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 compeles their effectiveness\(^1\)–\(^4\)

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 I/DD waiver (NC Innovations)\(^6\)
- Inequities: Non-Hispanic Blacks and Hispanic individuals less likely to receive waiver than non-Hispanic Whites\(^7\); Youth (≤21 years old), females, and rural residents less likely to receive waiver\(^8\)

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:
- 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-diagnosis

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)

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

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