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NC INTEGRATED CARE FOR KIDS

Integrated Care Round: Family Experiences with InCK Care Management

August 8, 2024, 12:00-1:00 pm

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Grounding for All InCK ICRs & Echos

- **Respect for All:** *There will be topics, situations, or maybe even resources that you as a person have various feelings about. We ask that in these spaces, we all show respect for all, by being supportive, caring, and professional.*
- **Take 2 and Pause:** *Discussion and hearing from you is so powerful, and what we strive for in these spaces. We ask that if you have shared twice, take a pause, to encourage colleagues to take the floor and share as well.*
- **Questions Encouraged:** *If you have a questions please ask, in most cases someone has the same one. Be BOLD and PROUD, ask it! You are always welcome to private chat La'Shanda Person and Josie Hatley as well!*
- **Play, Learn, Grow:** *Just like Fisher Price, we want you to enjoy this learning space, learn and grow from/with each topic!*



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Agenda

1. Clapper!
2. Family Engagement Research Findings
3. Breakouts: Research Findings Discussion
4. A Look Ahead

Clapper!

Kara Goel (Duke FN)



Thank you, Kara! We will miss you!!

"Kara has a huge heart for the families she works with. She takes the time to listen and be present with the families in a way that has really allowed her to build trusting relationships. Anyone who has worked directly with her can truly feel how much she cares about each individual child, their guardian(s), and the solutions available to them. I've always been able to count on her to ask clarifying questions and give honest feedback. I've really loved working with her- she's a real one!" - Kirsten A.

"Kara has absolutely embraced the NC InCK care management model! Whether she is referring kiddos for care management, reaching out for resource support to share with youth and families, promoting the development of age-appropriate goals, or just taking the time to build rapport with a family, she embodies everything InCK-y😊! It has been a true pleasure learning and sharing with Kara through this journey." - Judy L.

Family Engagement Research

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Overview

- Researchers are interviewing English-speaking families from three groups:
  - **Engaged in/graduated** from InCK care management (done—16 completed)
  - **Lost to contact** after initial InCK engagement (ongoing—6 completed)
  - **Declined** InCK care management services (will start in late August)
- Will repeat interviews with Spanish-speaking families from all three of the above cohorts starting in early fall, aiming for ~5 families from each group
- The following interview themes are from engaged & graduated patient interviews **only**

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Project Aims

Evaluate family experiences in NC InCK care management

Understand impact on clinical and economic resource needs

Identify opportunities to strengthen services

Assess effectiveness of communication channels

Explore potential barriers to utilization

Evaluate long-term impact on health outcomes

Recruitment Criteria

Interviewees were randomly selected from a pool of individuals meeting the following criteria:

- Engaged in InCK for 6+ months OR graduated from InCK
- At least two completed SAPs on file
- NOT in a current foster care placement or receiving Adoption Assistance
- Current residence in one of the five InCK counties
- Parent/caregiver able to communicate fluently in English

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A Reminder: InCK Standards of Care

- Provide intensive, integrated care management services
- Connect families to high-value community supports
- Engage non-clinical care team members in care management
- Address children's complex health needs
- Establish family-centered care plan goals

As we review research themes, think about how these standards are being reflected in families' experiences with InCK!

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Key Themes: Family & Caregiver Dynamics

- Women-led/Multi-gen Caregiving:
  - Slight majority were single, working (or job-seeking) moms. One respondent was single dad
  - Others were two-parent and multi-generational/grandparent-led households
- Caregivers' Busy Schedules and Personal Challenges:
  - Almost all caregivers worked and/or were full-time students
  - Many caregivers were dealing with trauma and/or major changes (relative deaths, job loss)

When she and I first met, I was **basically at the point of eviction**, going to court. I was jobless at that time…I was just pretty much trying to get back up on my feet.

I **don't really have the time to sit down and look for resources and stuff**. So when she calls, I'm like, "Oh yeah…let me answer the phone, I got these questions for you."

Key Themes: Family & Caregiver Dynamics

- Previous Care Management (CM) Experience:
  - Mix of no experience and limited (often negative) experience
  - Past CM interactions had narrow focus (e.g., job coaching, utilities help)
  - FNs' authenticity, lack of judgment, consistency helped families with negative past experiences engage with and trust their FNs

There's been times I've gone to social services and needed assistance with the light bill, and **that social worker would make me feel so small…**[FN] was like "We're going to help you. I'm going to help you get the help that you need."

…When I see her name in my email, **I know who that is.** Rather than like if a social worker from DHHS emails me, I might think it was spam because I don't know who they are.

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Key Themes: Decision To Participate & Communication

- Perceptions of Enrollment Process:
  - Often, assumption that child was selected for program by insurance/PCP
  - Assessment process seen as prep for FN
- Positive Initial Phone Call:
  - FN's personality and authenticity were key factors in engagement
  - Many decided to give the program a try b/c FNs led with support & warmth

> At first, I wasn't going to do [InCK], but **once I really started seeing how much help she was trying to give me**, and information about what we were talking about…That's what I really liked about her, **she was determined to help me and my daughter out as best as she could**.

> In the first call she asked, "What do you need help with?"…Once I had a conversation with her, **I could see that she was sincere in what she was doing**, and that right there had me. It's hard to find people that really want to do their job.

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Key Themes: Decision To Participate & Communication

…Even if I miss a call, **she doesn't make me feel like I'm wasting her time or that I'm not serious about [child's] health or about the help that she's giving me**…I know there are a lot of people who would have taken that very personally, and I just really appreciate her flexibility in that. **That has made such a huge difference in our constant communication and me being receptive to her phone calls**…

She never fails me. Like, **one time I text her. I didn't even call her.** I was like, "My tooth hurts, can you get me in with a dentist?" **She got me in the next week.**

- Communication Preferences:
  - Phone calls preferred for complex discussions
  - Written follow-up (patient portal, email) helpful for accountability, remembering info
  - Texting ideal for quick comms (e.g. rescheduling, requesting help) but not always available
  - Flexibility needed to stay in touch despite busy schedules, caregiver mental health challenges
- Communication Frequency:
  - Variation across members, from weekly to quarterly
  - FNs tailored outreach frequency to preferences
  - More frequent touchpoints helped some stay on track with goals
  - Several families were briefly LTC but reengaged

Key Themes: Support And Advocacy

- Resource Information:
  - Provision of useful health information and community resources
  - Overcoming health literacy barriers
- Service Navigation:
  - Completing applications, coordinating appointments, organizing follow-ups
  - Variation in booking appts. directly for families vs. providing info to families for follow-up
  - Assisting with follow-through and overcoming barriers to service

I had given [a utility bill relief program] a call and they didn't really respond back, so I called her, and then she called them, and she texted me right back. She was like **"I spoke to them, they're going to be right on it", and then they called me like the next day**…If there's something that's started and it's not moving fast enough, **she'll get right on it and get it done.**

I **wouldn't have been able to get [child] back in [for physical therapy] if the care manager hadn't been insistent and persistent** with getting in touch with them and reminding them and letting them know so they finally put us back in.

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Key Themes: Support And Advocacy

It's just basically like, well, **all 3 of my children are under her care**. So she speaks on all 3 of them, and what I can do different with each individual.

She sends me the pamphlets and the recipes so **we don't fall behind**—we don't go back, and we can just like stay focused and go forward…**I feel motivated. She does motivate.**

- Whole-Family Approach:
  - Supporting entire family unit, providing resources for caregivers (especially mental health resources)
  - Multiple interviewees were unsure which child was the one formally enrolled in InCK!
- Conversations with FN:
  - Regular engagement, judgment-free listening, affirmation, and empowerment. Positive and friendly
  - "Cheerleader," "personal assistant," "friend". Leading with "how can I help?"

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Key Themes: Adaptive & Holistic Care

- Proactive Outreach and Support Over Time:
  - Following up on changing needs and eligibility
  - Sharing resources family would not have otherwise known about
  - Serving as point of contact for family during tough times/changes
- Engaging CM as Part of the Team:
  - Collaborating with external entities, e.g., legal services after a crime

> Now that school is over, I can say that I've definitely been thinking of [FN] the past two months or so because **we're in this difficult spot, and the person I'm thinking of to contact to help is [FN].**

> **She just kind of pulled miracles for me**. Honestly, like, she was relentless on trying to get me resources and everything else.

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Key Themes: Adaptive & Holistic Care

She told me how to incorporate vegetables and fresh fruit and lunches and dinners and family walks, and **just doing a bunch of family stuff together to like motivate each other**.

We did address about **unplugging me off from the phone, social media, things like that**…it was just like, "Hey, maybe you guys wanna go out to the park, or you might wanna do this, or kind of try this…"

- Milestones and Goals:
  - Health-focused initial goals for patient and family, often around access to specific services
  - Financial/economic support goals like access to food, financial assistance for essentials
  - Goals for overall child wellbeing, e.g. recreation opportunities, improved school outcomes, more quality family time
  - More concrete goals for younger children vs. more abstract goals for older children

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Key Themes: Impact on Family & Overall Experience

- Improved Health and Lifestyle:
  - Better diet/nutrition, increased physical activity, and weight loss
  - Access to essential health care: primary and specialty care, behavioral health for kids AND caregivers, dental & vision
- Enhanced Quality Time:
  - Improved family dynamics through increased quality time and reduced admin burden for caregivers

We've been waiting [for an eye doctor appointment] for a year. **I talked to [FN] and had it accomplished in 45 days**.

[FN] goes the extra green mile every time to make sure that **both of my children can be seen by the same doctor**, and let me tell you, that's probably 30 phone calls each time.

[Child] and my two sons were… borderline diabetics, and **within four months they went from borderline diabetes to no diabetes at all.**

It definitely helps overall just because **it takes that stress off of me, which allows me to just be mom instead of professional.**

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Key Themes: Impact on Family & Overall Experience

- Academic Outcomes:
  - Improved school performance due to better health (physical and mental)
  - Increased access to services like speech therapy
  - IEP navigation help
- Economic Improvements:
  - Food supports, especially food stamps
  - Assistance with costs of basics like furniture, school supplies, rent/utilities
  - Connecting caregivers to professional development and job options

Their pencil pouches are full with everything they need. Erasers, colored pencils, and crayons. That just made it a lot easier for me, you know, to go on about my day and worry about more serious stuff because she's provided us with that stuff. **I don't have to worry about them.**

It's better, I ain't struggling. **I'm not struggling to pay bills. I'm not struggling to figure everything out and putting too much on my brain**.

Key Themes: Impact on Family & Overall Experience

- Support and Stress Reduction:
  - Significant reductions in caregiver stress due to improved economic stability and emotional support
  - Improved access to services across multiple domains
  - Increased sense of possibility and hope for the future (e.g. career growth plans for caregivers)
- Holistic Support:
  - Support for entire family, not just one child
  - Whole-family health improvements

I think [I'm] just showing up for myself like in more ways, and **I feel like the best way I'm showing up for myself is this program**.

When I go through stuff, [child] goes through stuff. Some people might not realize it, but it's like, **he's with me 25/8**. Not 24/7, 25/8. All the time.

In helping me, [FN] was helping [child].

Ever since she's been doing the calls and stuff, **it really has lifted me up**…I know that if I get in those situations, I can reach out to her.

It’s helped a lot mentally, because you know if…bills get behind or there’s something that you’re worrying about, “**How am I going to get this money to do this**?” **that affects your mental [sic] all over.** So it’s just, **she’s been there to like bridge the gap**. So it’s really helped out. It’s helped me out a lot.

The kids don’t really see it. The kids are kids. They just know they wake up, they go to school, they come home, they eat, and it’s everyday life, but, you know, as **a parent, you’re the one that’s always worried about, “What are we going to do for this? What’s going to be done about this?”**

I don't have the bill weighing on top of me. I can actually put the money together for the following month, and we can keep going.

I think the most helpful thing is having somebody that’s hearing it. **Sometimes we just need people to hear us**. We need people to see that we need the assistance.

I really think everybody on earth needs a [FN]… **Simplicity is probably something that every single mother on earth needs from time to time**, so the fact that she just got it, was cool with it, and has rocked the h*** out of her position since the very first interaction? **Not once has she changed, been rude, been short, not once has she sounded judgmental**. She’s just always positive. “Hey, how you doing? What can I do to help?”

Discussion

- Does anything from these interviews surprise you?
- How can we use these interview results to identify best practices in pediatric care management for InCK and beyond?
- What info/core competencies would you include in a job description to hire care managers like the ones people describe here?

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A Look Ahead

For more events in the 5 NC InCK Counties, check out our NC InCK Webpage and Facebook. Also, explore our new NC InCK training page for archived ICRs, takeaways, and shared resources.

Upcoming NC InCK Events:

Integrated Care Rounds: Children with Special Health Care Needs
Thursday, September 12th, 12:00-1:30 pm

Please contact Josie Hatley (anna.hatley@duke.edu) for the invitation for the ICR/Echo series.

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Upcoming Back to School Events:

Durham Rescue Mission Back to School Party: Aug. 9, 11 am-2 pm, Durham Rescue Mission, Durham

Carrboro/Chapel Hill Kidfest: Aug. 10, 9 am-1 pm, Carrboro Community Health Center, Carrboro

Queen's Chapel Back to School Party & Backpack Giveaway: Aug. 17, 10 am-2 pm, Queen's Chapel AME Church, Burlington

ACNC Mobile Wellness Center Back to School Giveaway: Aug. 24, 12-2 pm, Spellman Loop Lane, Henderson