# People are Waiting… What Are We Doing?
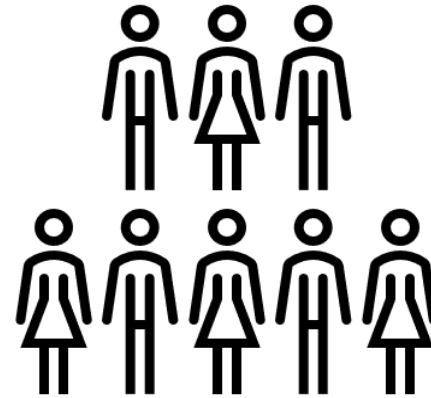
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Registry of Unmet Needs

(RUN) Project

# Project Overview

Explore  NC's Registry of Unmet Needs (RUN)

LME/MCO Survey Highlights

**Stakeholder Comments**

**Strategies from Other States**

**Collection of stories & videos**

**Commitment for Action**

# IDD Stakeholder Conversations

NCCDD Members

State CFAC

DD Consortium

Olmstead: Community Capacity Committee

 NC Provider Council – IDD Committee

NC Innovations Action Waiver Team

Money Follows the Person Stakeholder Committee

# Stakeholder Concerns

How do you find out about getting on the Registry?

High frustration and lack of hope while waiting

Low incentive to be on the Registry- due to wait

No regular updates from LME/MCO's

Need more information about available services (Do not send me to the web!)

People talk about the waitlist, but what are they doing?

Observation of other investments but not for people on the RUN

Schools & doctors need more education about how to make a referral

Citizens of NC need to know that 15,000+ people are waiting

# Stakeholder Suggestions

Build a statewide grassroots advocacy group

ONE VOICE....Nothing about us... without us.

Have members of the RUN present at the NC General Assembly, LME/MCO Boards, County Commissioner Meetings, etc.

Conduct TV, interviews, radio and other social media interviews of people waiting- tell our story!

Consider implementing more smaller waivers

Invite members of the RUN to help improve the  system

# Strategies From Other States

Interviewed Eight DD Council State Directors:

Georgia

Louisiana

North Carolina

Maryland

Tennessee

Texas

Washington

Wisconsin

# **Information from Other States**

CCR & Duke-Margolis Public Health conducted interviews

Developed a standard  IDD Waiver  & Waitlist Interview

Interviews completed

Gathering additional information through conversations with other state/national leaders

# Findings from Other States

**Political Interventions:**

Statewide grassroots advocacy reflecting ONE VOICE

Legislative champion(s)

Waitlist members participate in legislative sessions

Presentation by grassroots advocacy groups to legislators (not just providers & other professional interests groups)

Education on the growth rate of this population

**Management:**

Registry members are involved in ALL aspects of the agreed upon processes

Most waivers & waitlist are managed by the State's Medicaid Office

Most have a statewide database

Implement enrollment processes no matter where individual lives

Standardization of required documents (based on state's waiver)

Standardization of determination process (based on waiver)

Core services for those waiting (may vary by location)

Standardization of criteria for emergency requests or approvals

# Findings from Other States-continued

## Design

Utilization of data to create a tier waivers: (examples)

Employment/ Meaningful Day

Core services based on database information

Transition from School

## Interesting Facts:

**Wisconsin** negotiated with legislators prior to manage care implementation to establish if anyone meets criteria for a waiver, it will be seen as an entitlement (NO Waitlist)

**Georgia**, even with Olmstead, still dealing with waitlist and now dealing with cuts

**Maryland** has 3 waivers (Comprehensive Waiver for 21 & Older, Family Support for Under 21 & Community Support Services for over 21)

**Tennessee,** *Pathfinder* at Vanderbilt University (over 3000+ connections/services)

# Findings from Other States-continued

**Interesting Facts:**

**Washington,** de-institutionalization pushed for more waivers

**Texas**, completed evaluation, evaluating how to address gaps in real time & manage timely access to services, prioritizing certain populations, considering reduction allocations to serve more people.

**Louisiana,** Started in 2015 with a statewide group of committed waitlist members/still will place today, currently 4 Waivers moving to 1 waiver, moved away from First Come/First Serve to Priority, designed a priority tool/moving away from Supports Intensity Scale, created a culture where members understand & agree how determining priorities are decided

## Commitment to Action

**NC Council on Developmental Disabilities (NCCDD)**

**This research project was designed to inform the development of a Request for Applications (RFA) for a future 3-4 year initiative for NCCDD to support on the topic of the Registry of Unmet Needs by helping people with I/DD obtain the services and supports that they need to live in the community.**

**On May 13th & 14th, at the NCCDD Quarterly Meeting,**

**the members will be voting on this RFA.**

**So grateful for the opportunity to be with you today.....**