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Integrated Care Rounds: Family Engagement Research, Part II

February 13, 2025: 12:00-1:30 PM

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Agenda

1. Family Engagement Research Overview
2. Initial Outreach Experiences
3. Experiences with NC InCK Care Management
4. What's Next for the Care Model
5. Looking Ahead

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 if you would prefer.*
- **Play, Learn, Grow:** *Just like Fisher Price, we want you to enjoy this learning space, learn and grow from/with each topic!*



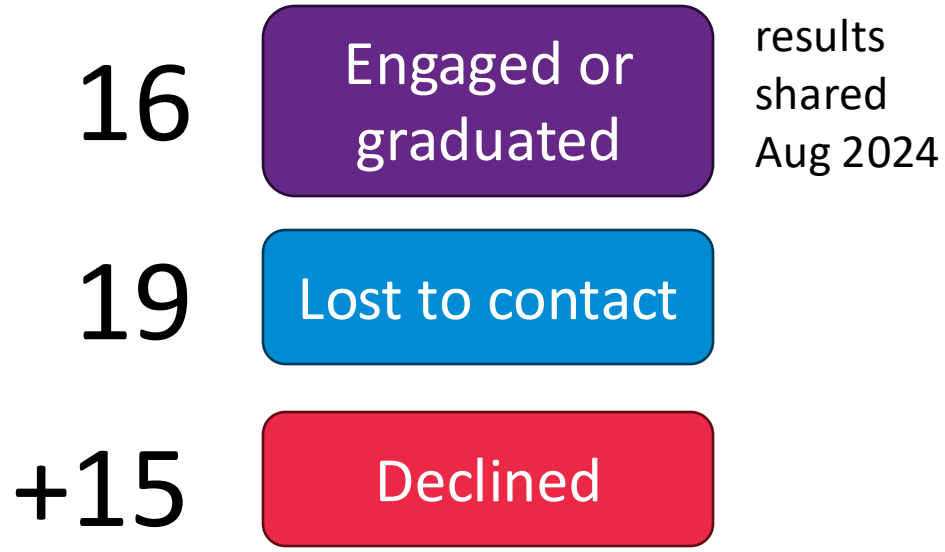
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Family Engagement Research Overview

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Overview

- Researchers interviewed English-speaking families from three groups.
- Interviews ongoing with Spanish-speaking families, aiming for ~5 families from each group
  - 6 engaged/grad interviews completed!
- Participants were compensated $50 for interviews and interviewed at times convenient for them, incl. nights and weekends.
- The following interview themes are from **declined** and **lost to contact** families



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A Reminder: NC 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/are not being reflected in families' experiences with InCK!

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Care Model Plans & Priorities for 2025

January-March: Continuing to refine initial outreach language to maximize enrollment

April-September: Navigating challenging cases, gray areas, and situations when needed resources just aren't available

October-December: Setting families up for success and long-term resilience after exiting care management

Recruitment Criteria – Declined

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

- Designated in NC InCK Virtual Health as Declined OR Lost to Contact without an initial SAP completed
- Active Standard Plan Medicaid coverage (NOT Medicaid Direct)
- Residence in one of the five NC InCK counties
- Primary caregiver(s) preferred language is English

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Recruitment Criteria – Lost to Contact

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

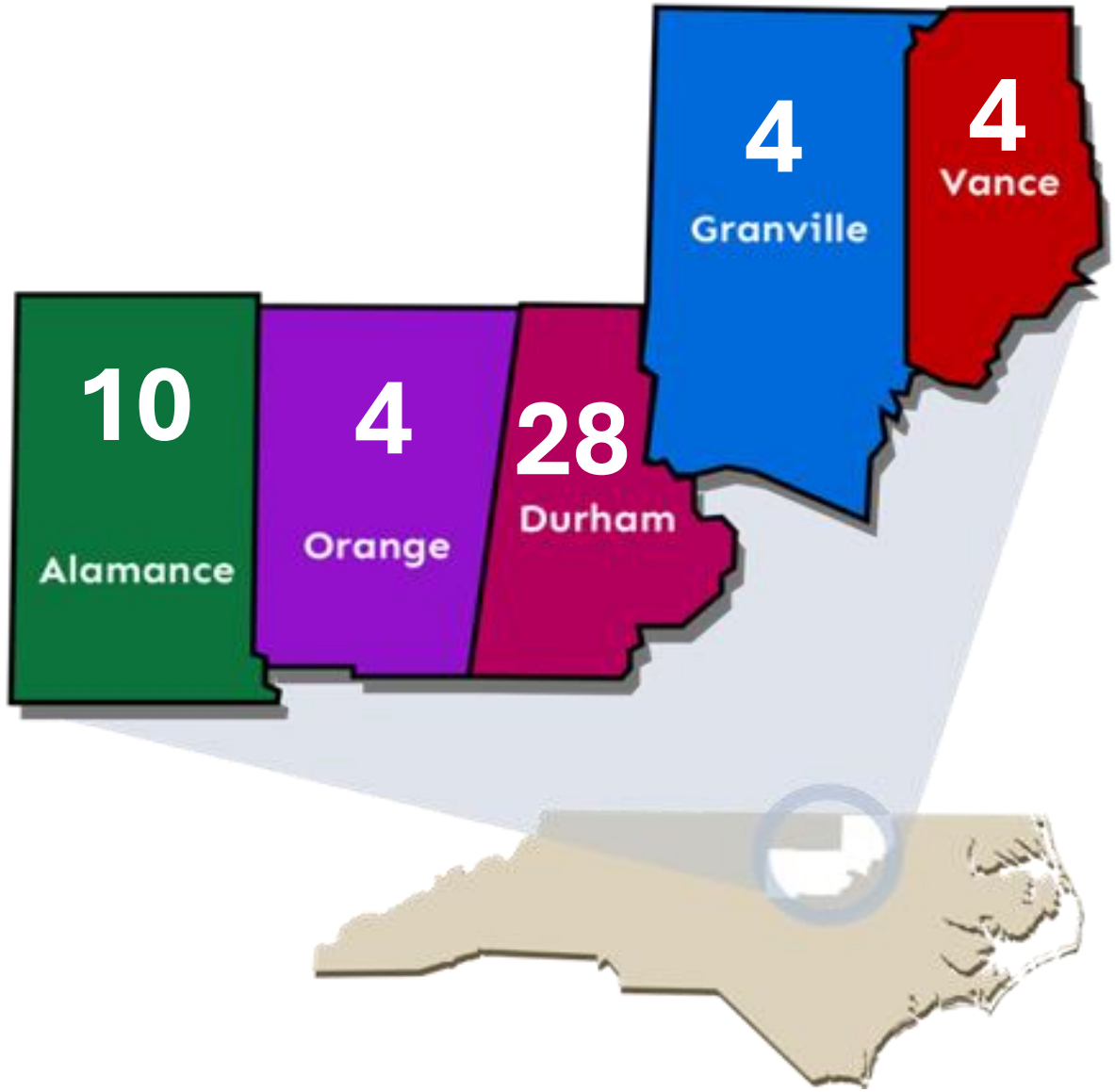
- Designated in NC InCK Virtual Health as Lost to Contact with at least one Shared Action Plan on file
- Active Standard Plan Medicaid coverage (NOT Medicaid Direct)
- Residence in one of the five NC InCK counties
- Primary caregiver(s) preferred language is English

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Study Population

Most interviewees were **mothers** (76%) and **grandmothers** (12%).

	N (%)
Child Race and Ethnicity	
Non-Hispanic Black	32 (64%)
Non-Hispanic White	10 (25%)
Hispanic/Latino	4 (8%)
Biracial	4 (8%)
Child Age	
0-5 yrs	10 (20%)
6-12 yrs	15 (30%)
13-17 yrs	17 (34%)
18-21 yrs	8 (16%)



Characteristics of Interviewees' Families

- Predominantly female caregivers, often from single-caregiver households or living with extended family
- Multiple families affected by substance use.
- Most families experienced some degree of challenges and trauma—major child & caregiver health needs (chronic and acute), family member deaths, job loss
- Many caregivers worked and/or were in school for career advancement, but others could not work due to health issues and caregiving responsibilities

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Initial Outreach Experiences

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Key Themes: Initial Outreach

- Many caregivers who declined had no memory of outreach
  - Some remembered multiple outreach calls but couldn't identify who they were from
  - Some had vague memory of friendly care manager offering resources.
- Helpful if outreach was linked to doctor's appointment or other event

The hospital usually has [a care manager], and then sometimes the individual doctors do. And then, now the insurance has one? And then the county has one… **At one point or another someone's called me from all of them.**

I am assuming that I got a call, and I guess I declined…**I think I was probably busy and was just trying to rush somebody off the phone.**

Key Themes: Care Management Expectations and Explanations

- Most people in both cohorts didn't know what care management was, even after outreach
- Many assumed it was exclusively medical or attributed outreach to the wrong program

See, when I talked to [the care manager], I thought she was more of doctor stuff, not necessarily like food banks and things like that…**when I think of Medicaid, I don't think of anything but doctors.**

Basically, what are they here for? Why do you want me to join? **If I know why and what, then I would definitely join.** If it could benefit [child] or help me out with her or anything, I would definitely join. I would do anything for her to be good.

I really didn't know what they offered. To be honest, **it was never broken down to me like this, this, this, this.**

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Key Themes: Caregiver Expectations for Independence/Self-Reliance

- Caregivers, including some who ultimately engaged, felt internalized shame around asking for and receiving help

I handle everything I need to handle by myself. You know, like, when my parents were alive and my aunt and uncle, I didn't tell them my finances. I didn't ask for help…**I just feel like as an adult, you should do that for your family yourself.**

To ask for help is to show a sign of weakness, and that was not the way that I was raised. So you know, it was like, **I'm not gonna ask for help for myself. I'm just gonna push through this and make it happen.**

It made me feel less of a grandmother, 'cause I couldn't…do this for them, and I shouldn't have felt like that because it was just being helpful.

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Key Themes: Worries and Concerns

- Lots of skepticism in both groups informed by prior negative experiences
  - Confusion about why they received a call
  - Concerns about legitimacy
  - Concerns about sharing too much
  - Concerns that the program wouldn't be helpful
- Care managers can help allay concerns about legitimacy

I was like, “Well, it could help me with the kids.” **I don’t want to turn anybody down. They might tell the [CPS] workers I didn’t want their assistance,** you know. Stuff like that. I just didn’t know.

Probably sometimes **I really don’t get involved like this with stuff like this because of my legal status.**

I've had a bunch of people call me. I had to start blocking numbers… I don’t know what's real. Y’all are all calling on the phone. I can't see you. I can't see y’all credentials… I could call and sound professional myself. **I don’t trust it.**

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Key Themes: Decision to Participate (Or Not)

- Caregivers who enrolled were often motivated by idea of potential benefit to children, especially if they had specific needs (like behavioral health)
- Caregivers who declined either…
  - Quickly dismissed call
  - Had specific concerns
  - Felt they didn't need it
  - Felt would be more work

I wanted things to be better for my daughter because, you know, her mother had passed, and she's still struggling with that.

I felt like it would actually be more work for me…I would still have to research those providers and then get back to them and say, "Oh, actually, that's not gonna work…" So I decided to just keep doing it myself.

I don't wanna have it and not need it…Because there's **somebody else that could use that resource** or could be waiting for that resource.

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Key Themes: Decision to Revisit Participation

73% (11/15) of participants who declined to participate or dropped out before completing SAP requested re-referral to InCK

If someone would have called me about that and explain it to me just the way you did, I'd've been all aboard…**Just the balance of being able to know that if I get into a situation where I need someone, to say, "Hey, can you help me? I'm in need."** And that one who can look and research and then find someone who can help me. Yes, that's very appealing.

I probably just didn't give the other person…time of day to say what he was trying to say. But **I would definitely be interested in starting [care management] services** for the kids with their Medicaid.

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Discussion: Implications for Initial Outreach

Care model priority for now through March: Continuing to refine initial outreach language to maximize enrollment

- How could we use information from these interviews to make initial outreach more effective?
- What kinds of services might be most important to highlight when talking to families to capture their interest?
- Are there outreach tools we could use to promote family awareness of care management BEFORE we call them for enrollment?

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Experiences with NC InCK Care Management

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Key Themes: Communication and Relationships

- Communication frequency tailored to families, but calls and MyChart could be burdensome (esp. when text/email unavailable)
  - Unscheduled phone calls especially challenging for families
- FNs perceived as compassionate and caring but not always equipped with lived experience or in-depth resource knowledge

She [FN] also had a daughter that she was fostering that she ended up adopting…**Talking with someone that has kinda been through some of this, it makes a difference.**

You know, I probably would have definitely worked with her more but…I never saw that there's notifications in MyChart, that I had a letter…All I know is that **the communication was hard as s***.**

The resources she gave me was like, **it never added anything new to my life**…But she was so sweet! I don't want to say anything about bad about her, she was so sweet. **That's probably why I continued talking to her as long as I did**.

Key Themes: Progress and Impact

I don’t have to worry**. I don’t have to stress so much about his education, about him being in a school setting all day long, and not feeling well**, and having to go get him every other day.

- Families who were successfully connected to resources reported at least some progress on goals

She was able to pull information that I couldn’t pull… legal information about guardianship.

It’s just like having like an assistant… she did everything while I was at work. So by the time I got off work, the appointments was scheduled. The medications was like already put in, made sure it was getting delivered on time. Everything, like **she did everything.**

I was stressing out that it wasn't gonna work out, that I shouldn't have taken custody of them… **Knowing that I got the resources, it made it a little bit easie**r to know, Okay, it's gonna take some time, but we can do this. We can get through this.

Key Themes: Progress and Impact

It wasn’t that significant… I'm on the waiting list for those things. **So I don't know if it will help or not because I'm still on the waiting list**.

Even though I didn’t receive the resources, just **having the thought that there are resources out there helped me! And I really appreciated her checking in on us.**

- Families who did not want or could not access resources saw minimal progress on goals and impact on child/family
- Some families noted intangible benefit of learning about resources and sharing challenges with sympathetic FNs

Key Themes: Barriers to Retention
Lack of Perceived Benefit

- Limited resource landscape and insufficient follow-up from FNs on obstacles
- Lack of need for FNs' systems navigation & resource ID help

I kept telling her, well, I've been calling for these resources to see if they'll help me with my rent or help me with my lights…but **nobody is reaching out, nobody saying that they have funds for me**. And she would just say, just keep calling. Just keep calling. I'm like, "I'm calling! Like, okay, what's the next step?"…**I just was like just talking just to talk. And I wasn't really receiving the help that I thought I was going to get**.

I guess I was hoping to be able to get information on stuff that I didn't know about. But then **I also am more resourceful than a lot of people…I didn't get anything different than I would have gotten at 2-1-1.**

Key Themes: Barriers to Retention
Lack of Perceived Benefit

- Misalignment between resources recommended and family preferences/goals
- Mismatch between program expectations and reality

I thought, like, maybe it was…funding that they might give us by participating in the program...And they can help out more like on a one-on-one case manager type basis. That's how I was thinking. But it wasn't like that. **It was more like she basically gave me everything else that I could look up my own self.**

She would tell me, "Wait, go see a psychiatrist. Cause he need to talk to a psychiatrist." **I was like, "He got family to talk to. He ain't gotta talk to no psychiatrist"**…I ain't pay all kind of money, go to no psychologist, psychiatrist and all of that if he can talk to me.

Well, I was looking for a resource that was going to help me not be homeless, and **none of those things helped me not be homeless. It's basically the same thing if you walk in social service and pick up a piece of paper.**

Key Themes: Barriers to Retention
Competing Family Priorities & Caregiver Overwhelm

- Sudden changes to caregiver/family member health or employment status
- Burden of frequent calls, esp. during work hours, and lack of asynchronous communication options (esp. text, email)

It was always something going on. And that gets frustrating when you are on the phone, and then you have two children in your ear, and another child yelling and screaming, and it just gets overwhelming and frustrating, and I didn't want to make her feel like I was angry with her, but **it was just a whole lot of stuff going on, and I really can't deal with all of this.** Let me get my kids together. Let me get dinner on. Let me get them sitting down at the table eating. Then we can have a conversation, cause that's a lot. **When you're trying to incorporate or work that into a full day, you know I only have 24 hours, and that's not enough.**

Now that I'm sitting down and having to talk with you, it does sound interesting… Well, in the moment, like I said, I wasn't…**I didn't really get to sit down and just be like in a quiet room, so I can really pay attention to what she was saying.**

Key Themes: Barriers to Retention
Competing Family Priorities & Caregiver Overwhelm

- Feeling of wasting FN time when caregiver lacked capacity to follow up on resource recommendations
- Lack of support for non-InCK-eligible family members and challenges with coordinating services across multiple care mgmt. programs
- Inability to find FN contact info to follow up and reengage after losing touch

It was just overwhelming…**I have a lot of children that have a lot of different things that I have to do a lot of different things for, so sometimes some things fall by the wayside**, and then it's, "Well, why didn't you do this? And why do you do that?" Well, people really don't understand. There's a lot going on. I may have a smile on the outside, but on the inside is just like, octopus arms, and…some of them are broken, and I can't use all of them.

I actually ended up saying, "You guys, **this may be beneficial…to someone that really, really needs it. And I'm wasting you all's time, because I barely can get on the phone with you**, because my job or the babies at home…there's always something going on."

Key Themes: Briefly-Engaged Participants

- Frustration w/ lack of follow-up/follow-through among a minority of participants. At least one participant either didn't receive or didn't remember follow-up
- Some participants overwhelmed by call frequency/unable to accommodate given work schedules. Several noted FNs did try really hard to reach them

I felt like it was kind of useless? Because she never really came back to me with information on how to get help with my light bill. I ended up having to pay it. You asked me what I needed and I'm telling you, but then you came back with nothing.

Yeah, life happened. I ended up getting a CPS case between the time I first started talking to them and now. So like, **that's kinda consumed everything right now.**

It was more or less me, not them…**they reached out pretty consistently** until one day I think they just didn't? Like, yeah, she's probably not gonna answer the phone kind of thing.

Key Themes: Patterns of (Re) Engagement

- 32% (6/19) of LTC interviewees requested reconnection to InCK post-interview; others noted they felt they could reach back out to FN if/when needed

It's been times like, I probably… **months done went by and I would call [FN]** and she'll be like, "Oh, well, let me reopen such and such, such and such…" I have her number saved in my phone, so **I know if I ever need, I know I can reach out to nurse [FN].**

I was actually thinking about her the other day. I was like, **'Wow! I miss her calls.'** I think because I had just quit my job… This would be a great moment for her to like, you know, call and just help me.

I guess it was just kinda that things had progressed into a normal family life…**Don't get me wrong, if I had needed them later, I woulda called.**

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Discussion: Implications for Engagement & Retention

Care model priority for April-Sept: Navigating challenging cases, gray areas, and situations when resources just aren't available

- How can we help families better understand the full scope of program services once engaged?
- How can we help families pivot to different goals if certain resources aren't available?
- How can we leave the door open for caregivers to reengage as-needed on their own terms?

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What's Next: Refining the Care Model

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Key Participant Recommendations for NC InCK

- Simplify initial outreach scripts
- Be careful about focusing too heavily on clinical needs during initial outreach
- Set clearer expectations re: scope of program and revisit scope regularly
  - Emphasize availability of non-clinical supports…
  - …BUT avoid over-promising scarce resources like rent assistance
  - Remind families periodically that they set the agenda and can change goals any time
- Explore options to share information and communicate asynchronously (e.g. via text); avoid unscheduled phone outreach

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I check my text messages more frequently than I do anything else. I rarely answer the phone.

Key Participant Recommendations for Pediatric Care Management Overall

- Publicize care management more broadly to increase general awareness
- Offer self-referral options to empower families and avoid reliance on health care providers/others to identify those in need
- Consider flexible models for family engagement that allow for participation as-needed rather than on a set timeframe

I wish it was like an option where **people was aware, and they could say, "Hey, I need this help. I can take advantage of this,"** versus, you know, just doctors, **I don't think people know, not unless you just tell them**…And you know some people…don't find it easy to ask for support.

If there were more money out there for people needing help…[FN] was very helpful. **There's just not enough funding**, that's all.

A Look Ahead

Reminder: Request a certificate of attendance for today's ICR at this link

Upcoming NC InCK Events:

Integrated Care Rounds:
Intimate Partner Violence
Thursday, March 13th:
12:00 pm – 1:30 pm

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

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NC Pre-K Applications are OPEN!

Working with any children who will be **4 on or before August 31, 2024?** Consider NC Pre-K!
For more information, instructions, and to apply, direct to the county/district link:

Alamance (opens 2/15) Durham	Orange Chapel Hill-Carrboro	Granville Vance

Resource Highlights

Girls in Leadership Academy (Bull City Futsal): Free 10-week leadership development program for middle school age girls. Meeting 2x a week from February 27 – May 4th. Register here.

Durham YouthWorks: Summer employment and career readiness program for youth ages 14-24. Application deadline: February 21, 2025, at 12:00am Midnight.



Resource Reminders

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Resource Highlight: VITA Programs

VITA Programs offer free, in-person tax preparation support for low- and middle-income NC residents. **VITA spots fill up fast!** Help families gather needed documentation and find and make an appointment (or plan a walk-in visit) at a nearby VITA site.

- Alamance County (United Way of Alamance): Appt booking open NOW; Spanish-language appts. available on Thursdays. Book online here or call 336-203-3332. **Limited to Alamance County residents**.
- Durham (and Wake) County (Reinvestment Partners): Appt booking open NOW; Spanish-language help available at Raleigh Centro para Familias Hispanas location. Book online here or call 919-286-1822. **Open to all regardless of county.**
- Granville County (Granville County Libraries): Walk-ins only at South Branch (Creedmoor) on Mondays from 5-8 pm, Jan. 27-April 14 and at Thornton Branch (Oxford) on Saturdays from 10 am-2 pm, Jan. 25-April 12. **Open to all regardless of county.**
- Orange County (Orange County Department on Aging): Appt. booking open NOW; Spanish-language help available. Book online here or call Laura Prinzhorn, 919-245-4240. **Open to all regardless of county**.

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Resource Highlight: Free Online Filing

- **Direct File**: Newly-available IRS tool allowing many taxpayers to **file state AND federal taxes directly with the IRS for free**. Opens in late January. Check eligibility to use Direct File here.
- **GetYourRefund**: Free online tax filing program for families making less than $66,000/year. Filers receive support from IRS-certified tax preparers (services available in Spanish). Opens at **1 pm on January 31.** Sign up to be notified once the service is live or visit GetYourRefund.org on or after January 31.
- **MyFreeTaxes:** Free online self-filing option for people making less than $79,000/year. Does **NOT** include any filing assistance. Opens in late January.

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Resource Highlight: Tax Assistance for Seniors

Many InCK patients live with older caregivers who qualify for free tax filing assistance based on their age.

- Durham County (Durham County Public Library): For **50+ Durham Co. residents only.** Walk-in sessions begin January 29th and continue through April 11th. See website for details.
- Granville County (Granville County Senior Center): Appt booking open NOW **for 60+ Granville Co. residents only**. Call 919-693-1930.
- Vance County (Vance County Senior Center): Appt booking open NOW for **55+ Vance Co. residents only**. Call 252-430-0257.

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Appendix

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Characteristics of Declined Interviewees' Children*

Characteristic	Total n (%)
Family Care Mgmt. Entity	
CCPN	9 (50%)
Duke	7 (39%)
UNC	2 (11%)
Child Service Integration Level	
1	3 (17%)
2	7 (39%)
3	8 (44%)
Child Gender	
Female	8 (53%)
Male	7 (27%)

Characteristic	Total n (%)
Child Race & Ethnicity	
Non-Hispanic Black/AfAm	8 (53%)
Non-Hispanic White	2 (13%)
Biracial	3 (20%)
Hispanic/Latino	2 (13%)
Child Age	
0-5	4 (27%)
6-12	5 (33%)
13-17	4 (27%)
18-21	2 (13%)
Family County of Residence	
Alamance	5 (33%)
Durham	7 (47%)
Granville	1 (7%)
Orange	1 (7%)
Vance	1 (7%)

Characteristics of Lost to Contact Interviewees' Children*

Characteristic	Total n (%)
Family Care Mgmt. Entity	
CCPN	9 (47%)
Duke	7 (37%)
UNC	2 (11%)
WellCare	1 (5%)
Child Service Integration Level	
1	3 (16%)
2	7 (37%)
3	9 (47%)

**As of time of interview, not during InCK engagement*

Characteristic	Total n (%)
Child Gender	
Female	6 (32%)
Male	13 (68%)
Child Race & Ethnicity	
Non-Hispanic Black/AfAm	12 (63%)
Non-Hispanic White	7(37%)
Child Age	
0-5	3 (16%)
6-12	5 (26%)
13-17	6 (32%)
18-21	5 (26%)
Family County of Residence	
Alamance	2 (11%)
Durham	10 (53%)
Granville	3 (16%)
Orange	1 (5%)
Vance	3 (16%)