

# Holistic Care Coordination

## Environmental Scan of Holistic Care Coordination in Kansas

*July 2023 Addendum  
Spanish-Language Focus Groups*



## **Authors**

This report and its analysis were completed by Samiyah Para-Cremer Moore, M.Sc., Analyst, Kansas Health Institute; Mariana Ramírez, LCSW, Director, JUNTOS Center for Advancing Latino Health; and Mariana Hildreth, Communications and Community Outreach Coordinator, JUNTOS Center for Advancing Latino Health.

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## Background

The Kansas Department of Health and Environment (KDHE) and the Kansas Health Institute (KHI) conducted the first phase of the environmental scan that focuses on assessing existing holistic care coordination (HCC) services, programs, and payment models. As defined in the Holistic Care Coordination Environmental Scan Request for Proposal (RFP), an effective HCC model focuses on all aspects of family life, allowing for stronger supports around cross-system navigation and addressing the primary needs identified by the family, including physical, social and emotional health services, housing, education, legal and financial aid.

## About this Report

This report addendum complements the *Holistic Care Coordination in Kansas* report to include findings from additional focus groups. Since the development of the initial report, three additional focus groups were conducted in Spanish, including two focus groups with parents/guardians of children age 0–8 who are receiving care coordination services or have received these services in the past 12 months and one focus group with individuals who are receiving prenatal or postpartum care or have received these services in the past 12 months. The goal of the focus groups was to gain an understanding of the experiences of Kansas residents who are parents of children age 0–8, pregnant or postpartum with receiving holistic care coordination. These focus groups were conducted in partnership with JUNTOS Center for Advancing Latino Health. Detailed methodology for the focus groups is described in *Appendix A*. Questionnaires for focus groups with parents and pregnant or postpartum individuals are available in a separate document, available [here](#).

This report includes the key themes that arose in the Spanish-language focus groups. Themes are summarized in English. For each key theme a few representative quotations are included. These quotations are presented in Spanish to represent participants' words as spoken. English translations are included below each quotation. Questionnaires for the focus groups are available in both Spanish and English in the appendices.

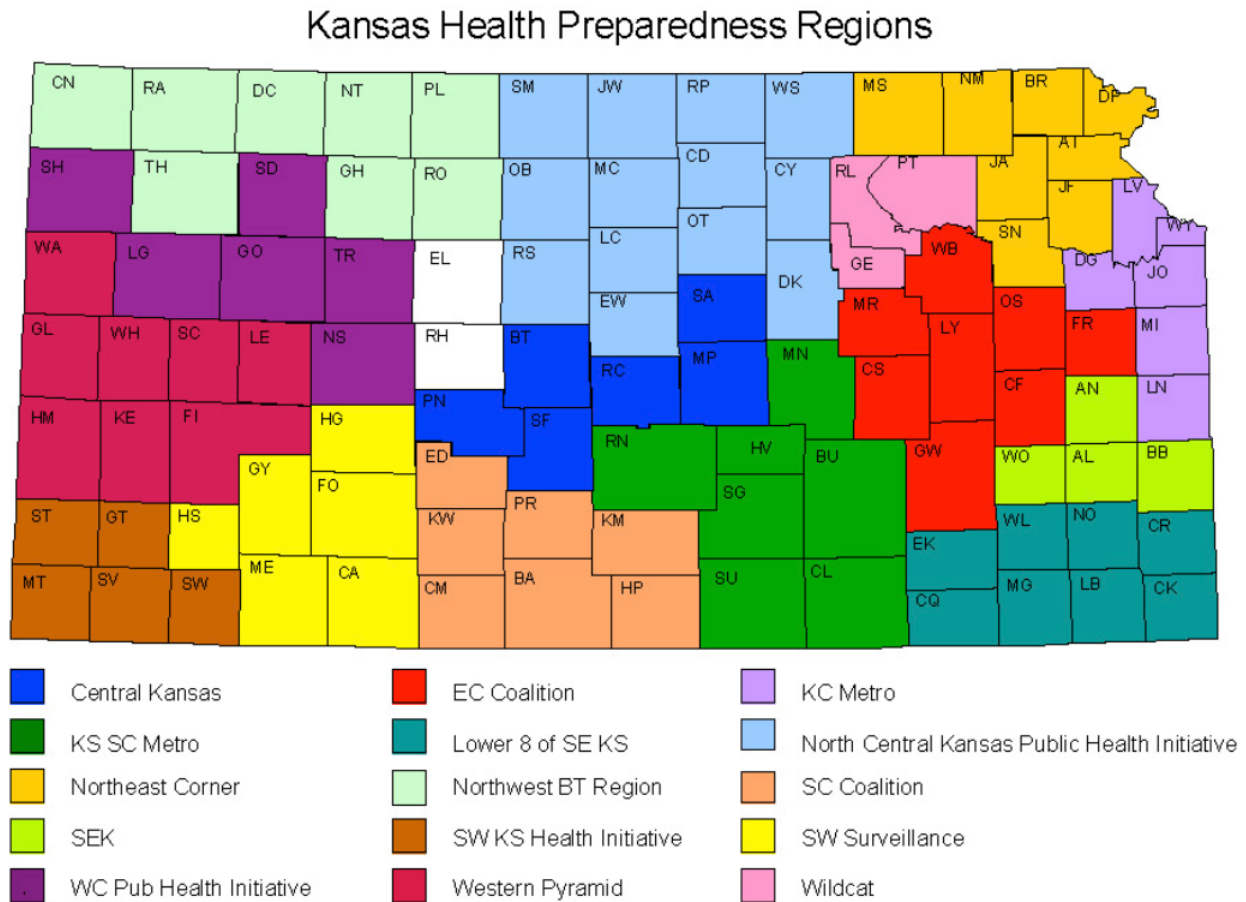
## Overview of Participants

There were 17 participants across the three focus groups, including 14 participants in the parent focus groups and three participants in the pregnant or postpartum focus group. Participants

lived in four counties across the following KDHE 2022-2023 Public Health Emergency Preparedness Regions (Figure 1).

- Kansas City Metro
- Lower 8 of Southeast Kansas
- Southwest Kansas Health Initiative
- Western Pyramid Public Health Region

Figure 1. KDHE 2022-2023 Public Health Emergency Preparedness Regions



Source: KDHE – Bureau of Community Health Systems  
Prepared by Bureau of Epidemiology and Public Health Informatics

Detailed demographic data for participants of the pregnant or postpartum focus group are not provided to further limit potential risk of identification.

For the two parent focus groups, all 14 participants self-identified as mothers, were between the ages of 23–39, and had from two to three children. These participants had at least one child age 0–8, but child ages ranged between two months and 16 years. One participant reported having twins. Several participants were also currently or recently pregnant. In the past 12 months, participants said their children had received preventative/well care such as checkups (13 participants), specialty medical care (two participants), or mental health services (one participant). Seven participants also described other services they received, including assistance with scheduling medical appointments and connecting to other programs or services. All 14 participants said their children had only received care within Kansas in the past 12 months and that a designated care coordinator had helped coordinate their child’s health care needs in the past six months. When asked which health insurance their children were covered under, 11 participants said Medicaid/KanCare, one participant said private insurance, and one participant said their children were uninsured.<sup>i</sup>

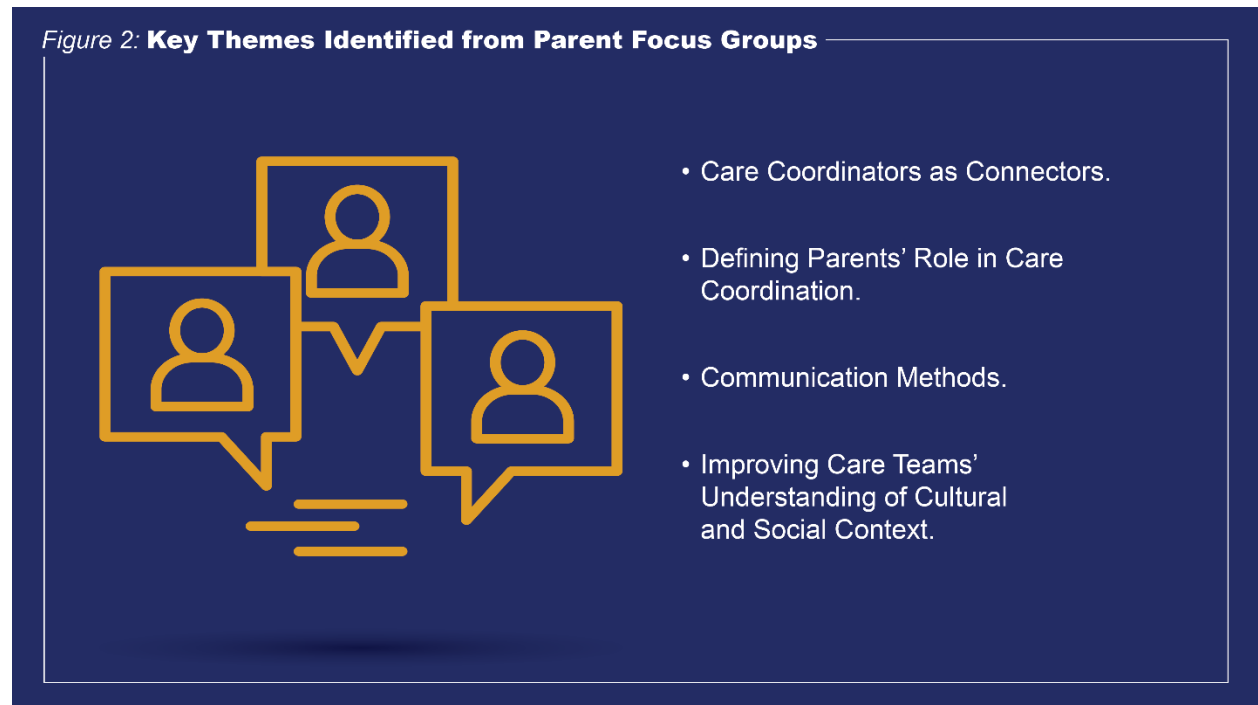
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<sup>i</sup> One participant declined to answer this question.

## Parents of Children Age 0–8

The following key findings were identified during the analysis of focus groups with parents of children age 0–8. Key themes were identified because they were most frequently mentioned by participants during the two focus groups (*Figure 2*).



### ***Care Coordinators as Connectors***

Parents described the role of care coordinators as connecting them with information, resources and other care team members. Although in some cases, participants described instances where the coordinator failed to communicate an opportunity or resource in time to meet their child's needs, participants also described positive interactions with care coordinators. One participant said she felt it was a privilege to have a care coordinator because of the powerful role they play in getting their children care, comparing it to fighting a battle side by side.

Participants highlighted the role of care coordinators using their bilingual skills to connect them with their medical team. This was particularly helpful when there was a lack of bilingual capacity in the clinics. Another participant described how their coordinator would connect them with resources she didn't know existed – like a local health department resource that helped her replace a damaged car seat for her child. Another way that participants described the care coordinators' role was through education and help scheduling appointments with different

medical providers and social service agencies. Some participants also described how they received support from their care coordinator related to understanding their insurance coverage and helped with applications for resources for their children such as diapers, housing, transportation or programs like the Special Supplemental Nutrition Program for Women, Infants, and Children (WIC). However, not all participants within the focus groups were offered this assistance from their care coordinator.

When asked ways to improve care coordination, a few participants provided examples where they did not feel supported by their care coordinators because they felt the coordinator was not following up on the goals established in previous sessions or did not tell them about the resources available until their child was no longer eligible for the service.

## ***Representative Quotations***

“Pero quiero pensar que cuando tenemos a alguien que trabaja con nosotros, con cualquier coordinador, o promotora de salud, que son personas que están para estar como en la batalla con nosotros, decímoslo así. Están de la mano con nosotros.” *But I like to think that, when we have someone working with us, like a coordinator or health promoter, they are people who are there to fight the battle with us, let’s put it that way, who are side by side with us.* -Parent

“En mi experiencia, que son buenas las visitas, pero si usted ya platicó un tema y la siguiente visita le vuelven a repetir el mismo tema, o como que es una meta y le dice, o se le olvida no sé si a la persona que está trabajando, o realmente como que no hay el recurso, pues ser honesto, decir pues <no hay un recurso con la meta que usted tenía en este momento.>” *In my experience, visits are good, but if you already talked about one topic, and the next visit they talk to you about the same topic, or the same goal and you tell them, or I don’t know if the person who is working forgets about it, or it’s that the resource is not available, in which case it would be better to be honest and say, “There is not a resource available for your current goal.”* -Parent

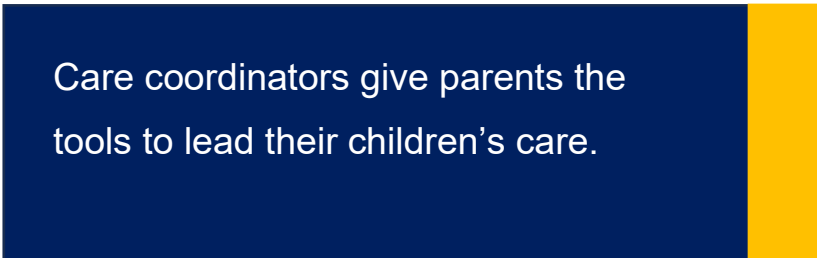
“Ese es como el trabajo más que nada de ellas, como ayudarnos a llegar al recurso que a veces se nos hace difícil. Y si no podemos solas llegar a ese recurso, pues siempre incluirlas en ese aspecto, creo yo.” *That is their job, more than anything else, to help us reach a resource that otherwise may be difficult for us to get. And if we cannot reach that resource alone, then always include them in that respect.* -Parent



## ***Defining Parents' Roles in Care Coordination***

Both parent focus groups described their role in their children's care coordination. Although there was overlap in the descriptions of their roles, two distinct perspectives emerged. In one group, participants described their responsibilities in the care coordination process as working to understand all steps of the process and their children's care. In cases where confusion exists, participants described that it was essential for them to ask clarifying questions until they understand.

The second parent focus group also described the importance of being involved in their children's care coordination. However, parents in the second focus group described their role as the leader of communication within the care team and as an advocate for their children's care. Instead of seeking just to understand, parents described how care coordinators give parents the tools to lead their children's care and that if parents do not take this lead, it hurts them and their child. One participant provided an example of how several undocumented parents that they know in their community have recently found the medical coverage of their children (who may be U.S. born)<sup>ii</sup> is being taken away and how she, in the role of *Promotora de Salud* (health promoter), is helping her neighbors to understand their children's insurance and renewal steps. The participants described that it is important to be able to continue their children's care if their care coordinator no longer can work with them.



Care coordinators give parents the tools to lead their children's care.

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<sup>ii</sup> Full Medicaid coverage for non-citizens is limited to refugees, veterans, persons who attained Legal Permanent Resident Status more than five years ago, and a small number of other individuals with specific immigration statuses. Other non-citizens, including the undocumented, cannot receive Medicaid coverage, but may qualify for [SOBRA coverage](#).

## Representative Quotations

“Porque como madres de nuestros hijos somos las primeras que tenemos que saber todo el proceso de nuestros hijos. Y en este caso sí. Sí he estado... hay cosas que yo pregunto y a veces tengo dudas, y yo lo que más quiero es que me las aclaren para poder estar satisfecha en ese punto. Y siento que sí he sido respondida en todo eso.” *Because as mothers of our children, we are the first ones who should know the whole process of our child. And in this case, yes. There are things that I ask and sometimes I have doubts and what I want the most is to have them answered so that I can be satisfied. And I feel that they have answered all of that.* -Parent

“Entonces, cuando nos dan un recurso, tenemos que, pienso yo, que aprender a ir nosotros, por nosotros mismos, y creo que es algo que como promotora [de salud] yo he estado tratando de ayudar a mis clientes más, en decir, okey, aquí está el recurso, pero, o sea, como decimos siempre, enséñales a pescar, no les des nada más el pescado.” *So, I think that when we are given a resource, we should learn to fend for ourselves. And this is something that, as a [health] promoter, I have tried to help my clients with by telling them, "Here's the resource," but, as the saying goes: teach a man to fish, don't just give him the fish.* -Parent

“Entonces, tenemos que tener en cuenta eso como padres, porque igual a veces nos quedamos a medias. <Ah, la promotora siempre me hace las citas con mi pediatra>. Entonces, un día la promotora la corren, como digo, se deja el trabajo, sin ninguna notificación, o lo que sea, entonces, yo no tengo la información del pediatra de mis hijos porque la promotora me lo hacía todo. Entonces, creo que ahí es más responsabilidad como nosotros de padres que la promotora.” *So, as parents, we have to keep that in mind because sometimes we get caught in the middle because, "The promoter has always made my appointments with my pediatrician." But if one day the promoter gets fired or leaves the job without any notification, or whatever, then I won't have the information about my children's pediatrician because the promoter used to do everything for me. I think the responsibility is on us parents and not on the promoter.* -Parent

## ***Communication Methods***

When asked their preferred method of communication with their care coordinator, participants most frequently described a mixture of phone calls and text messages. Both methods were described as very convenient because they could be accessed anywhere, anytime. In some cases, participants also used a patient portal like *MyChart* to communicate with their coordinators. One participant shared that she did not receive information from her health system about the availability of a patient portal but after providers mentioned it several times, she inquired about it, received help to register and found it easy to use. She described using the portal in Spanish but sending messages to the doctors in English. Another participant described how her care coordinator uses WhatsApp because most of the clients she works with prefer it, but the participant shared that it is not her preferred method of contact. One participant in each focus group also shared that they also receive in-person communication and home visits from their coordinators, and they value and enjoy those visits.

### ***Representative Quotations***

“Pues, por teléfono se me hace bien. Porque si tal vez yo estoy ocupada o algo por el estilo, solo puedo hablar con ella o... porque siento que si está más aquí, estoy como atrasadita, ¿me entiende?” *By phone. It's good for me. Because if maybe I'm busy or something like that, I can talk to her. Because I feel like if we're here, takes time, you know what I mean?*

-Parent

“No sé si como que a ella en su facilidad del día, o no sé si la mayoría de sus clientes lo hacen así por WhatsApp, para ella es mejor por WhatsApp y siempre me dice, ay, se me olvida que usted es mensaje de texto. Entonces eso sí es algo que no me gusta. Su presencia es una vez al mes, personalmente la veo. Lo disfruto mucho así, cuando viene y platica un momento conmigo de los recursos que hay disponibles en la comunidad.” *I don't know if she finds that difficult or maybe most of her clients communicate by WhatsApp because for her it's better by WhatsApp and she always tells me “Oh, I keep forgetting that you prefer text messages,” so that's something I don't like. I see her in person once a month and I really enjoy it when she comes and tells me about the resources that are available to the community.*

-Parent

“Pero en caso de que yo llegue a necesitar algo y es antes de la cita, entonces ellos siempre me dicen que puedo mensajearles, o llamarles. Y me gusta porque mensajes de texto es lo que más utilizo, casi no me gusta hacer llamadas, entonces me gusta más con mensaje de texto.” *And they tell me that, should I need something before the appointment, I can always text them or call them. And I like it because texting is what I use the most. I don't like to make calls. I like it better by text message.* -Parent

## ***Improving Care Teams' Understanding of Cultural and Social Context***

Participants described challenges they encountered when working with their care coordinators and other members of the care team including experiences where the parents felt they were not being listened to and instances where their coordinator did not understand their social and cultural context and how to incorporate this into the care plan. One example mentioned in both groups was hesitation around using care coordination programs or receiving resources because of fear of retaliation from immigration authorities or that the government will take their children away. One participant also shared that a care coordinator they worked with didn't realize that the resources the families qualify for differ depending on where they immigrated from and how (e.g., asylees). One recommendation from participants was that care coordinators working with immigrant families were equipped with information about program eligibility, particularly regarding immigrant status. Another recommendation was to make information about programs and program eligibility more available and in other languages, particularly for recent immigrants. Participants in both groups also offered examples of positive interactions and the steps taken by their care coordinators to gain further understanding of the cultural dynamics and contexts. One participant described these efforts and mutual respect between the coordinator and the parents being essential to care coordination.

Make information about programs and program eligibility more available and in other languages, particularly for recent immigrants.

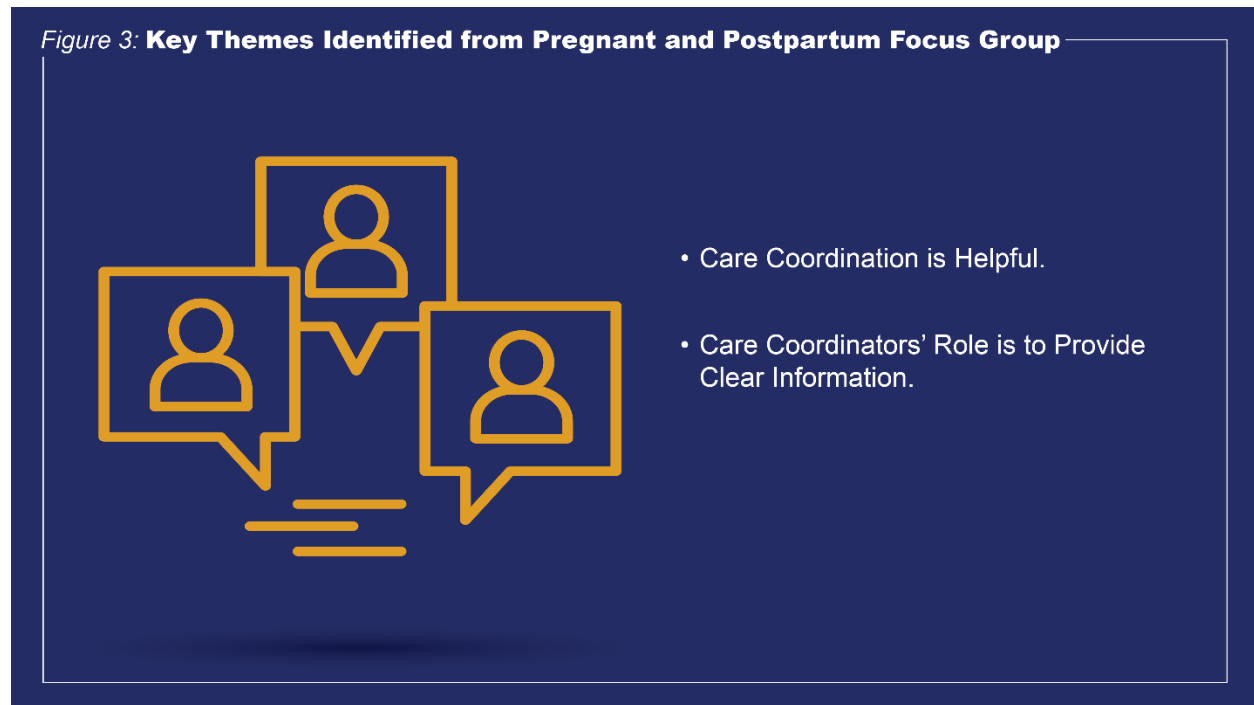
## Representative Quotations

“La doctora de mis bebés, ella no es hispana, ni hablan casi nada español tampoco. Pero ella entiende que son diferencias, ¿no? Y ella trata, trata de entender las diferencias que tenemos. Y siempre ha sido muy amable, muy respetuosa. Siempre trata de poner la integridad de mis hijos antes de que cualquier otra cosa.” *My babies’ doctor is not Hispanic and she doesn’t speak Spanish, but she understands that these are just differences, right? And she tries to understand the differences that we have. She has always been very kind and very respectful. She always puts the integrity of my children first.* -Parent

“Por ejemplo, mis hijos están en *Padres como Maestros* y el hecho que tenga el logo del gobierno no me genera ninguna duda, sin embargo, a otras personas sí. Yo vivo en un lugar de departamentos y la persona que me visita este, me pidió que si la refería con otras personas porque vio una situación insegura que le pareció con uno de mis vecinos, con los niños, entonces yo hablé con mi vecina y le comenté y le aclaro, le dije, <este programa no tiene nada que ver con... aunque sí tiene logo, tiene que ver más con escuelas públicas que con gobierno, no le va a generar ningún inconveniente en ese sentido.> Entonces ya fue como que <ah>, ella se relajó.” *For instance, my children are in "Parents as Teachers" and the fact that it has the government logo does not generate any doubt in my mind, but for other people it does. I live in an apartment building and the person who visits me asked me to refer her to other people because she saw a situation that seemed unsafe to her, with one of my neighbors, with the children. So, I talked to my neighbor and I told her and she was kind of doubtful and I told her, "This program has nothing to do, even though it has the logo, it has more to do with public schools than with the government. It is not going to generate any inconvenience in that sense" and then she relaxed.* -Parent

## Pregnant and Postpartum Individuals

The following key findings were identified during the analysis of the focus group with participants who were pregnant or postpartum. Key themes were identified because they were most frequently mentioned by participants during the focus group (*Figure 3*).



### ***Care Coordination is Helpful***

Focus group participants described care coordination as helpful and a positive experience. One participant said that care coordination during her recent pregnancy helped her feel much safer and more confident than she did during their first pregnancy when she did not receive care coordination. This participant described the key difference as having a single person who helps share information and guides them through next steps. Participants described types of care coordination offered to them including receiving help to apply for resources like WIC, Medicaid and baby diapers.

Two participants also shared instances where they were offered resources but said no.

Care coordination during her recent pregnancy helped her feel much safer and more confident than she did during their first pregnancy.

One of these participants explained further that they didn't accept the resources like transportation help because their spouse helps them with these things and they felt another person could need the resource. Participants also described how their coordinator directly worked with their doctors and clinics to help schedule appointments and, for one of the participants, their coordinator also attended their appointments to assist with communication and information sharing. Another participant described receiving this help via text messages or phone calls with their coordinator.

### ***Representative Quotations***

“Sí, yo pienso que sí es más fácil llevar todo eso a la misma vez de lo que yo no recibí anteriormente, y creo que tal vez eso sí me afectó, pero pienso que esta vez, estoy segura que no, porque ya siento como más seguridad en esas personas conmigo y yo también con ellas, que sé que están al pendiente de mi salud mía y la de mi bebé.” *Yes, I think it's easier this way than when I didn't receive that service. I think previously, it did affect me. But I think this time, I'm sure it won't because I feel more confident working with these people and them also with me. And I know they are taking care of me and my baby.* -Pregnant or postpartum individual

“Pues, de esa manera, ahorita no tengo ningún inconveniente porque mi esposo me ayuda y negué ese servicio porque yo dije, "¿para qué? A otra persona que si lo necesita.” *I don't have any inconvenience with that because my husband helps me. And I rejected that service because I thought, what for? Another person could need it.* -Pregnant or postpartum individual

### ***Care Coordinators' Role is to Provide Clear Information***

Participants described the care coordinators as having the important role of providing clear information. Participants primarily described positive experiences in which their care coordinator explained difficult processes, like navigating next steps after a surprise medical bill during pregnancy within the context of the patient's status. Areas for improvement requested by a participant was for care coordinators to spend more time explaining resource materials provided by other members of the care team and more time clarifying the application processes for different programs.

## Representative Quotations

[¿Pudieron resolver esa situación?] “Ahorita no, pero ya del otro, de que ella ya me explicó todo el por qué, por mí, por mi estatus, es más difícil. Entonces, ya ella me explicó muy bien los pasos que yo tengo que hacer ya al final de mi embarazo.” *[Were you all able to resolve the situation?] Not right now, but she explained to me why it happened. Because of my status things are more difficult. So, she explained to me very well what I have to do at the end of my pregnancy.* -Pregnant or postpartum individual

“Que desde que uno empieza con las citas, le expliquen a uno todo eso, porque igual la primera cita también, nomás a mí me dieron unos papeles que era de, o sea, para saber dónde están los hospitales, y saber cómo las instalaciones, pero solo eso. O sea, ya hasta ahorita que fue [nombre de la coordinadora] otra vez, la que ella me dijo que si ya sabía en qué hospital iba a ir. Yo pienso que sí sería bueno que desde que uno empiece con su cita, pues le den toda esa información.” *That when you start with the appointments, people explain all these things to you. Because in the first appointment, they only gave me some papers. It was to know about where the hospitals and all the facilities are. But they were just about that. And it wasn't until now that [name of care coordinator] came again, she asked me if I already knew which hospital I was going to go. So, I think it would be good that from the first appointment, they give you all that information.* -Pregnant or postpartum individual



## **Appendix A: Spanish-Language Focus Group Methodology**

As defined in the Holistic Care Coordination (HCC) Environmental Scan Request for Proposal (RFP), an effective HCC model focuses on all aspects of family life, allowing for stronger supports around cross-system navigation and addressing the primary needs identified by the family, including physical, social and emotional health services, housing, education, legal and financial aid. To better understand the experience of Kansas residents who are parents of children age 0–8, pregnant or postpartum, the Kansas Health Institute (KHI) conducted focus groups with participants from around the state.

### **Target Population and Interview Process**

The target populations for these focus groups included:

- Parent/guardians age 18 years of age or older of a child (children) age 0–8 who are currently receiving or have received HCC services during the past 12 months in Kansas and/or other states.
- Individuals age 18-44 years who are currently receiving or have received HCC prenatal or postpartum services during the past 12 months in Kansas and/or other states.

Focus group eligibility also required that participants live in Kansas, were able to understand and speak Spanish, could participate remotely over Zoom or phone and could provide informed consent of their own volition.

Participants were recruited using Kansas Health Institute (KHI), JUNTOS Center for Advancing Latino Health, and Kansas Department of Health and Environment (KDHE) statewide networks of community, medical and public health partners to share announcements of the focus group opportunity with the community members they serve via emails and social media. Potential participants were then screened for eligibility by the JUNTOS research team. Focus group recruitment began on May 23, 2023. Recruitment closed on June 19, 2023.

KHI and JUNTOS scheduled the focus groups with participants after receiving their informed consent documents. Three focus groups were conducted. All focus groups were conducted remotely using Zoom web-conferencing software. The focus groups lasted approximately 60 minutes. JUNTOS and KHI team members conducted the focus groups. Focus groups were

semi-structured and informed by the questionnaires, which are available in a separate document, available [here](#).

Facilitators prioritized and, in some cases, modified questions as appropriate based on participant discussion. The focus groups were recorded and then transcribed for analysis.

### **Data Analysis**

Interview transcripts were analyzed using NVivo qualitative data analysis software to assist with analysis. The KHI research team read and then open-coded the interview transcripts. The coding followed a systematic, iterative process involving 1) Initial a priori coding based on interview guide sections and questions; 2) Open coding line-by-line of all transcripts (during this process, the research team listened to the audio recordings); 3) Secondary and tertiary coding of nodes within each a priori code in NVivo to create themes; and 4) Themes were then summarized and exported from NVivo for review and discussion by the research team. During this process, analytical memos were maintained in NVivo to describe steps of analysis and reasons for thematic creation.