      based participatory action research for Roma health justice in a deprived district of Spain.

      International Journal of Environmental Research and Public Health. 19:3722.

      https://doi.org/10.3390/ijerph16193722

Miranda, D., Garcia-Ramirez, M., & Albar-Marin, M. J. (2020). Building meaningful advocacy

      for ethnic-based health equity: The *RoAd4health* experience. *American Journal of*

      Community Psychology, 66, p. 347-357.

Murray, R., Caulier-Grice, J., & Mulgan, G. (2010). *The open book of social innovation* (p. 2).

      London: National Endowment for Science, Technology and the Art.

      https://youngfoundation.org/wp-content/uploads/2012/10/The-Open-Book-of-Social-

      Innovationg.pdf

Ruiz, J. M., Campos, B., & García, J. J. (2016). Special issue on Latino physical health:

      Disparities, paradoxes, and future directions. *Journal of Latina/o Psychology, 4*(2), 61-66.

      http://dx.doi.org/10.1037/lat0000065

Rimmer, J. H., Yamaki, K., Davis, B. M., Wang, E., & Vogel L. C. (2011). Obesity and

overweight prevalence among adolescents with disabilities. *Preventing Chronic Disease,*

8(2):A41. http://www.cdc.gov/pcd/issues/2011/ mar/10_0099.htm.

Author, (2020).

Authors, (2016).

Authors, (2018).

Authors, (2020)

Thomas, D. R. (2006). A general inductive approach for analyzing qualitative evaluation data.

American Journal of Evaluation, 27(2), 237-246.

https://doi.org/10.1177/1098214005283748

https://doi.org/10.1016/j.healthplace.2008.08.011

Villatoro, A. P., Dixon, E., & Mays, V. M. (2016). Faith-based organizations and the affordable

care act: Reducing Latino mental health care disparities. *Psychological Services, 13*(1),

92-104. https://doi.org/10.1037/a0038515

Wolff, T., Minkler, M., Wolfe, S., M., Berkowitz, B., Bowen, L., Butterfoss, F D., & Lee, K. S.

(2015). Collaborating for equity and justice: Moving beyond collective impact. *Nonprofit*

Quarterly. Available from https://nonprofitquarterly.org/collaborating-equity-moving-

beyond-collective-impact/

Zimmerman, M. A. (2000). *Empowerment theory: Psychological, organizational, and*

community levels of analysis. In J. Rappaport & E. Seidman (Eds.), *Handbook of*

community psychology (p. 43–63). Kluwer Academic Publishers.

https://doi.org/10.1007/978-1-4615-4193-6_2

Table 1

Summation of Data Collected from Visual Service Mapping Cards

Asset	Service Usage (# of participants)			Transportation[*]			Frequency[+]	Satisfaction
	Yes	No	Desired	Walk	Drive	Transit		
Park	21	0	0	12	3	2	weekly	3.41
Church	18	3	0	12	4	2	weekly	3.63
Doctor	18	1	2	5	6	7	yearly	3.67
School	15	4	2	6	3	6	weekly	3.57
Recreation Center	15	6	0	8	1	1	weekly	3.75
Dentist	14	2	5	3	4	7	yearly	3.64
Community Agency	14	6	1	7	2	0	weekly	3.69
Rehabilitation Facility	7	11	3	1	3	3	weekly	3.57
Mental Health	6	11	4	0	4	2	monthly	3.50
Other Service	1	N/A	3	N/A	N/A	N/A	monthly	N/A

[*] *N* varies due to some participants failing to complete all portions of cards
[+] Represents the majority of reported frequencies for this service (>50% of reports)