



INTRODUCTION

- Medicaid Home- and Community-Based Services (HCBS) Waivers fund long-term services and supports in the community versus institutions in compliance with the 1999 *Olmstead v. L.C.* U.S. Supreme Court decision
- HCBS Waivers increase quality of life and address unmet needs of those with intellectual and/or developmental disabilities (I/DD)¹⁻³
- Centers for Medicare and Medicaid Services (CMS) approval of diverse Waiver designs among States complicates evaluating their effectiveness^{1,2,4}
- In North Carolina:
 - 12+ year waiting list (“Registry of Unmet Needs”)⁵
 - Only 22% of 53,531 Medicaid beneficiaries with I/DD or ASD on NC Medicaid are enrolled in the IDD waiver (NC Innovations)⁶
 - Inequities: Non-Hispanic Blacks and Hispanic individuals less likely to receive waiver than non-Hispanic Whites⁶; Youth (<21 years old), females, and rural residents less likely to receive waiver⁶



Purpose: Identify effective strategies for improving access to I/DD Waiver slots by examining how States have a) designed and adapted their I/DD Waiver systems; b) shortened their waiting lists; and c) addressed unmet needs and inequities

METHODS

- **Sample:** 8 states represented by 10 state Developmental Disabilities Council Directors & DHHS leaders
- **Semi-structured Interviews**
 - Duration: 68.5 min (range 53-92 min)

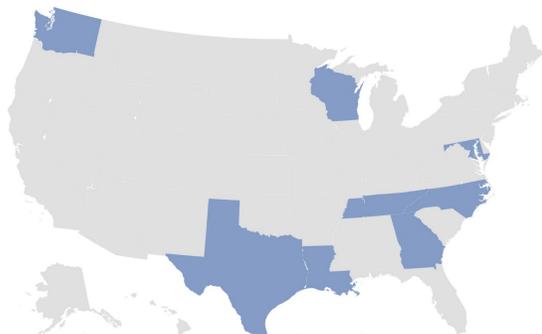


Figure 1: States Included (N = 8)

RESULTS

Waiver Duration Structure (n):

- Lifespan (3)
- Separate children & adult (2)
- Combination (3)

Approval Process (n):

- First-come, first-served (4)
- Need-based (3)
- Employment and crisis status first (1)

All states reported that it is **not easy** to sign up for the Waiver (Quote 1)

Exemplar Quotes

1. *“It’s like going into a room of curtains, and when one is pulled back, all you see is the next curtain.”*
2. *“Only the most informed, empowered, confident families who have navigational capital, time and expertise are going to be able to make it through.”*
3. *“We can scream and scream and scream about people on the waiting list. And that film just makes it a lot more human.”*

Unmet Needs:

- No existing process for surveying unmet needs
- Lack of service providers, particularly in rural areas
- Low direct support professional (DSP) wages
- Problems helping people with I/DD get employment
- Lack of “true self-determination and choice”
- Many invisible to the Waiver system (not on waiting list)
- **Underserved subpopulations:** Rural, Historically Marginalized Populations, LGBTQ+, children, transition age, aging individuals, dual-diagnosed

Strategies to Address Unmet Needs:

- Legislative advocacy
- Partnership with community organizations
- Partnership with universities or protection & advocacy groups
- Collaboration with other State and local governmental agencies

Table 1: Descriptive measures of I/DD Waivers (N=8)

Outcome	North Carolina	Sample mean (range)	# states analyzed
# I/DD waivers	1	3.6 (1-10)	8
# waiver slots	13,138	19,814 (10k-60k)	6
# on waiting list	~14,000	27,155 (0-159k)	8
Waiting list time (y)	~10	9.1 (0-15)	5

Waiting List:

- Alternate names for waiting lists
- Wide range in waiting list size, long wait times (Table 1)
- Some states administer waiting lists and Waivers on local level
- Personal political/social influence can shorten wait (Quote 2)
- Medicaid agencies do not publish waiting list data
- Limited options for people waiting and not on Medicaid

State Waiting List Reduction Strategies:

- Prioritize sub-populations
 - LA eliminated waiting list by assessing high need individuals
 - GA proposed redirecting high-need funds to low-need recipients
- Implemented tiered Waiver enrollment (incremental funds by need)
- Lobbying and grassroots advocacy (Film *6000 Waiting*, Quote 3)

Mechanisms for Increasing Slots:

- Dependent on legislative action for State match appropriations
- “Stretch” existing funds through tiered enrollment
- Legal action via *Olmstead* and ADA protections yields variable results

Strategies for Improvement:

- Broaden Waiver capacity
- Streamline the application process
 - Case manager explains process to families
 - Flow charts, social stories, videos explaining process
 - One-size-fits-all application system
- Greater emphasis on self-determination and rights
- Increase DSP wages
- Enhance Supported Employment
- Improve housing options and close institutions

DISCUSSION

- NC I/DD Waiver slots are allocated disproportionately by age, race, sex, and geography. Other states express concern about similar inequities but often not formally studied
 - Other states working to tackle underserved populations in five-year plans, but under-resourced
- Many individuals are eligible but remain unaware of the I/DD waiver thus are “invisible” to the system
- First-come, first-served can contribute to inequities
- The lack of State waiting list transparency is problematic
- Tiered waivers have eliminated high need waiting lists and reduced per slot expenses
- Cross sector partnerships are crucial for improved advocacy and Waiver slot allocation
- Low DSP wages are a concern for all states



POLICY RECOMMENDATIONS

- Invest in the administrative oversight of a centralized database to maintain accurate waiting list eligibility and demographic data
- Sustainable State and federal appropriations for funding to increase the number of Waiver slots
- Address inequities and barriers to Waiver enrollment to ensure that all eligible people learn about, apply for, and receive a slot

REFERENCES

1. Leslie DL, Iskandarani K, Dick AW, et al. The effects of Medicaid home and community-based services waivers on unmet needs among children with autism spectrum disorder. *Medical care*. 2017;55(1):57.
2. Leslie DL, Iskandarani K, Velott DL, et al. Medicaid waivers targeting children with autism spectrum disorder reduce the need for parents to stop working. *Health Affairs*. 2017;36(2):282-288.
3. Eskow K, Chasson G, Summers JA. A Cross-Sectional Cohort Study of a Large, Statewide Medicaid Home and Community-Based Services Autism Waiver Program. *J Autism Dev Disord*. 2015;45(3):626-635. doi:https://dx.doi-org.proxy.lib.duke.edu/10.1007%2Fs10803-014-2217-4
4. Keim-Malpass J, Constantoulakis L, Letzkus L. Variability In States’ Coverage Of Children With Medical Complexity Through Home And Community-Based Services Waivers. *Health Affairs*. 2019;38(9). doi:https://doi.org/10.1377/hlthaff.2018.05413
5. Sirko J. North Carolina Failed Ruby: 15,000 Others Still Waiting. NC Policy Watch. Published June 21, 2021. <http://www.ncpolicywatch.com/2021/06/21/north-carolina-failed-ruby-15000-others-still-wait/>
6. Franklin M, Bush C, Davis N, et al. Inequities and Medicaid Waivers for Intellectual/Developmental Disabilities. In: *Academy Health*; 2021. <https://academyhealth.confex.com/academyhealth/2021arm/meetingapp.cgi/Paper/47203>