First In Families of North Carolina
COVID-19 Registry of Unmet Needs Relief Initiative

NC Council on Developmental Disabilities: Community Living Committee

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Le'Carla McNair
Quillo Connect Project Coordinator, FIFNC

David Le
Quillo Connect Outreach and Engagement Coordinator, FIFNC

Quillo Connect Objective and Goals

The Objective of this initiative was to:

better identify the needs of our community

provide meaningful connections to NC specific or NC relevant information and encouragement to self-advocates and family members

better understand and address the needs of those who are currently on one of NC's MCO Registry of Unmet Needs.

The Goals of this Initiative were:

1. Families who are and are not receiving waiver services will share how they have been impacted by the pandemic.
2. Persons with I/DD will be engaged in advocacy by creating NC-specific content for Quillo app.
3. Persons with I/DD and their networks will access a new micro-learning technology.
4. NC Specific Content will be guided by Persons with I/DD using the app.
5. Data will inform the broader expansion of the app to the NC's I/DD population.

Objectives Met and Results

We recruited **nine authors as self-advocates**, some working with family members (or teams), and they **were trained** and **compensated for their work** to create content and help us develop the app.

- Quillo Connect now includes **50+ NC specific videos** (and growing) made through the creative initiative of our authors. Total video archive now over 600!

- Videos are close captioned in English and Spanish, and we have several videos for Spanish-speaking audience.

- Support and training for our authors is ongoing.

- Video content covers all six domain areas of Charting The Life Course

DURHAM: FIFNC Quillo Connect Authors and team discussing important topics for videos, June 2021

Objectives Met and Results

As of December 31, 2021 there were 93 active users on the app who are viewing and making videos.

We are still seeking more participants! No COST to USERS.

- Users are **surveyed** periodically to determine usefulness of the app and determine how the app benefits the quality of life both for people receiving services and those who are on Registries of Unmet Need throughout the state

- User feedback continues to inform what topics should be further explored.

FIFNC Quillo Connect Author Janie shares her experience about accessibility at a local beach
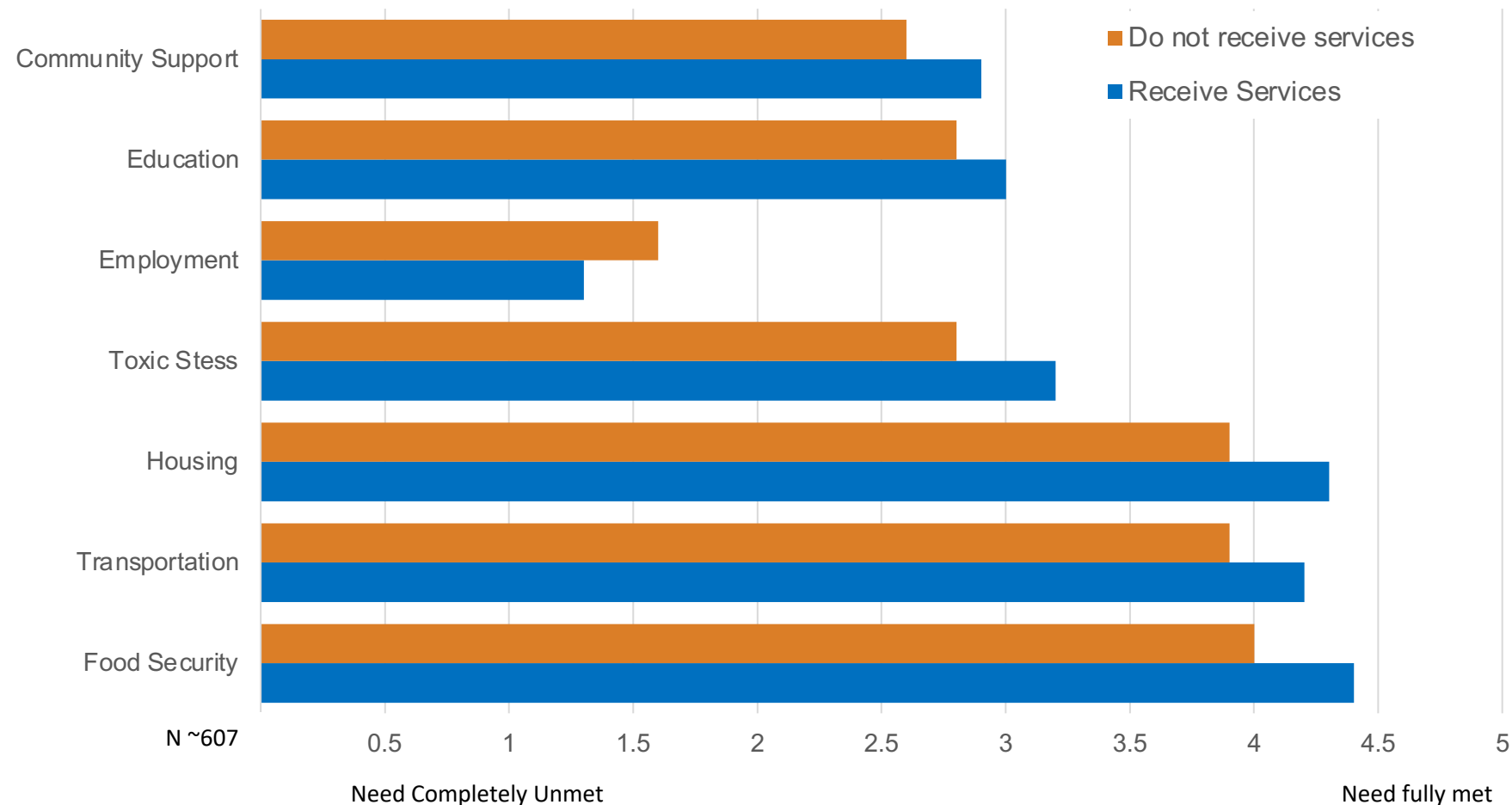
About our Survey of Individuals/Families Statewide

Distributed Survey to ~5000 families Statewide to identify Pandemic-related Social Determinants Needs

- Of 607 Respondents
  - 93% were family members; 7% were self-advocates
  - 46 distinct counties represented: Most concentrated counties are Wake (14%), Mecklenburg (10%), and Durham (8%)
  - 38% reported receiving waiver approximately 24% of respondents are on a Registry of Unmet Needs
- Waiver status
  - 37% on the Registry of Unmet needs; 17% not receiving services and not on registry of unmet needs
  - 35% receive Innovations (or another) Medicaid Waiver
  - **10% OF RESPONDENTS RESPONDED THAT THEY WERE UNSURE OF THEIR STATUS**

Social Determinants of Health: Waiver vs Waiting

Respondents were asked to rate their quality of life in the following areas. (0 = complete lack; 5 = fully met)

While the needs were close to the same for each population, those who are not receiving waiver services scored their access to resources lower than both the average (of all respondents) and markedly lower than those who receive the waiver.

Successes and Challenges

9 Key authors accomplished their goals in **making NC-specific video content as** self-advocates with lived experiences of disability

- Are inspired to be the **voice of disability in their local community** through this platform
- Planning a continued future with Quillo Connect and FIFNC for **future video content and ongoing feedback** for the trajectory of this application in the state

While we have 93 active user as of December 31, 2021, this number continues to grow

- App development delays
- Short duration of recruitment phase
- Lack of usage by some who were initially interested

Successes and Challenges

User engagement during the COVID-19 pandemic was primarily over Zoom (9 online sessions) and through email

- Accessibility problems
- On the few occasions we met in-person; engagement increased

Circle video-sharing functionality was a central part of the initial announcement during the app rollout

- Delayed development and release until early January prevented this function from being utilized by users
- Potential implications for day-to-day support process

What's next?

Continuing to expand the NC Content video database, more stories, more information on system navigation

- Newest feature! Users can connect and communicate directly with their network with private videos in "Circles"

- Collecting and analyzing more data on usage and impact through testimonials surveys, usage data, and updated dashboard functions (coming soon)

FIFNC and Quillo presented at i2i Pinehurst Conference in December 2021.

Sustainability and Growth

Our goal is that Quillo Connect will become a standard for NC information sharing through LME/MCO collaboration and investment. All including those awaiting services will have a user-friendly platform with relevant and timely information.

FIFNC is actively working to expand the launch of Quillo Connect for individuals and their families on the Registry of Unmet Needs as well as adults who are on the waiver but can benefit
- *Vaya has funded 300 licenses for their members (actively recruiting!)*
- *100 licenses have been awarded by DHHS for those on the Registry of Unmet needs in 24 Eastern NC Counties (beginning July 1, 2022)*
- *Our Goal is that Quillo Connect will be available at no cost to self-advocates and families by further investment by regional LME/MCOs.*

Thank you and Questions!

Thank you Community Living Committee for your insight and investment!

Le'Carla McNair
Project Coordinator
lmcnair@fifnc.org

David Le
Outreach and Engagement Coordinator
david@fifnc.org