

STATE OF NORTH CAROLINA

IN THE GENERAL COURT OF JUSTICE

F I L E D  
SUPERIOR COURT DIVISION

WAKE COUNTY

FILE NO.: \_\_\_\_\_

2017 MAY 24 A 10:37

SAMANTHA R., by her Guardian, TIM R., )  
 MARIE K., by her guardian, EMPOWERING )  
 LIVES GUARDIANSHIP SERVICES, LLC, )  
 CONNIE M., by her guardian CHARLOTTE R., )  
 JONATHAN D., by his guardian MICHAEL D., )  
 MITCHELL T., by his guardian, BETSY S., and )  
 DISABILITY RIGHTS NORTH CAROLINA, )

Plaintiffs,

v.

COMPLAINT  
(COMP)

STATE OF NORTH CAROLINA, THE )  
 NORTH CAROLINA DEPARTMENT OF )  
 HEALTH AND HUMAN SERVICES, and )  
 MANDY COHEN, in her official capacity )  
 as Secretary of the North Carolina Department )  
 of Health and Human Services, )

Defendants.

*"Every system is perfectly designed to get the results it gets."*

**INTRODUCTION**

1. Thousands of North Carolinians with intellectual and/or developmental disabilities ("I/DD") are living segregated, institutionalized lives, or receiving inadequate support to remain integrated in their communities because of the design, funding, and administration of the Defendants' health and human services system.
2. North Carolina ranks 48<sup>th</sup> in the overall effect of state policies and practices on promoting independence for people with I/DD.
3. There are over 10,000 North Carolinians on waiting lists for services needed to leave institutions or avoid institutionalization.

4. Plaintiffs, Samantha R., Marie K., Connie M., Jonathan D., and Mitchell T., and Disability Rights North Carolina (“DRNC”) bring this action to enforce the rights of North Carolinians with I/DD to receive services in the most integrated setting appropriate to their needs, as required by the North Carolina Persons with Disabilities Protection Act (“NCPDPA”), N.C. Gen. Stat. Ch. 168A, and the North Carolina Constitution (“NCSC”).
5. Defendants, the State of North Carolina, the North Carolina Department of Health and Human Services, and Mandy Cohen, Secretary of the North Carolina Department of Health and Human Services (herein referred to collectively as “Defendants”) because of systemic flaws in the design, funding, implementation, and administration of the Defendants’ health and human services system, violate the NCPDPA and NCSC by:
  - a. keeping some North Carolina citizens with I/DD institutionalized unnecessarily,
  - b. placing citizens of North Carolina with I/DD at risk of segregation or institutionalization, and
  - c. segregating North Carolina citizens with I/DD.
6. Defendants have undertaken a systematic and harmful cost-cutting process affecting those North Carolina citizens who are receiving community-based services and who have relied on publicly funded community-based services that is illegally increasing their risk of segregation and institutionalization.

#### PARTIES

7. Plaintiff Samantha R., an individual with I/DD and a citizen and resident of Cabarrus County, North Carolina, is currently institutionalized at a State-operated facility in Morganton, North Carolina.

8. Plaintiff Marie K., an individual with I/DD, is a citizen and resident of Rockingham County, North Carolina.
9. Plaintiff Connie M., an individual with I/DD, is a citizen and resident of Gaston County, North Carolina.
10. Plaintiff Jonathan D., an individual with I/DD, is a citizen and resident of Wake County, North Carolina.
11. Plaintiff Mitchell T., an individual with I/DD, is a citizen and resident of Gaston County.
12. Plaintiff Disability Rights North Carolina (“DRNC”), a North Carolina non-profit corporation, with its principal place of business in Raleigh, North Carolina serves as the federally-mandated protection and advocacy (P&A) system for people with disabilities in North Carolina.
13. DRNC is a “person” authorized to seek legal and equitable relief.
14. Defendant North Carolina Department of Health and Human Services (“the Department”) is the “single State agency” responsible for administering and supervising the public health benefits program at issue in this case. N.C. Gen. Stat. § 108A-54.
15. Defendant Cohen is the Secretary of the Department, and is sued in her official capacity as the official charged with control and oversight of the Department.
16. Defendant, the State of North Carolina, is one of the fifty states of the United States.

#### **JURISDICTION AND VENUE**

17. The jurisdiction of the Court is invoked pursuant to N.C. Gen. Stat. §§ 1-75.4 and 168A-11.
18. Venue is proper in Wake County pursuant to N.C. Gen. Stat. § 1-82 because Plaintiff DRNC and Defendants have their primary places of business in Wake County.

## FACTS

### The Need and Legal Requirements for Integrated Services

19. People with intellectual disability (ID) (formerly mental retardation) have “significantly sub-average general intellectual functioning existing concurrently with deficits in adaptive behavior and manifested before age 22.” N.C. Gen. Stat. § 122C-3 (22).
20. Individuals with a developmental disability (DD) have a condition that manifests before age 22, is likely to continue indefinitely, reflecting a need for lifelong or extended services, and produces functional limitations in three or more of the following areas: self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency. N.C. Gen. Stat. § 122C-3 (12a).
21. Examples of disabilities that may be considered DDs include cerebral palsy, Down Syndrome, and autism.
22. ID and DD are referred to collectively herein as I/DD.
23. Where an individual *without* an I/DD may progress through development from childhood through adulthood without special interventions, individuals with I/DD require additional training, habilitation, and support to achieve and maintain independent living skills such as self-care, daily living skills, physical, occupational, or speech therapy, and vocational training.
24. In the absence of appropriate habilitation and ongoing support, individuals with I/DD are vulnerable to needless dependence and institutionalization.
25. Defendants provide for physical and behavioral health services for individuals with I/DD through Medicaid, which includes State and federal funding, and through purely State-funded services.

26. Behavioral health services are those services related to a non-physical health need, such as habilitative or rehabilitative services, or support services including training and support in skill development, supervision or prompting and direct assistance with independent living, vocational training and support, crisis management, and support in obtaining and maintaining housing.
27. Habilitative services and supports include training and care that help someone with I/DD acquire, improve, or retain new skills and functional abilities that may not be developing typically or at the same pace as a person without a developmental disability. N.C. Gen. Stat. § 122C-3 (16).
28. Rehabilitative services include assistance and support for performing daily personal care and other activities of daily living, when skills have been lost. N.C. Gen. Stat. § 168-8.
29. Some individuals with I/DD may require personal care services, in which a direct caregiver performs the task for the person by providing direct, hands-on assistance with activities of daily living, including eating, bathing, dressing, toileting, or mobility.
30. Defendants must provide for treatment, habilitation, and rehabilitation for individuals with I/DD in the least restrictive setting appropriate to the individual's need. N.C. Const. Art I §19; N.C. Gen. Stat. §§ 168-8, 168A-7; 10A N.C.A.C. 28D .0101.
31. A governmental entity in North Carolina may not operate its service system in a manner that leads to segregation or institutionalization or creates an impermissible risk of segregation or institutionalization. N.C. Gen. Stat. § 168A-7.
32. Operating a service system that promotes segregation or institutionalization violates the North Carolina Constitution and State law. N.C. Const. Art I §19; N.C. Gen. Stat. § 168A-7.

## North Carolina's Institutions Serving Persons With I/DD

33. Defendants pay to house individuals with I/DD in institutions in North Carolina such as state-operated developmental disabilities centers (DD Centers), privately-operated intermediate care facilities (ICFs), and adult care homes (ACHs), (referred to collectively as "institutions" or "facilities") where there is restriction of the residents' movements, visitors, and access to food.
34. Hallmarks of these facilities in North Carolina include rigid and restrictive rules and schedules, limited freedom of movement, lack of choice regarding timing and content of meals, roommates, décor, and how and where to spend free time, resulting in the lack of meaningful contact with family, friends, or peers without disabilities.
35. Some residents of these institutions in North Carolina, on information and belief, experience dangerous conditions and discriminatory treatment that result in lasting trauma, injuries, and loss of function, including sexual and physical abuse and neglect, and chemical or physical restraint.
36. Defendants provide funding for persons with I/DD placed in these institutions as an entitlement.
37. Many persons with I/DD who reside in institutions, on information and belief, would prefer home and community-based services but cannot access funding for such services.

### Institutional Settings Restrict Self-Determination and Create Dependency

#### State-Operated DD Centers / Public ICFs

38. State-operated DD Centers in North Carolina are large, congregate institutions with an average census in 2016 of approximately 1169 North Carolinians with I/DD.
39. DD Centers provide very structured environments, with very little opportunity to develop independent living skills, as the facility controls meals, medications, and activities.

40. Residents of DD Centers do not have the opportunity to choose with whom to live or the basic conditions of their environment.
41. Many individuals housed in DD Centers, on information and belief, would prefer to live in the community and could be served in the community.
42. The State-operated DD Centers are licensed in North Carolina as public intermediate care facilities (ICFs).
43. The average cost in 2015 for housing an individual at a DD Center in North Carolina was about \$235,000 per year.
44. In 2001, the North Carolina General Assembly directed the Department to reduce the number of individuals in public ICFs by specific amounts over several years.
45. For 2016, the DD Centers in North Carolina operated at approximately 88% of their full capacity.
46. The Department did not implement or achieve the reductions mandated by the General Assembly in 2001.
47. The current North Carolina State policy for downsizing State-operated DD Centers is to transfer residents to private ICFs when possible. (Chapter 17, 2017 State Medical Facilities Plan.)
48. Defendants violate the NCSC and NCPDPA by their reliance on DD centers which is inconsistent with the principle that individuals must receive public services in the least restrictive environment.

#### *Private ICFs*

49. Like public ICFs, private ICFs are congregate institutions with specified times and menus for meals, visits, and with other restrictive attributes of institutional living.

50. There are over 300 private ICFs in North Carolina, with the capacity to house approximately 2700 individuals with I/DD.
51. Private ICFs have at least six beds per facility, with some having more than 100 beds.
52. Among smaller ICFs, there is significant variation in the quality of life of the residents, both in terms of living conditions and opportunities for community involvement.
53. It costs about \$110,000 per year, on average, to house an individual in a private ICF.
54. According to the 2017 State Medical Facilities Plan, issued by the Department, there are 5,107 ICF beds in North Carolina for people with I/DD, including those in the State-operated facilities and private ICFs.
55. The 2017 Proposed State Medical Facilities Plan concludes “that North Carolina has a more than adequate number of ICF/IDD beds in comparison to other southeastern states.” (Chapter 17, 2017 State Medical Facilities Plan.)

#### *Adult Care Homes*

56. Adult Care Homes (“ACHs”) are congregate institutions and are restrictive of independence and integration.
57. Family Care Homes (“FCHs”) are licensed under the same regulations as ACHs. N.C. Gen. Stat. § 131D-2.1(9).
58. ACHs have seven or more beds while FCHs have up to six beds.
59. There are approximately 1300 individuals with I/DD living in ACHs and approximately 400 living in FCHs.
60. On information and belief, hundreds more individuals with I/DD are living in ACHs, but have not been identified to the State as individuals with I/DD.
61. ACHs provide room and board, but not habilitation, for the monthly fee paid to the facility.



62. Most ACHs provide some amount of personal care services to assist some residents with activities of daily living that are not included in the monthly rate, but which are reimbursed separately by Medicaid or private insurance.
63. ACHs are ill-equipped to care for individuals with behavioral health needs, yet Defendants have relied on ACHs as “a major component of the long-term care system in North Carolina.”  
Preface, State/County Special Assistance for Adults Manual.  
(<https://www2.ncdhhs.gov/info/olm/manuals/doa/sa/man/Preface.pdf>)
64. Housing individuals with I/DD in ACHs does not provide the appropriate treatment or setting for those individuals.
65. Individuals with I/DD continue to be placed in ACHs because of a shortage of more appropriate community alternatives for individuals with I/DD and because of financial incentives embedded in the system, even when their wishes or needs could be better supported in their community. North Carolina Institute of Medicine, *Short- and Long-Term Solutions for Co-Location in Adult and Family Care Homes: a Report of the NCIOM Task Force on the Co-Location of Different Populations In Adult Care Homes*, p. 19. Morrisville, NC; 2011 (“NCIOM Report”).
66. ACHs “are part of a larger system that has failed to provide adequate options and supports for individuals with disabilities.” NCIOM Report, p. 21.
67. As part of its reliance on ACHs, the State, using a combination of State and county funds, pays ACHs the difference between an individual’s income, usually Supplemental Security Income (SSI) or Social Security Disability Income (SSDI), and a rate set by the State for room and board at the ACH.
68. The subsidy to ACHs is called Special Assistance (SA).

69. The State pays over one hundred million dollars in SA each year to ACHs.
70. In 2016, the State determined to further subsidize the ACHs by providing them a stipend for each resident who was eligible for SA for a period of one year, without any concomitant provision of any additional service by the ACHs. 2016 N.C. Sess. Laws 94, s. 12C.7.(c) & (e); 2016 N.C. Sess. Laws 123, s. 5.3.
71. Although designated “temporary financial assistance to facilities [ACHs],” the General Assembly further ordered the Department to develop a plan to increase future payments to ACHs. 2016 N.C. Sess. Laws 94, s. 12C.7.(c) & (e); 2016 N.C. Sess. Laws 123, s. 5.3.
72. The aim of the above-referenced plan for increased future funding is “a long-term solution” to support the continued placement of individuals with disabilities in ACHs. 2016 N.C. Sess. Laws 94, s. 12C.7.(e).
73. During the 2017 legislative session, the North Carolina State Senate proposed to continue temporary financial assistance for two more years.
74. Defendants’ financial support of ACHs does not promote the general welfare because such payments foster and promote segregation of people with disabilities in inappropriate institutional settings and violate the requirement of the NCPDA and NCSC that the State provide services in the least restrictive setting appropriate to the needs of people with disabilities.

**Defendants Fail to Promote Discharge from Institutions and Fail to Enforce Discharge Planning Requirements**

75. Defendants deliver community-based behavioral health services exclusively through public local management entities (LMEs), which contract with the Department as Managed Care Organizations (MCOs). N.C. Gen. Stat. § 122C-3.

76. LME/MCOs are public entities “responsible for the management and oversight of the public system of mental health, developmental disabilities, and substance abuse services at the community level.” N.C. Gen. Stat. § 122C-115.4.
77. LME/MCOs’ sole purpose is to administer behavioral health services. N.C. Gen. Stat. § 122C-115.4.
78. LME/MCOs have a responsibility to “assure clients’ care is coordinated, received when needed, likely to produce good outcomes, and is neither too little nor too much service to achieve the desired results.” N.C. Gen. Stat. § 122C-115.4(b)(5).
79. For those with behavioral health needs who want to leave institutional settings, their care must be coordinated across settings, including through discharge planning, and they must receive assistance for a successful transition into ongoing treatment and support in the community. N.C. Gen. Stat. § 122C-115.4(5).
80. LME/MCOs do not reliably develop effective community-based service plans while an individual is in a facility.
81. LME/MCOs do not reliably identify or arrange for actual community-based services to have in place in advance of a transition to the community.
82. An individual ready for discharge from a facility may have nowhere to go and/or no services in place to support a community placement because the individuals attempting to manage the transition, including facility staff or family members, lack the expertise or power to identify, secure, or obtain authorization for appropriate services in a timely manner.
83. There are, on information and belief, many individuals with I/DD for whom inadequate discharge planning has prolonged institutionalization and/or resulted in inadequate community transitions that segregate them and/or place them at risk for re-institutionalization.

84. Defendants' failure to enforce the requirement that LME/MCOs help individuals leave institutions leads to prolonged institutionalization for many individuals with I/DD in violation of the NCPDA and NCSC.

85. By failing to enforce a requirement that LME/MCOs actively assist in providing transition services, Defendants have failed to ensure that individuals with I/DD who are ready for discharge from institutions receive necessary support to transition to community living in violation of the NCPDA and NCSC.

### **Impediments to Community-Based Services**

#### **Financial Incentives for Service Reductions**

86. LME/MCOs receive a per member/per month sum to provide for behavioral health services for individuals in their catchment areas who need them, which is referred to as the capitated rate.

87. An individual requiring publicly-funded behavioral health services must obtain those services through their assigned LME/MCO based upon where they live in the State.

88. The capitated rate system incentivizes budget reductions for beneficiaries irrespective of any change in the need for services.

89. The contract between the Department and the LME/MCOs provides that funds remaining in a reserve account maintained by an LME/MCO become the property of the LME/MCO on termination or expiration of the LME/MCO contract.

90. The LME/MCOs, on information and belief, currently maintain fund balances well in excess of the funds needed for reserves.

91. While LME/MCOs retain these fund balances, many individuals with I/DD remain on waiting lists for services, or have seen their services reduced or eliminated, increasing their risk of segregation or institutionalization.
92. Permitting LME/MCOs to retain funds at the termination or expiration of their contracts discourages the appropriate expenditure of funds on community-based services, incentivizes the denial of those services, and diverts resources intended to serve eligible individuals, including those with I/DD.
93. Defendants have permitted an LME/MCO CEO to receive an annual compensation package worth over one million dollars, well above market rate for the position in North Carolina.
94. Permitting excessive payments to LME/MCO employees using public funds diverts resources intended to support eligible individuals, including those with I/DD.
95. Defendants have structured their community-based behavioral health system in a way that increases the risk that individuals with I/DD will become segregated or institutionalized in violation of the NCPDA and NCSC.

**Defendants' Elimination of Case Management Limits Access to Services**

96. Case management services provide an individual with a knowledgeable advocate who understands the behavioral health system and is able to ensure that the individual has an appropriate plan of care and array of services.
97. Case managers advocate for the best interest of their clients, including identifying and securing services.
98. Defendants have significantly curtailed case management services for those with I/DD.

99. In the absence of case management services, many individuals with I/DD and their families are not equipped to navigate the complex system of services, funding options, and the processes for accessing habilitative and rehabilitative support.
100. There are many North Carolinians with I/DD, on information and belief, who need case managers to navigate the service system, but do not have them.
101. In the absence of effective case management services, family members or guardians of persons with I/DD in North Carolina are in the position of trying to help arrange for and manage services, and advocate for their retention when faced with reductions.
102. Family members and guardians are often ill-equipped to manage the health system to avoid the segregation or institutionalization of persons with I/DD in North Carolina.
103. Reliance on family members or guardians of persons with I/DD increases the risk of segregation or institutionalization, including in the following ways:
- a. Aging parents become unable to provide the level of support they once were, or are themselves in need of care.
  - b. Public guardians have significant caseloads and are much more likely to place a ward in a facility, where the individual's shelter, food, and medication needs are addressed.
  - c. Most public guardians lack the time, training, and resources involved in supporting a ward in the community.
  - d. Many guardians lack knowledge of the service system and are daunted by the challenges of advocating for needed supports for persons with I/DD thereby making institutionalization appear to be the only option.
104. There are many individuals in North Carolina with I/DD who, on information and belief, are segregated or institutionalized or at risk for segregation or institutionalization because they

do not have the professional advocacy and expertise of case managers to ensure that they receive sufficient community supports.

105. Defendants have virtually eliminated case management services for persons with I/DD which is an impediment to accessing community-based services in violation of the NCPDA and NCSC.

**Inadequate Provider Networks**

106. Defendants must maintain a provider network sufficient in number, type, and geographic distribution to serve qualified individuals with behavioral health needs. N.C. Gen. Stat. § 122C-115.4.
107. On information and belief, there are many individuals with I/DD who are unable to access needed community-based providers due to Defendants' inadequate provider network.
108. Defendants have not set network adequacy standards for the LME/MCOs and have failed to ensure the actual provision of necessary services.
109. Defendants do not, on information and belief, monitor the number of network providers accepting new clients.
110. Defendants have failed to ensure that their contractors pay rates to providers that are sufficient to maintain a stable and adequate network of providers.
111. Defendants' failure to ensure adequate provider networks is an impediment to accessing community-based services in violation of the NCPDA and NCSC.

**Defendants' Primary Program for Individuals with I/DD Is Insufficient to Meet the Needs of Those with I/DD Who Are Segregated or Institutionalized or At Risk of Segregation or Institutionalization**

112. Defendants operate a Medicaid waiver program for people with I/DD, referred to as the Innovations Waiver.

113. The Innovations Waiver is Defendants' primary community-based program for individuals with I/DD.
114. A waiver allows for the provision of expanded services to a set of qualified individuals while waiving certain Medicaid requirements such as income limits and statewide availability or comparability of specific services.
115. To be eligible for the Innovations Waiver, an individual must be deemed to need a level of care that would entitle them to be served in an ICF.
116. Individuals who need an ICF level of care are at risk of institutionalization without services to support them in the community.
117. Approximately 12,000 individuals with I/DD have Innovations Waiver slots, which are intended to provide supports and services as an alternative to institutional living.
118. The State may expand the number of individuals served under the Innovations Waiver.
119. Over 10,000 individuals with I/DD in North Carolina are currently on the Innovations Waiver waiting list, called the Registry of Unmet Needs.
120. Prior to being placed on the Registry of Unmet Needs, an individual is assessed to determine whether he or she is likely to be eligible for a Waiver "slot."
121. Despite minimal increases in the number of available Waiver slots over time, on information and belief, North Carolina's Registry of Unmet Needs is growing.
122. The wait for Innovations Waiver slots varies, but hundreds of people have been waiting 10 years or more.
123. Apart from Waiver services, very limited options are available to provide long-term support to individuals in North Carolina with I/DD who are at risk of segregation or institutionalization.



124. While on the Registry of Unmet Needs, individuals with I/DD who need an ICF level of care are at risk of segregation or institutionalization.

**Defendants' Systematic Reduction of Budgets Increases the Risk of Segregation or Institutionalization**

125. In or about November 2016, Defendants promulgated to their LME/MCO contractors a budget matrix that the LME/MCOs now use to designate budgets for individual Innovations Waiver enrollees.

126. Many Waiver beneficiaries have received notifications of an intent by Defendants' agents to reduce individual budgets over three years, with the expectation that there will be a concomitant reduction in support services over time.

127. The new budget matrix has seven levels, each with a general description of the type of services individuals in that group will "likely need."

128. Each level has a budget for individuals based on whether the individual is a child or adult, and the individual's type of living situation.

129. The only other variable factor in determining the budget assigned to an individual is the individual's score on an instrument called the Supports Intensity Scale (SIS).

130. The results of a SIS, on information and belief, depend on the skills and abilities of the individual administering and scoring the instrument.

131. Neither the SIS nor the budget matrix, on information and belief, accounts for the level of family or other support an individual has available to rely on to supplement services paid for through the LME/MCO.

132. The budget levels set in the Defendants' matrix, on information and belief, are the same in every geographic area of the State and are not based on a determination of the actual cost of providing the needed care for individuals who fall into the categories in the matrix.

133. The budget matrix, on information and belief, imposes an across-the-board reduction for thousands of individual Waiver participants.
134. Defendants have allowed their LME/MCO contractors to deny or reduce services in reliance on the budget matrix.
135. There are many individuals, on information and belief, who are facing service cuts that eliminate support that was previously deemed, and continues to be, medically necessary.
136. Defendants' systematic reduction of budgets for home and community-based services places many individuals with I/DD at risk of segregation or institutionalization in violation of the NCPDA and NCSC.

**Defendants' Failure to Enforce Their Contracts with the LME/MCOs Has Increased the Risk of Segregation and Institutionalization**

137. The LME/MCOs employ a system for limiting services called "utilization management," which is similar to an insurance approval process for medically necessary services.
138. Defendants' contracts with the LME/MCOs define "medically necessary" for purposes of conducting utilization management, but the actual definition used by some LME/MCOs differs in significant ways.
139. LME/MCOs are also required, pursuant to their contracts with Defendants, to publish clinical practice guidelines that are consistent with valid and reliable clinical evidence or the consensus of providers.
140. Denials or reduction of services by LME/MCOs in their utilization management process must be consistent with clinical practice guidelines.
141. The LME/MCO must give clinical practice guidelines to providers and make the guidelines available to enrollees so the standards for decision-making are clear and transparent.

142. Defendants' LME/MCO contractors, on information and belief, do not have, publish, or follow clinical practice guidelines for individuals with I/DD that are consistent with the requirements for those guidelines.

143. There are many individuals with I/DD, on information and belief, whose service requests have been limited or denied based on improper definitions of medical necessity and/or without basis in appropriately promulgated, valid and reliable clinical practice guidelines.

144. Defendants have failed to require that the LME/MCOs apply the standards of medical necessity and utilization management to which they agreed, in violation of the NCPDA and NCSC.

**Defendants Improperly Permit LME/MCOs to Require that Services "Fade" Over Time, Without Regard to Ongoing Needs**

145. Individuals with I/DD have support needs that are ongoing and life-long.

146. Although a long-term goal of some services is to increase a person's functional abilities and independence, the need for supports does not necessarily decrease.

147. The LME/MCOs define some services in such a way that they are designed to "fade" or reduce over time.

148. Fading requirements contradict the required application of medical necessity criteria and clinical practice guidelines, and are inconsistent with the needs of people with I/DD for ongoing support.

149. There are many individuals who have had services denied, on information and belief, because of a lack of a plan to fade services, despite having continuing needs that do not fade.

150. Defendants' fading requirements place people with I/DD at risk of segregation or institutionalization in violation of the NCPDA and NCSC.

### The Futility of Individual Appeals

151. Individual appeals of annual denials are futile to address the risk of segregation and institutionalization because they do not address the cumulative effects of annual service cuts and because Defendants allow the LME/MCOs to use improper criteria and subvert the appeals process so that it does not deter LME/MCOs from reducing or denying services.
152. Denial letters issued by the LME/MCOs are oblique and do not contain required clinical rationales or reasoned explanations that are understandable to a reasonable person.
153. Defendants' failure to require that the LME/MCOs utilize ascertainable standards and provide sufficient notice regarding denials and reductions violates the NCSC, and individual appeals are futile to address the systemic risk of segregation and institutionalization.

### Defendants' Awareness of Inadequacies in the I/DD System

154. Defendants are aware of the deficits in their system perpetuating segregation and institutionalization.
155. Studies and reports for at least the last ten years have identified institutional bias in the I/DD services system in North Carolina.
156. Defendants have failed to address meaningfully those biases identified in those studies and reports.
157. While LME/MCOs are required to provide support for people with behavioral health needs, Defendants' structuring of incentives for institutionalization and insufficient oversight of the LME/MCOs have led to a harmful cycle of benefits cuts and to instability in the service system in violation of the NCPDA and NCSC.

**Plaintiff Disability Rights North Carolina Has Standing on Behalf of its Constituents**

158. Individual Plaintiffs, and other constituents of Plaintiff DRNC, have been segregated or institutionalized or have been put at risk of segregation or institutionalization based on serial cuts by their LME/MCOs, and have had no effective remedy to address the cumulative effect of service cuts over time in violation of the NCPDA and NCSC.
159. Individual Plaintiffs, and other constituents of Plaintiff DRNC, have pursued appeals of specific service cuts and denials.
160. Individual appeals did not and cannot address the fundamental failures and system gaps that have caused their segregation or institutionalization or risk of segregation or institutionalization.
161. System changes to Defendants' health and human services are not available in individual appeals.
162. As the duly-designated Protection and Advocacy System (the P&A) for the state, DRNC is federally mandated and authorized to pursue legal, administrative, and other appropriate remedies or approaches when the rights of individuals with I/DD within North Carolina may have been violated. 42 U.S.C. § 15043 (a)(2).
163. Thousands of individuals with I/DD are currently segregated or institutionalized or at risk of segregation or institutionalization as the result of Defendant's policies and practices.
164. Delays in enforcing the right to services in the least restrictive environment is detrimental to the health and liberty interests of individuals with I/DD.
165. DRNC represents the interests of, and is accountable to, members of the disability community.

166. The Board of Directors of DRNC must be, and is, representative of the disability community and must, and does, have a majority of members who are either individuals with disabilities (including I/DD) or family members, guardians, or advocates for such individuals.
167. DRNC conducts annual surveys to determine specific areas of advocacy on which the organization will focus.
168. DRNC is required to, and does, seek public comment on the direction of its work, and conducts listening sessions to identify community concerns.
169. Members of the disability community may file grievances if they are wrongly denied services, or disagree with an action taken by DRNC.
170. Ending discriminatory practices in the publicly funded behavioral health program is germane to DRNC's overarching purpose: the protection of, and advocacy for, the rights of individuals with disabilities.
171. In this action, DRNC represents the interests of the Individual Plaintiffs and other constituents of the organization who have I/DD.
172. Although individual constituents have standing to bring this action, it is the unique duty of DRNC to bring this action to remedy a systemic wrong that affects a range of constituents who would not otherwise be in a position to bring individual actions.
173. Based on DRNC's role as the P&A, DRNC has associational standing to bring this action on behalf of itself and eligible individuals with disabilities who have been or will be discriminated against in the administration of publicly funded behavioral health services.
174. The facts set forth in paragraph 19 through paragraph 164 above in whole or part apply to the claims of the Individual Plaintiffs.

**Plaintiff Samantha R.**

175. Samantha R., age 28, is institutionalized in a DD Center, but she and her parents would prefer that she live in the community, and she could do so with necessary services and supports.
176. Samantha is non-verbal, and has I/DD, physical disabilities, and substantial medical needs.
177. Samantha lived at home with her family for most of her life, with support services provided by Defendants, which enabled her to participate actively in family and community life.
178. After several service cuts, Samantha's LME/MCO failed or refused to provide appropriate alternative community placement options, resulting in Samantha being forced to enter a DD Center.
179. Samantha's parents were provided a list of more than 70 providers to contact, only three of which were even potentially equipped to handle her medical and behavioral needs, and none of which had space available or were willing to serve Samantha.
180. Her parents agreed to place Samantha R. in an institution only after years of trying, unsuccessfully, to navigate the complex service system without a case manager, and without an adequate network of community-based providers.
181. Defendants have failed to take adequate steps to help Samantha leave the DD Center and return to her life in the community.
182. Samantha now lives a segregated life at a cost far greater than the cost for her to live in the community.

**Plaintiff Connie M.**

183. Connie M. is an individual with I/DD.
184. Connie uses a wheel chair, is generally unable to communicate verbally, and has ongoing and extensive life-long medical needs.

185. Connie receives community-based services that Defendants determined are necessary for her to remain in the community and avoid institutionalization.
186. Connie receives services through the Innovations Waiver.
187. Defendants have issued rules under the Innovations Waiver that place Connie's community based services at risk and increase her risk of segregation and institutionalization due to cuts to her service budget.
188. On or about August 31, 2016, Connie received notification that her budget will be cut by more than thirty thousand dollars and will continue to be cut over the next three years, with the tacit expectation that there will be a concomitant reduction in her support services over time.
189. The cuts to Connie's budget were not due to any improvement in her medical conditions or to a change in her needs.
190. Connie received a further notification that some of her services would be limited or required to "fade" after 90 days, not because the services were not medically necessary or because of clinically validated practice guidelines, but because of the LME/MCO's improper policy of placing time limits on such services.
191. In November 2016, Connie's LME/MCO denied her request for 19 hours per day of a service that provides for habilitative training and personal care.
192. Connie was denied services exceeding 16 hours per day, despite her LME/MCO's recognition that she needs 24-hour care to avoid institutionalization.
193. The reason given for limiting Connie's service hours was that there had been no plan submitted explaining how her services would fade after 90 days.
194. Connie's guardian requested a modification to the 90-day fading plan policy, but Connie's LME/MCO did not respond or provide any written rationale for the refusal of the request.



195. While Connie's LME/MCO has agreed to restore her services for now, the cycle of denials and appeals is subject to recurrence every 90 days due to the LME/MCO's insistence that Connie justify her ongoing needs every 90 days.

196. Connie is at risk for segregation and/or institutionalization based on her needs and circumstances should Defendants' ongoing efforts to reduce her services be successful.

**Plaintiff Marie. K**

197. Marie K. is a 28 year old woman, dually diagnosed with I/DD and mental illness.

198. Marie is on the Registry of Unmet Needs for the Innovations Waiver.

199. Due to lack of appropriate options, Marie was placed in an 80-resident ACH, where she received no significant treatment and endured abuse and neglect.

200. When advocates for Marie K. became aware of her situation and complained of the conditions at the ACH where she lived, the LME/MCO failed to assist Marie and her guardian with a discharge to a different residence.

201. Marie was eventually moved to an FCH, where she has received no skill building or habilitative services and is at risk for additional crises because her LME/MCO has failed to ensure she has appropriate supports and services in place.

202. The toll that managing Marie's care took led Marie's step-mother to relinquish guardianship of Marie.

203. In November 2016, Marie was hospitalized again for self-injurious behaviors and three weeks later, despite efforts to identify appropriate community-based services, she was discharged back to the FCH without adequate services.

204. Marie's LME/MCO has not provided her with access to services that properly address her I/DD and mental illness, which increases her risk of segregation and institutionalization.

205. Defendants have segregated Marie and increased her risk of institutionalization by placing her in inappropriate settings without the services and supports she needs.

**Plaintiff Jonathan D.**

206. Jonathan D. is 41, has autism, and is deaf.

207. Jonathan is on the Registry of Unmet Needs for the Innovations Waiver.

208. Jonathan is from Raleigh, but is segregated from his community in a group home in Morganton, North Carolina, three hours from his family.

209. For years, Jonathan has expressed his desire to live closer to his family, but his LME/MCO has failed to identify or provide an appropriate service provider in or near Raleigh.

210. In 2016, Jonathan suffered a behavioral crisis upon returning to the group home after a long weekend visit with his family due to his dismay over having to leave his family, and he was admitted to a State psychiatric hospital due to the crisis.

211. Jonathan's LME/MCO failed to locate or develop living options closer to his family while he was hospitalized.

212. The LME/MCO provided Jonathan's family a list of ACHs, which are inappropriate for Jonathan, and a list of other facilities, none of which accepted Jonathan.

213. Without other options, Jonathan returned to the group home where he continues to live segregated from his family.

214. Since returning to the group home, Jonathan has become more withdrawn, and resistant to participating in treatment.

215. Jonathan's group home provider has explained to Jonathan's LME/MCO, to no avail, that Jonathan will likely not progress or benefit from treatment until he is able to move closer to his family.

216. Because Jonathan's LME/MCO failed to engage actively in discharge planning to identify and provide appropriate community-based services, and has failed to develop or maintain a provider network that is adequate to meet his needs, Jonathan is segregated and at an increased risk of institutionalization.

**Plaintiff Mitchell T.**

217. Mitchell T., who is 21, has autism, I/DD, and significant behavioral health needs.

218. Mitchell has received the Innovations Waiver services that Defendants determined were medically necessary for him to remain in the community and avoid institutionalization.

219. Defendants have issued rules under the Innovations Waiver that place Mitchell's services in jeopardy and place him at risk of segregation or institutionalization.

220. In September 2016, Mitchell received notification that his budget would be cut each year for three years.

221. The series of cuts to Mitchell's budget were not the product of any change in his needs.

222. Mitchell's LME/MCO partially denied his service request, not because the services were not medically necessary, or based on identified clinical practice guidelines, but because the services exceeded his budget matrix assignment.

223. Mitchell appealed his LME/MCO's facially improper partial denial of services, but a quarter of his plan year had gone by when the appeal was resolved.

224. Mitchell faces the prospect of the same process repeating for his next plan year because his LME/MCO has already forecasted that his budget will be cut again.

225. Because Mitchell's LME/MCO has announced its intention to reduce his budget based on Defendants' new budget matrix, and because the services Mitchell needs are medically

necessary to enable him to live in the community, Mitchell is at risk of segregation or institutionalization.

**FIRST CLAIM FOR RELIEF**

**(Violation of the North Carolina Persons With Disabilities Protection Act)**

226. Plaintiffs adopt and restate the allegations set forth in paragraphs 1 –225 of this complaint.

227. Individual Plaintiffs and DRNC's constituents are qualified individuals with disabilities.

228. It is a statutory requirement in North Carolina that "[a] covered governmental entity shall administer its services, programs, and activities in the most integrated setting appropriate to the needs of persons with disabilities." N.C. Gen. Stat. § 168A-7(b).

229. Covered governmental entities may not discriminate by denying "the benefits of services, programs, or activities because of a disability or [refusing] to provide reasonable accommodations, including auxiliary aids and services necessary for a known qualified person with a disability to use or benefit from existing public services operated by such entity." N.C. Gen. Stat. § 168A-7(a).

230. Defendants' failure to provide appropriate habilitation, rehabilitation, and support services to individuals with I/DD in the most integrated setting appropriate to their needs, and failure to reasonably accommodate the needs of individuals with I/DD in their publicly funded behavioral health programs, constitute discrimination against Individual Plaintiffs and constituents of DRNC with I/DD on the basis of a disability.

**SECOND CLAIM FOR RELIEF**

**(Violation of the North Carolina Constitution: Procedural Due Process)**

231. Plaintiffs adopt and restate the allegations set forth in paragraphs 1 – 225 of this complaint.

232. The North Carolina Constitution provides that “[n]o person shall be . . . disseized of his freehold, liberties, or privileges . . . or in any manner deprived of his life, liberty, or property, but by the law of the land.” N.C. Const. Art I., § 19.
233. Defendants, through their agents, have violated the procedural due process rights of Individual Plaintiffs and other constituents of DRNC in the operation of their service system for individuals with I/DD.
234. Individuals receiving or applying for services have a property interest in certain publicly funded benefits, and a right to notice and an opportunity to be heard with regard to denials or reductions of such benefits.
235. Defendants, through their agents, have failed to provide constitutionally adequate notice with regard to service denials or reductions, and have failed to require their contractors to follow ascertainable procedures and standards in the operation of Defendants’ service system for people with I/DD.
236. Individual Plaintiffs and constituents of DRNC have been harmed by Defendants’ violation of their procedural due process rights in their operation of the service system for people with I/DD.
237. There are no adequate remedies at State law for Defendants’ procedural due process violations of N.C. Const. Art I., § 19.

### **THIRD CLAIM FOR RELIEF**

#### **(Violation of the North Carolina Constitution: Substantive Due Process)**

238. Plaintiffs adopt and restate the allegations set forth in paragraphs 1 – 225 of this complaint.
239. Defendants have violated the substantive due process rights of Individual Plaintiffs and other constituents of DRNC in the operation of their service system for individuals with I/DD.

240. Individuals receiving, applying for, or in need of I/DD services have a liberty interest in receiving services in the least restrictive setting appropriate to their needs, in receiving services outside of segregated or institutional settings, and in not being placed at risk of segregation or institutionalization.
241. Through the design and operation of their service system for people with I/DD, Defendants have infringed the liberty interests of Individual Plaintiffs and other constituents of Plaintiff DRNC.
242. Individual Plaintiffs and constituents of DRNC have been harmed by Defendants' violation of their substantive due process rights in their operation of the service system for people with I/DD.
243. There are no adequate remedies at State law for Defendants' substantive due process violations of N.C. Const. Art I., § 19.

**FOURTH CLAIM FOR RELIEF**  
**(Violation of the North Carolina Constitution: Emoluments)**

244. Plaintiffs adopt and restate the allegations set forth in paragraphs 1 – 225 of this complaint.
245. The North Carolina Constitution provides that “[n]o person or set of persons is entitled to exclusive or separate emoluments or privileges from the community but in consideration of public services.” N.C. Const. Art I., § 32.
246. Defendants have permitted the payment of separate emoluments to ACHs and LME/MCOs and their employees in violation of N.C. Const. Art I., § 32.
247. Payments to ACHs to subsidize the provision of institutionalized services is contrary to the public interest.
248. Payments to LME/MCOs that are diverted to excessive compensation and/or to fund balances, the disposition of which the State does not limit or control, violate N.C. Const. Art

I., § 32 because they do not serve the public purpose for which those funds were designated: the provision of home and community-based services to individuals with I/DD and other disabilities.

249. Individual Plaintiffs and Plaintiff DRNC's constituents have been harmed by the diversion of important public resources which are not being used for needed home and community-based services.

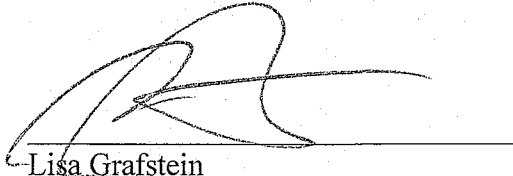
250. There are no adequate remedies at State law for Defendants' violations of N.C. Const. Art I., § 32.

WHEREFORE, Plaintiffs respectfully request that the Court grant the following relief:

1. Declare Defendants' actions, policies, procedures, and practices as alleged herein violate the North Carolina Persons With Disabilities Protection Act, and the North Carolina Constitution.
2. Enjoin Defendants' discriminatory administration of their publicly funded behavioral health programs and order Defendants to administer publicly funded behavioral health programs in compliance with the North Carolina Persons With Disabilities Protection Act, and the North Carolina Constitution.
3. Retain jurisdiction over this action to ensure Defendants' compliance with the mandates of the Court.
4. Award Plaintiffs the costs of this action and reasonable attorneys' fees.
5. Provide such other and further relief as the Court deems to be just and equitable.

This the 24<sup>th</sup> day of May, 2017.

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