



## COVID-19 Registry of Unmet Needs Relief

Start Date April 1, 2021

### System Gap Addressed

- The COVID-19 pandemic has disproportionately affected people with intellectual and other developmental disabilities (I/DD) compared to the general population.
- As a result, many people with I/DD have had to isolate at home to stay safe and avoid the risk of exposure to COVID-19, but they have also faced reduced services or no services if their Direct Support Professionals (DSPs) and care providers became sick or if their families did not want to expose them to people outside of their household.
- However, individuals with I/DD who are on the Registry of Unmet Needs waiting for Innovations Waiver services might not be receiving any type of formal caregiving or other services while isolating at home alone or with their families waiting for relief.
- NCCDD intends to determine and meet needs of individuals with I/DD who are on the Registry of Unmet Needs whose unmet needs were exacerbated by the COVID-19 pandemic and to recommend future advocacy and initiatives to the Council related to the Registry of Unmet Needs.

### Initiative Goals and Timeline

- This initiative is designed to provide certain types of relief for individuals on the Registry of Unmet Needs whose unmet needs were exacerbated by the COVID-19 pandemic.
  - First In Families of North Carolina (FIFNC) proposes a web/mobile-based app as one solution to information sharing that delivers short (60-second) educational and encouraging videos, for and by adults with I/DD.
  - Videos provide role model stories, information and tips of all types, and inspirational stories.
  - FIFNC will create 50 NC specific videos to add to Quillo's library of over 1000 videos available to all users.
  - Responses by people with and without services, through surveys and ongoing feedback, will drive all new content.
  - Quillo Connect videos can also be created by users and eventually viewed and shared publicly or privately within one's chosen network.
  - Quillo Connect is available to users and their networks or can help the user build a network.

### Description of Activities

- Survey the families in the contractor's database who are not receiving Innovations Waiver services for topics that interest them for micro-learning through an app.
- Survey the individuals with I/DD in the contractor's database who are receiving Innovations Waiver services to have data to contrast.
- Recruit six people with I/DD and/or family members will to "author" 25 North Carolina-specific, 60-second videos to add to the Quillo library of more than 1,000 videos.
- Recruit at least 200 people with I/DD in North Carolina to be the first users of the Quillo Connect app and launch the app at no cost for them and everyone in their personal support network.

## COVID-19 Registry of Unmet Needs Relief (continued)

### Achievements and Outcomes to Date

- 624 North Carolinians who experience I/DD or are a caregiver provided information about their waiting list status, ranked needs and quality of life during the pandemic and shared how they access information and community.
- Partnered with NCCDD's Peer Mentoring initiative to hire two participants as Quillo Connect authors and invite users.
- Nine self-advocate users were hired to create North Carolina-specific videos from their lived experience. The group has delivered more than 55 videos and continues to create as volunteers.
- Over 100 users statewide (and their networks) are active on the application.
- There are Spanish language videos on topics such as "What is 211?" and "Alternatives to Guardianship."
- Every video on Quillo Connect is close-captioned in both English and Spanish.
- Partner agencies and advocates are using the app to share about their programs. Examples include:
  - "Welcome from Medicaid Director."
  - Durham Center for Senior Living is preparing videos on recognizing dementia symptoms in people with I/DD who are aging.

### Expected System Change as Result

- North Carolinians with I/DD will have access to a new, North Carolina-specific software-based application that will coincide with and complement the rollout of Medicaid Transformation in North Carolina.
- This initiative will demonstrate the effectiveness of an easy and inclusive technology to provide individuals with I/DD the opportunity to use and create accessible informational videos that Managed Care Organizations and other providers can use to communicate clearly and directly with consumers and patients about Medicaid Transformation.
- Individuals with I/DD who are not connected to the formal service system will report feeling more connected to others, feel informed on possibilities to reach their goals, and feel more confident in sharing their knowledge.
- At least 200 North Carolinians with I/DD will have access to a new NC specific software to provide individuals with I/DD the opportunity to consume and create informational videos.
- Users will better inform the platform through feedback, surveys and usage data.
- Self-advocates and family members who typically are perceived as being on the user end of the DD system will have an opportunity to contribute through production of the helpful videos.
- The Council and others will have better data on the differences among people on the Registry versus those receiving services, in terms of what are biggest challenges, other pandemic-related challenges and what areas of focus they want more information on.
- Quillo Connect will become a standard for North Carolina information sharing through Local Management Entity/Managed Care Organization (LME/MCO) collaboration and investment. All awaiting services will have a user-friendly platform with relevant and timely information.
- FIFNC is working with two LME/MCOs to support the launch of Quillo Connect in their catchment areas. This tool should assist with the transition by LME/MCOs to Tailored Plan Managers. LME/MCOs will be encouraged to add value to their ability to better help more people and in a way that encourages self-determination, goal discovery, positivity and high expectations.