

COMMUNITY SPOTLIGHT

Kansas caregivers generate actionable solutions for improved developmental health experiences

In Fall 2022, as part of the All in for Kansas Kids strategic plan implementation efforts, the University of Kansas Center for Public Partnerships and Research (CPPR) conducted a survey to learn how Kansans understood the topic of early childhood developmental health, developmental screening processes, individual experiences with developmental milestones, and what local resources were available.

Results of the survey were collected as a first step to create improvements to existing outreach efforts and prioritize new initiatives and education. Nearly 1,500 families and providers across the state participated in the survey. Three themes emerged from feedback: gaps in awareness of developmental health, milestones, and screenings; family overwhelm in trying to navigate and access timely developmental health information about their child(ren); and, identifying who to trust for culturally responsive sources of information and supports.

Information gathered from that survey supported the next step of CPPR hosting six virtual family engagement sessions in Spring 2023, focusing on developmental health – the overall growth and development of a child, birth through five years old, including physical, cognitive, and social-emotional growth patterns. The Developmental Health Family Engagement Sessions included five sessions facilitated in English and one session in Spanish, with a total of 93 parent and caregiver participants. In each session, parents and caregivers were asked to generate ideas of small, actionable solutions to improve developmental health experiences for all families in Kansas.

Participant ideas and solutions were captured by Sara O’Keeffe, CPPR, and Diego Perez, Orange Sparkle Ball, through visual graphic recordings. Please view the collective graphic recordings in English and Spanish.

Some of their solutions included:

Featuring developmental health in community family engagement opportunities such as:

- Play groups
- Parent groups
- Health and education fairs
- Learning sessions with providers

Increasing home-based supports such as:

- Family resource kits with developmentally appropriate items
- Technology-based tools/supports from birth through 5
 - * Text options; Email options; Pamphlets
 - * QR code key fob for developmental health resources

Ensuring developmental health information is available through a centralized resource hub

- FAQ section
- Educational resources and learning opportunities
- Conversation scripts to help talk with providers about concerns
- Local screening events and opportunities

Elevating family voice through:

- Family/Provider partnerships/leaderships/councils
- Family engagement in local and state systems
- Social networking opportunities

Increasing community awareness of developmental health screenings and resources for families with partners such as:

- Local health care providers
- Early childhood professionals
- Community-based organizations
- Faith communities

CONTACT

If your community or organization would like to learn more or is interested in implementing the ideas developed through these sessions, please contact Rachel Gardner at rachelgardner@ku.edu.

VISUAL NOTE SUMMARY

Graphic Recorder, Sara O'Keefe, listened in on the process and created a visual summary as well as a written summary which can be found on the next page.

DEVELOPMENTAL HEALTH ACTIONABLE SOLUTIONS

PARENT-DRIVEN SOLUTIONS

3 Themes
formed from 1400 parent survey responses (Fall 2022)

- 1 Knowledge Awareness
- 2 Access Equity
- 3 Interventions ongoing SUPPORT

All In For Kansas Kids

Kansas
Children's Cabinet and Trust Fund

GAPS in Access to INFORMATION
KNOWLEDGE LOCAL RESOURCES
SPECIALISTS
EXPERTISE
SUPPORT
Screening
Free RESOURCES
AVAILABILITY

Feeling unsupported
current REALITY
"As parents, we are drowning!"

CONCERNS DISMISSED by provider
EARLY intervention is key!!

TENSION
TRUST IN PARENTS INTUITION

Every child's developmental timeline is different

HIGH level INSIGHTS
Clear timeline for: Developmental Milestones

USEFUL TOOLS
Activities for interacting with your child
Especially during "transitions" of self-advocacy of more in a culture of more

Mailings
Timed with CHILD'S GROWTH

Here's where you go / How you get connected
ASQ into the parents AND follow-up with...
What is an ASQ? (no ASQ answers)
OR BEING able to learn about MULTILINGUAL child's development
SPEECH DELAY?
Train Parent Child Play Group FACILITATORS
MORE SUPPORT from community members on basics

Child's diagnosis should be delivered in-person

"Resource Advocate" "Consultant"
More outreach ADVOCATE / NAVIGATOR FOR PARENTS FROM BIRTH ON...

EXPAND HOME VISITING CAREGIVER
Someone who knows...
ONGOING SUPPORT
CHECK ON PARENTS CHILD'S DEVELOPMENT
SHARE WORRIES IN PROBLEMS

Free RESOURCES
no matter your income
Free PROGRAMS / FINANCIAL AID

Characteristics of a preferred Provider:
✓ NOT a know it all
✓ empathetic
✓ encouraging

NOT ENOUGH SPECIALISTS
OPTIONS when therapists ARE NOT AVAILABLE
More info on specialists

SATURATE marketing
MEDICAID to KIDS

EXPAND MEDICAID
All PARENTS DESERVE ACCESS TO HEALTHCARE
Change Policy

POST
BETTER INFO by and for health insurance

PARTUM SUPPORT
AVAILABLE for everyone!

Insurance info must be easy to read - to the point, & reliable
What exactly is the difference between...?

THE HEALTH OF THE WHOLE FAMILY

DOUGLAS
OTHER PARENTS
PARENTS at same level as you
CHURCH PARENTS
FAMILY
ELDER
HOME VISITOR

OVERLAPPING GUIDANCE and SUPPORT
CDC
MILESTONES APP
NURSES
WIC
RESEARCHERS
LEAD CHILD CARE EDUCATORS
TEACHERS
EARLY INTERVENTIONISTS
PEDIATRICIAN

"Having a TRUSTED PROVIDER is so IMPORTANT for a family's health & well-being."

TRUSTED SOURCES FOR DEVELOPMENTAL INFO

"I want parents to know to keep questioning, advocating & looking for solutions, especially if your family is NOT being treated with respect (by your provider)."

Visual Note Summary

TRUSTED SOURCES

Kansas parents were asked what sources they trust for advice on developmental health. The sources they identified were pediatricians, nurses, early interventionists, other parents, elders, home visitors, doulas, lead child care educators, and WIC, as well as a handful of online apps.

Parents mentioned the importance of having a trusted medical provider for the health and well-being of a family, as well as a 24-hour nurse phone line for urgent health questions, which was seen as a lifesaving resource when immediate access to a medical provider wasn't available.

The parents who had experienced difficulties with their provider, as well as those who had positive provider experiences, were encouraged to continue to look for additional support, either outside of their provider's practice or with a different provider.

During the sessions, parents actively shared additional opportunities to help families connect to resources from community organizations and intervention services. Having these additional resources helped families supplement care from their primary provider and found that community resources helped them gain more comprehensive services and support.

PARENT AND CAREGIVER FEEDBACK

There were repeated comments from Kansas parents concerning the increased need for person supports and expansion of services, such as home visiting, doulas, patient navigators/resource advocates; improvement in accessibility of communication; information and services for parents as well as expressing the need for increased, creative outreach efforts.

Person supports and expansion of services

Parents supported increasing person supports and expanding services such as home visitors, doulas, patient advocates, or Early Head Start educators with whom they have rapport and can see routinely as a valued support. These relationships held value because they provided ongoing supports as needs arise and were curated to a family's needs. Professionals in these roles checked on the well-being of all members in a family and were agile in tailoring outreach for all types of caregivers.

Accessibility of communication, information and services

Many families shared that they found the information they were given on early developmental health overwhelming, which primarily happened after their baby was born or when they completed adoption or gained custody. Parents voiced a preference for receiving information about developmental expectations while they are considering conceiving or earlier on in the adoption or custody process.

Information delivered to parents should be: easy to locate and access, culturally competent, empathetic, and in the family's language. Kansas Early Childhood Developmental Services (formerly Tiny-k) has been supportive and a window into other helpful resources. Parents requested the information be useful and free, regardless of income. Parents and caregivers reported that information was not always accessible or timely. Waitlists for intervention and support can sometimes be many months long.

Parents wanted more clarity on early childhood development milestones, especially those typical after one year of age, when provider visits are less frequent. Caregivers said this would help them to be more prepared to identify and respond to suspected delays.

Creative Outreach Efforts

Outreach tailored to every type of caregiver is needed – whether they are an adoptive parent or grandparent. Go to families, meet them where they are, or would already be going – like a library, bookmobile, church, school, foodbank, park – and events like a family fun day with a bounce house. More casual spaces offer the opportunity to reach more families and lessen obstacles. Lack of transportation, lack of time, lack of child care, and lack of access to reliable phone, technology or internet are barriers. There is a need for multiple, overlapping ways to connect with families to ensure their needs are met.

Centralized Information Sharing

Creating a centralized place, such as a website or web portal, for resources that are tailored to your language, location, and age(s) of your child or children.

Actionable solutions mentioned in the visual summary

Expansion of in-person services

- Expand home visiting, Early Head Start, and make services available to everyone.
- Creating more patient navigator and resource advocate positions for parents from prenatal through the first few years of a child's life.
- Provide doulas for every family to help navigate pregnancy through postpartum.

Increase accessibility of information and communication

- Opt-in mailing that is timed with your child's growth with helpful information and activities to do with your infant/child
- More information on ASQs and specialists.
- Provide information in family's native language
- Laminated milestone chart 0-3 years to put on your fridge.
- More information on development of children who are learning multiple languages
- Workbook on how to advocate for your kid in a provider's setting
- More information on emotional and vocabulary milestones
- Information on Immigrant parent's rights in all languages
- Simplified, reliable information on health insurance, specifically Medicaid in all languages
- Education, just like for birthing and breastfeeding, offered on early childhood development
- Teach parents brain-building activities, how to work with your child whether they have diagnosed delays or not
- Pediatricians offering livestream classes, Q&A for the public
- Provider after hours availability and communication via email
- Telehealth for rural and working families
- A child's diagnosis delivered in-person by the provider

Creative Outreach Efforts

- Opt-in texting that follows the age, milestones and your family's location. Sign up for topics, receive podcast recommendations, etc.

- Incentivize with food, money, and child care
- App to reference activities that support a child's development
- Keychain with QR code to 1800 Children
- Drop-in Guidance offered at health fairs, public libraries, etc
- Use accessible language such as "Free vision and hearing screening" rather than developmental health screening.
- TV at OBGYN, Pediatrician/Family doctor's office that scrolls facts and tips about development
- Parent/Child play group facilitators and community members trained on basics of developmental health.

Centralized information sharing

- Centralized web portal that is available 24 hours a day, with current, reliable, easy to navigate information all in one place. Supported by multiple organizations, vetted by pediatricians and parent reviewed to empower community trust, and address real needs of parents, offer information on:
 - * Health insurance (specifically for immigrant families)
 - * Clear timeline of Milestones
 - * Activities to support your child's development and achievement of milestones, especially social/emotional and address language development in multi-lingual families
 - * Accessing services like WIC
 - * Preparing for birth
 - * Carseat info. Anything from laws, to installation, to where you can get one free
 - * Child care, searchable across the state
 - * Local parent communities, activities, events
 - * Breastfeeding, supplies and support
 - * Robust FAQ's and chat feature
 - * Information on specialists, and how to get a referral