# *Prioritizing Individuals with Developmental Disabilities for HCBS Waiver Slots*

# *Final Project Report*

Prepared for the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services

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# Executive Summary

Our objective was to understand how the LMEs are using the CAP-MR/DD Prioritization tool (hereafter, the prioritization tool), and its ability to determine which individuals with developmental disabilities should receive HCBS waiver services in North Carolina. We conducted interviews with representatives from 10 LMEs across North Carolina about their use of the prioritization tool. We addressed the following research questions:

- How do LMEs use the prioritization tool?
- How do LMEs perceive the strengths of the prioritization tool?
- How do LMEs view the limitations of the prioritization tool?
- What do LMEs think should be done to improve the prioritization tool?
- In what other ways could the prioritization tool be used?

Our major findings are:

***Finding 1:*** *All 10 LMEs are currently using the prioritization tool for new waiver applicants and have either administered or are in the process of administering the prioritization tool to their current waiting lists.*

***Finding 2:*** *Overall, the prioritization tool improves the prioritization process by increasing consistency across the state.*

***Finding 3:*** *LMEs supplement prioritization tool scores with assessments, evaluations, and their personal knowledge about individuals.*

***Finding 4:*** *Staff responsible for using the prioritization tool need training and ongoing technical assistance.*

***Finding 5:*** *Instructions and terminology used in the prioritization tool should be clarified.*

***Finding 6:*** *There is concern among some LMEs about using the same prioritization tool for children and adults.*

***Finding 7:*** *There is concern among some LMEs about the subjectivity of the prioritization tool.*

***Finding 8:*** *The prioritization tool does not collect enough information to be used for specific waiver assignments.*

Based on these findings we recommend:

***Recommendation 1:*** *Provide statewide training on the prioritization tool for LME staff.*

***Recommendation 2:*** *Provide clarification of prioritization tool terms and instructions.*

***Recommendation 3:*** *Establish a technical assistance program for staff who administer the prioritization tool- for example, a "Frequently Asked Questions" web site.*

***Recommendation 4:*** *Revise the prioritization tool and consult with a work group of prioritization tool administrators when doing so.*

# Introduction

Unmet service and support needs for individuals with developmental disabilities are among the most persistent public policy issues facing the country's service delivery system. In 2006, 42 states reported that the number of people on formal state waiting lists for residential services alone was 64,990 [1]. However, this number, which is approximately equal to 13% of the 489,465 participants with developmental disabilities supported by the HCBS Waiver across the country [2], is just the tip of the iceberg because many states do not keep official waiting lists. Thus, Prouty and his colleagues estimated that nationally, the total number of people with developmental disabilities awaiting residential services was likely closer to 84,500, or about 30% higher than official estimates [1].

Although North Carolina's CAP-MR/DD Waiver program offers opportunities to address some of these unmet needs, inevitably the expansion of system capacity in the state will not keep pace with growth in service demand because of aging of family caregivers, the increased lifespan of people with developmental disabilities, and the current economic and fiscal crisis. Thus, how to prioritize people for the continuing limited number of waiver slots will remain a challenge in the foreseeable future.

Recently, the North Carolina Division of Mental Health, Developmental Disabilities, and Substance Abuse Services (Division) designed the *CAP-MR/DD Waiver Prioritization tool* to address this challenge. Recognizing that the design of an evaluation instrument is only the first step in assessing the instrument's usefulness, the Division asked the Developmental Disabilities Training Institute (DDTI) to evaluate how staff members of Local Management Entities (LMEs) perceive the value of the prioritization tool. This report is the result of that request.

# Background

North Carolina is not alone in facing the challenge to address the service needs of many thousands of people with developmental disabilities. In 2004, 206,427 individuals were on waiting lists for 102 HCBS waivers nationally [3]. In 2006, a survey of selected states' waiting lists and prioritization processes found that:

- States maintained a variety of lists to track individuals with developmental disabilities who needed services. These lists were variously termed waiting lists, registries, planning lists, or interest lists.
- Some states administered a single, centralized list for each waiver.
- Other states delegated authority for maintaining a list to regional or county entities and required a data reporting procedure to intermittently adjust waiver services and slot allocation.
- States' procedures for adding individuals to a list varied. Some states conducted eligibility assessments for waiver services prior to adding individuals to a list. Other

states added people without conducting assessments and only required such evaluations when there were waiver slots available.

- Some states enacted laws and policies that required new waiver slots to be allocated based on the individual's date of application for services or the date individuals' names were placed on a waiting list. Of these, some states had exceptions for people who were transitioning from existing Medicaid-funded institutional services to HCBS waiver services.
- While all of the states included in the study considered an individual's application date for prioritization decisions, most states also used some form of "urgency of needs" test to prioritize applicants for waiver services.
- States differed with respect to how people moved off of a list and began receiving services [4].

In 2008, the Division asked LMEs across North Carolina to begin using the prioritization tool to order individuals on their waiting lists and allocate waiver slots. The prioritization tool is used to determine if an applicant has "emergent/crisis" or "routine" needs. Those with emergent/crisis needs should receive priority over individuals with routine needs. Applicants who are determined to have routine needs are ranked according to their score on the prioritization tool, and waiver slots are allocated accordingly.

## *Study Method*

Data for the study were gathered from telephone interviews with personnel who administer the prioritization tool at 10 LMEs across the state. The Division provided us with the names of both the target LMEs to contact as well as specific interview respondents from each LME. The LMEs chosen represented a range of geographical diversity and size from the 24 total LMEs in the state. The interviews were conducted in Spring 2009 for the purpose of seeking information on the CAP-MR/DD Waiver Prioritization tool. Specifically, the interviews were developed to answer the following study questions:

- How do LMEs use the prioritization tool?
- How do LMEs perceive the strengths of the prioritization tool?
- How do LMEs view the limitations of the prioritization tool?
- What do LMEs think should be done to improve the prioritization tool?
- In what other ways could the prioritization tool be used?

# Results

The results of the interviews are organized into seven major themes, discussed below. They are:

1. Current use of the prioritization tool
2. Perceived strengths of the prioritization tool
3. Need for additional information
4. Concerns about specific sections of the prioritization tool
5. Using the same prioritization tool for both children and adults
6. Subjectivity of the prioritization tool
7. Other uses of the prioritization tool

### *Theme 1: Current use of the prioritization tool*

Each of the 10 LMEs interviewed are currently using the CAP-MR/DD Prioritization tool in their respective regions. The prioritization tool is administered to all individuals seeking enrollment in the CAP-MR/DD waiver program and is used to place applicants in order of the urgency or level of their need.

Each of the 10 LMEs also indicated that they are in the process of administering the prioritization tool to individuals on their current waiting list. The objective of administering the prioritization tool is to reprioritize those individuals who applied for waiver services before the prioritization tool was developed.

The LMEs identified two types of prioritization tool administrators in their respective regions. Nine use LME staff such as a care coordinator or developmental disabilities specialist to administer the prioritization tool. The remaining LME has case managers complete the prioritization tool and return it to the LME. LMEs varied on whether or not they completed the form through face-to-face interviews (whether in an LME office or at the applicant's home) or by phone. One LME conducted face-to-face interviews with individuals who achieved a certain score when the prioritization tool was administered by telephone.

Notably, no LMEs have used the prioritization tool to make any slot allocations because waiver slots are currently frozen in the state.

### *Theme 2: Perceived strengths of the prioritization tool*

LME respondents generally reported positive feelings about the prioritization tool. Respondents indicated that the prioritization tool improves the prioritization process because it provides consistency across the state and it gives LMEs a concrete way to explain waiver slot allocation to families. One respondent noted that previous prioritization policies varied across the state. This individual stated that a positive step had been taken because families can now expect to have similar experiences with prioritization no matter where they live in North Carolina. Several respondents said that the prioritization tool is the best way to capture the needs of individuals.

LME respondents noted a number of other strengths in their use of the prioritization tool. The most commonly cited benefits included: (1) the prioritization tool provides updated information about who is on the waiting lists; (2) positive experiences providing face-to-face interviews and home visits; and (3) the prioritization tool removes bias or the ability to "pick and choose" who will receive a CAP waiver slot. One LME staff member considered the prioritization tool's brevity and relative ease of use a strength.

### *Theme 3: Need for additional information*

Interview respondents most frequently said they were concerned about allocating waiver slots based solely on the prioritization tool score. All but one individual stated they did not feel the prioritization tool could be used effectively in isolation. The LME respondents stated that they continue to supplement the prioritization tool with additional information such as assessments and evaluations from therapists, medical doctors and schools and their own personal knowledge of a family's needs. Thus, the prioritization tool has been made an important part of prioritization but is not the sole determinant of allocated slots.

Half of the respondents said they collect additional information because the prioritization tool does not account for all the variation among waiver applicants and individuals often score between numbers or do not fit into the outlined categories. Other LME respondents noted they sometimes have several people with similar scores and that in such cases they consider additional information before prioritizing these applicants for slot allocations. Some respondents noted other relevant issues they consider: (1) whether or not a waiver applicant is living with a single parent or older parents, (2) parents' employment status, (3) availability of natural supports, (4) current paid supports the person is receiving, and (5) an applicant's insurance status. One respondent stated, "People's lives are just more complex than what a prioritization tool can gather by itself."

### *Theme 4: Concerns about specific sections of the prioritization tool*

Respondents also expressed concerns about specific sections of the prioritization tool. This was particularly the case with the sections on "Emergent/Crisis Needs," "Habilitation Support: Behavior," and "Medical and Related Support Needs."

#### *Emergent/Crisis Needs*

While the instructions for this section state that if an individual meets the criteria for emergent or crisis needs the prioritization tool does not need to be completed, almost half of the respondents felt they needed to collect the remaining information to get an accurate picture of the person's needs. Respondents also requested more clarification on the emergent needs listed. Statements such as "at risk of significant physical harm" or "pending homelessness" appeared too subjective and open to interpretation. In several interviews, LME staff described

conversations with parents of applicants who felt their child met the criteria for emergent needs, but the LME staff disagreed. For example, one LME spoke of a child with autism who often leaves his home without supervision. The family felt their child was at significant risk for physical harm, while the LME staff did not consider the concern an emergent need. LME staff would like additional information or guidelines for these categories to better explain to a family the criteria they must meet.

### *Habilitation Support: Behavior*

Four respondents cited concerns with the behavior section of the prioritization tool. Several said they are unsure if they are required to fill out all three behavior sections or only ones applicable to the applicant. They noted the first section does not allow for behaviors that occur less often than daily, so in some instances they "score up" on this question. Respondents are also uncertain about this section's language, particularly the phrase "professional intervention." They are uncertain what constitutes a professional intervention and if it applies to a one-time occurrence, such as the development of a behavior plan, or to an ongoing intervention. One LME also expressed concerns about the subjectivity of the phrase "beyond what the family or existing supports can manage" and how to accurately assess this issue.

### *Medical and Related Support Needs*

Almost half of the respondents had questions or concerns about this section of the prioritization tool. The most common question was how to define "specialized training/specialized staff" or "professional medical interaction." The respondents are uncertain if they should consider therapies, such as occupational, physical, or speech therapy within this category. Also, some respondents expressed uncertainty about how to judge if medical concerns are "beyond what the family or existing supports can manage" and how this consideration should be separated from specialized training and staff needs, which appear as two separate categories on the prioritization tool. One respondent also suggested more medical needs might be considered in this section including tube feedings and catheter use.

## *Theme 5: Using the same prioritization tool for both children and adults*

Three LME respondents expressed concerns about using the same prioritization tool to assess both children and adults. Some respondents felt the prioritization tool gives an inflated score for children who are, naturally, more dependent on someone else for care. While the prioritization tool does use the phrase "typical for age" in some sections, respondents said determining what constitutes age-appropriate behaviors and needs is difficult. For example, some do not think that areas addressing communication and sleep adequately consider someone's age. More generally, some were concerned about using the same prioritization tool fairly. Several respondents questioned the fairness of giving a waiver slot to a child over an adult with a slightly lower score. One said waiver services are more imperative for an adult with significant personal care needs versus a child with similar needs because of other factors the

prioritization tool may not consider, including an adult's aging parents and the level of care an older individual requires.

### *Theme 6: Subjectivity of the prioritization tool*

Half of the LME respondents stated they have concerns that the prioritization tool is open to subjective interpretation by those administering it. Some specific concerns are addressed above, including the uncertainty about terms or phrases, but others said they were also concerned about the lack of clarity in some of the instructions. As one respondent indicated:

> *"Overall, clearer instructions is the most important recommendation. The instructions should be user-friendly for families, legal guardians, case managers, and LME representatives. Clearer instructions will provide a better opportunity for information to be gathered and presented in a more empowered manner, and it gives all parties involved a document to reference when there is doubt about how information should be interpreted or applied when completing the prioritization tool."*

Some staff also shared experiences in which they felt a family member or case manager tried to "manipulate" an applicant's place on a waiting list by falsely elevating an individual's score. These LME respondents suggested that a sound, standardized prioritization tool that cannot be easily influenced or that has safeguards to protect against manipulation is needed. Some said developing a less subjective prioritization tool would help accomplish this goal. Furthermore, one respondent suggested that all individuals involved in administering or completing the prioritization tool should be required to sign a statement of integrity attesting that all information is truthful and accurate. She stated, "It is sad to say, but there are many times when inaccurate information is given; so the integrity of the information shared to complete the prioritization tool is of upmost importance."

In general, respondents are interested in receiving additional training to ensure the prioritization tool is administered correctly and in line with the Division's expectations.

### *Theme 7: Other uses of the prioritization tool*

Respondents were questioned about other possible uses for the CAP-MR/DD Prioritization tool, specifically if they think the prioritization tool can be used to assign individuals to the Supports or Comprehensive waiver programs. All but one LME respondent said they would ***not*** feel comfortable using the Prioritization tool score to assign an individual to a specific waiver. Generally, respondents reported that the prioritization tool does not gather enough person-specific information to accurately make such assignments. Several individuals also noted that no correlation has been shown between a prioritization tool score and the cost of a person's CAP plan; although two respondents speculated that higher scores on the prioritization tool would, indeed, correlate to a higher dollar amount on a cost summary.

Several LME respondents suggested that mock cost summaries or preliminary cost summaries be developed for waiver assignment. However, one respondent opposed this idea because of the amount of time needed to develop the cost summary. Two LME respondents noted the prioritization tool could possibly be used in conjunction with the Supports Intensity Scale, which is administered by a trained assessor. One individual said that waiver assignments should not be made until a person-centered plan is developed.

#### *Other concerns*

Other concerns expressed by one or two LME respondents include:

- Not all LMEs have the same staffing capacity to administer the prioritization tool.
- The prioritization tool does not address if certain needs could be met through other funding sources. For example, could adaptive equipment be purchased with other dollars?
- The prioritization tool does not address an individual's eligibility for Medicaid.
- How does the Division define disability in the prioritization tool's question related to whether more than one person living in the household has a disability?
- Some families are concerned that someone will take their child away if they say the child is at risk for institutionalization.

## *Summary*

The interviews produced a mixed assessment of North Carolina's CAP-MR/DD Prioritization tool. Respondents agreed that the prioritization tool has many strengths, including (1) the potential to provide consistency throughout the state in allocating waiver slots; (2) updated information about the needs of individuals on a waiting list; and (3) ease of administration. Alternatively, respondents believed that the prioritization tool could be improved. They felt the prioritization tool should obtain more information, but overall, the questions should be more specific and less subjective. Respondents expressed particular concern about the wording, format, and directions for three of the prioritization tool sections: emergent/crisis needs, behavior needs, and medical and related support needs. They also suggested that more training is needed and that they were uncomfortable using the same instrument to prioritize children and adults.

## *Recommendations*

The LMEs have only recently begun administering the CAP-MR/DD Prioritization tool to people on their waiting list. Moreover, in its recent report entitled *Successful Transitions for People*

*with Developmental Disabilities,* the North Carolina Institute of Medicine [5] recommended that the Division "adopt a validated and reliable assessment instrument that can be used for people with I/DD to provide information on the person's relative intensity of needs." If the Division were to actually implement that recommendation, then it is not at all clear if and how the prioritization tool would continue to be used.

However, based on the findings of this study, which was undertaken to enhance the implementation of the prioritization tool, we suggest the following as the four most critical recommendations:

### *Recommendation 1 – Provide statewide training on the CAP-MR/DD Prioritization tool for Local Management Entities staff.*

Almost all respondents requested additional training on the prioritization tool. Training could fruitfully address the Division's expectations in administering the prioritization tool; how additional assessments and evaluations could be combined with the prioritization tool; and section-by-section training on how to interpret the listed measures. The Division may want to consider offering trainings or training materials to case managers and CAP-eligible individuals and their families to ensure that the prioritization criteria are understood.

### *Recommendation 2 – Provide clarification of the prioritization tool's terms and instructions.*

Respondents noted that certain terms and phrases in the prioritization tool are confusing and administrators sometimes make subjective judgments while administering the prioritization tool. The Division could revise some of the prioritization tool's wording to ensure clarity and eliminate terminology with ambiguous or multiple meanings. Clearly defining terminology and expanding prioritization tool instructions to include definitions and examples would be helpful.

### *Recommendation 3 – Establish a technical assistance program for staff who administer the prioritization tool.*

Establishing a "Frequently Asked Questions" website or including information about the prioritization tool in memos or community bulletins could help accomplish the important task of providing technical assistance. Such action would ensure that the prioritization tool is administered correctly and consistently across North Carolina.

### *Recommendation 4 – Revise the prioritization tool and consult with a work group of prioritization tool administrators when doing so.*

We suggest forming a work group of individuals responsible for administering the prioritization tool to recommend specific changes to the prioritization tool. This work group can use their own experiences with the prioritization tool to help anticipate challenges that may arise from any further changes to it.

While we only outline four broad recommendations above, we consider each of the LME respondents' suggestions important and worthy of consideration. Again and again, LME staff said they want to be fair and equitable to those waiting for services and to accurately and sincerely explain slot allocation decisions to applicants and their families. We believe with the recommendations outlined in this report, the CAP-MR/DD Prioritization tool can be a useful and successful addition to the prioritization process, and that LMEs can feel confident in making waiver allocations.

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