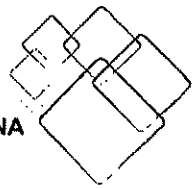
DISABILITY RIGHTS
NORTH CAROLINA
Champions for Equality and Justice



September 8, 2010

Cindy Mann, Deputy Administrator and Director
Center for Medicaid, CHIP and Survey & Certification
Centers for Medicare & Medicaid Services

John L. Wodatch
Civil Rights Division, Disability Rights Section
United States Department of Justice

Dear Ms. Mann & Mr. Wodatch:

As the federal Protection and Advocacy system for the state, we write to raise concerns with North Carolina's proposals related to Medicaid Personal Care Services ("PCS") program. North Carolina plans to switch a limited number of existing PCS recipients to a "new" in-home care benefit and eliminate PCS benefits for more than 20,000 recipients. No appeal rights will be afforded to these recipients. At the same time that North Carolina seeks to restrict PCS for those living in the community, the state also requests CMS approval for a waiver program through a 1915(i) State Plan amendment to provide PCS services with lower eligibility criteria in the institutional setting of adult care homes. We believe that these proposals, if approved by CMS, would violate the rights of many North Carolinians with disabilities, threaten what progress has been made to meet the mandates of *Olmstead*, and fail to honor the national initiative to support community living. Because the various elements of North Carolina's PCS program are deeply intertwined, we strongly urge CMS to withhold its approval for any part of a plan regarding PCS in North Carolina that will endanger people with disabilities in North Carolina or force them into large, institution-like facilities.

The North Carolina Department of Health and Human Services ("NCDHHS") often portrays its adult care home facilities as "community placements" but—as explained in Disability Rights NC's recent complaint to the U.S. Department of Justice—they are in reality something much more akin to institutions due to their large size and geographic and social isolation.[1] Adult care homes in North Carolina are large facilities with high resident-to-staff ratios and are often located in rural areas of the state with very little access to transportation, community activities or social opportunities. Approving a 1915(i) program for PCS in these facilities while simultaneously slashing the in-home PCS program will likely force thousands of North Carolinians with disabilities out of their homes and communities because they would no longer qualify for in-home PCS and could only access those services in a facility. Such a plan not only erodes the progress that has been made since *Olmstead* but also contravenes the intent of the more recent legislation that was intended to make 1915(i) programs easier to implement

[1] Disability Rights NC submitted a complaint on behalf of individuals with mental illness living in adult care homes in NC in July 2010. For that complaint, Disability Rights NC completed a survey of 15 adult care homes throughout North Carolina that largely serve individuals with disabilities that often include mental illness. As described in the complaint (copy enclosed), these facilities are typically large, institution-like settings that are segregated from the community.

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and encourage community living, not make it easier for states to push people towards more institutional placements.

NCDHHS' Plan to Replace the Current PCS Program

It is our understanding that NCDHHS plans to substitute one PCS program for another. The new program will serve substantially fewer recipients due to stricter eligibility criteria. No appeal rights will be granted to those currently receiving services who do not meet the eligibility criteria for the new service. The proposed new PCS program consists of two services: In-Home Care for Children (IHCC) and In-Home Care for Adults (IHCA). While IHCC will adhere to the requirements of EPSDT, IHCA imposes stricter eligibility requirements than both the current PCS program and the PCS program administered in adult care homes. At present, to be eligible for in-home PCS an individual must require hands-on, limited assistance with at least two Activities of Daily Living (ADLs). Under the proposal submitted by NCDHHS, the eligibility criteria will increase to either (a) limited assistance with three ADLs or (b) extensive or dependent assistance with two ADLs. This new standard is much higher than that required to receive PCS in an adult care home.

A limited number of those currently receiving PCS will transfer to the new service at the time of implementation, but NCDHHS estimates that 22,000 current recipients will be terminated from the program entirely. If the state were to proceed by changing the eligibility criteria for its existing PCS, each affected recipient would have the right of appeal. However, by eliminating the service entirely and replacing it with a "new" service, the state seeks to circumvent a recipient's right to appeal. Many of these individuals rely on PCS to safely remain in the community. With no right of appeal, these individuals have no entitlement to continue to receive services. Recipients who are terminated without appeal rights must then submit an application for the new service—a process that currently takes weeks or months. For many, the termination of PCS, even temporarily, would severely compromise their ability to remain in the community. Once admitted to a facility, a return to the community would prove difficult for a substantial number of individuals.

To compound the problem, NCDHHS is threatening PCS providers with recoupment if they provide services based upon the maintenance of service requirement when the PCS recipient's appeal is ultimately unsuccessful. Providers also report that when they provide services after an appeal is filed the State often refuses to reimburse them for the services. As a result, providers are reluctant to assist in the appeal process and may be unable to provide services without reimbursement. Because they no longer receive continued services during the appeal, some recipients are not exercising their appeal rights at all. Others are not exercising their right to appeal because the notices they have received contain very limited information that does not allow them to evaluate whether they should appeal.

North Carolina's proposal to terminate in-home PCS and create two "new" programs is a contrivance designed to eliminate the appeal rights of thousands of current PCS recipients. Current problems associated with the lack of appeal rights and maintenance of services are already pushing North Carolinians with disabilities into less integrated settings. Approval of the proposed plan that heightens eligibility for community services and allows for automatic eligibility for the same type of services upon admission to a facility would accelerate institutionalization of people with disabilities who could be served in the community at an equivalent or lower cost to the State.

PCS in the Community is Not Comparable to PCS in Adult Care Homes

The criteria for receiving in-home PCS under the current and proposed PCS service definitions (collectively, "in-home PCS") and for receiving adult care home PCS are not comparable. As explained earlier, to be eligible for in-home PCS under the current service definition, an individual must require hands-on, limited assistance with two ADLs. Under the proposed service definition for IHCA, the eligibility criteria will increase to either: (a) limited assistance with three ADLs or (b) extensive or dependent assistance with two ADLs. To be eligible to receive PCS services in adult care homes, an individual need only show that he requires some assistance in one ADL or some supervision. Additionally, unlike adult care home PCS, "personal hygiene" and "transferring" are not ADLs that can be taken into account when determining eligibility for in-home PCS.[2]

An individual's cognitive capacity is also factored differently when requesting in-home PCS as compared to adult care home PCS. For in-home PCS, cognitive capacity might be considered, but only as a factor in increasing hours once the applicant's eligibility has been established. In contrast, adult care home PCS contains no such restrictions. This difference has a substantial impact on individuals who require some assistance with ADLs but may not need substantial physical assistance. Such individuals would qualify for adult care home PCS but not in-home PCS.

Adult care home PCS does not have a monthly cap and there is no use of a formula to limit hours of services. The average adult care home resident receives over 60 hours of PCS services per month. An adult care home resident may also receive Enhanced PCS and Special Care Unit PCS, which provide additional services. On the other hand, the amount of an individual's in-home PCS services is determined through an independent assessment performed by a nurse and a computer-calculated formula. Using a scoring algorithm, an individual's services may range from 20 to 60 hours a month (80 hours a month if the individual qualifies for PCS-Plus).

The comparability issues between the two types of PCS have existed for some time, but have become more acute with the recent requirement for an independent assessment for in-home PCS but not adult care home PCS. While the state seeks to sidestep the comparability problem through the proposed 1915(i) program, in doing so it creates a tremendous institutional bias and thus runs afoul of *Olmstead*. Congress enacted the provision in the Affordable Care Act allowing CMS to waive comparability for 1915(i) programs to give States more flexibility to provide home and community-based services and decrease institutionalization. Instead, North Carolina is using this authority to encourage institutionalization. The proposal made by NCDHHS would maintain the same level of benefits for residents in adult care homes while sharply restricting access to the same service to residents in their own homes. If CMS approves this proposal, the waiver of comparability would promote

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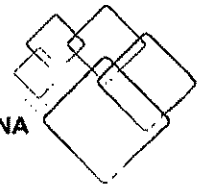

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institutionalization and thereby discriminate against and violate the rights of thousands of North Carolinians with disabilities.

Administrative and other Problems with the Current PCS Program

Problems related to the administration of the existing PCS program have recently arisen. In our view, these problems will likely persist and continue to have a significant negative impact on applicants for and recipients of in-home PCS. As a result of the administrative problems, individuals whose physicians have already determined the need for PCS have entered institutions, been hospitalized or died after waiting weeks and months for an assessment and authorization to receive services with little, if any, information about eligibility or their rights. These problems are unlikely to be addressed by NCDHHS' proposed plans. It is more probable that the problems, or very similar ones, will continue, transfer to any new program, and become worse. In general, NCDHHS has shown a propensity to neglect its responsibilities concerning its PCS program by failing to hold its contractors accountable for their errors and delays; failing to amend the State Plan before allowing such a contractor to perform utilization review; and allowing the contractor excessive administrative discretion.

In 2009, North Carolina's Division of Medical Assistance ("DMA")—a division of NCDHHS and the State's designated Medicaid agency—entered into a sole-source contract with the Carolinas Center for Medical Excellence ("CCME") to conduct independent assessments for in-home PCS. Under the contract, CCME is responsible for initial assessments, continuing assessments, and change-of-status reviews for in-home PCS. The contract between DMA and CCME specifically states the number of recipients CCME is expected to dismiss through its assessments. CCME began the independent assessments on April 1, 2010 and began using a computerized algorithm—one not set out in DMA's policies—to determine the amount of service hours to authorize.

The State Plan states that NCDHHS is the single state agency responsible for utilization review and that NCDHHS does not rely upon a Quality Improvement Organization for its utilization review. Nonetheless, NCDHHS has given CCME a tremendous amount of discretion when conducting utilization review. The notices sent to PCS recipients terminating or reducing their services are sent from CCME but do not always include copies of CCME's assessment. DMA also regularly refers recipients and applicants to CCME about matters of policy. Many PCS policies, and almost all of the recent ones, are only found on the CCME website.

The CCME assessment and authorization process has been riddled with delays and other problems of administration. It is estimated that several thousand individuals have been referred to in-home PCS by their physicians since April 1, 2010, the effective date of the contract. Relatively few individuals have actually been authorized to begin receiving PCS since then. North Carolina's contract with CCME provides that assessment, eligibility, and authorization for PCS are to occur within thirty business days of an initial application. Thirty business days is an unreasonably long period of time given the immediate medical needs of most PCS applicant, but CCME most often fails to meet even this lengthy timeline. Hundreds of individuals have waited months for an initial assessment. Even after completion of the initial assessment process, applicants and recipients still wait weeks or months for notification of their eligibility. In many cases the applicants are no longer in their homes by the time they receive an authorization to receive PCS.

People who need in-home PCS and have been referred by their physician are suffering during these lengthy delays. For example, one applicant was discharged from a skilled nursing facility to her private residence with the understanding that this individual would receive home health and in-home PCS. After learning how long it would take to begin receiving PCS, the individual's need for immediate assistance forced her to return to the skilled nursing facility. Another individual died after waiting three months without ever receiving an assessment. Children are also waiting weeks and months for assessments, notwithstanding EPSDT requirements. Given CCME's delays, by the time the process is complete, the assessment is often dated and may not reflect the individual's current conditions and needs. The use of outdated assessments is especially troubling when these assessments are employed to terminate services or deny eligibility.

Until very recently, CCME's administrative delays also had a substantial effect on PCS recipients who wanted to change providers. DMA required that CCME conduct an independent assessment of any recipient who requested a change in provider before the recipient could obtain services from a new provider. As is the case with new applications and reauthorizations, this process can take months. If the recipient refused to remain with the old provider through this extended process, the recipient, who has already been determined to be eligible, was not receiving PCS services. The "solution" offered by CCME—that individuals continue to receive PCS from the current providers until the process is carried out—runs contrary to the right that recipients have a choice when selecting a provider. While for some time recipients whose providers had gone out of business were also in this situation and forced to wait, DMA (after pressure from advocates) eventually permitted an exception to allow the new provider to deliver services under the existing authorization until a new assessment could be completed. As of a few days ago and after months of rights violations an extended version of that exemption has been extended to those who wish to change providers.

Although advocates and provider agencies can inform applicants and families about the state's and CCME's excuses for the long delays, applicants and family members can learn very little from CCME or the state regarding the status of an application. Inquiries to CCME regarding application status or assessment scheduling either go unanswered or yield very little information for applicants/recipients and their families. At the same time, NCDHHS does not notify anyone of their right to appeal or otherwise provide any information or assistance to address the lengthy delays. When PCS applicants receive a notice of denial, or when PCS recipients receive a notice reducing or terminating their services, the notice letter relies exclusively on boilerplate language. No explanation of the basis for CCME's decision to deny, reduce or terminate services is given, nor does the notice include information, such as a copy of the assessment, that would provide the individual enough information to make an informed decision about appealing.

DMA has acknowledged these delays and other problems, but states only that CCME has had difficulty getting RN assessors hired and trained. CCME has only hired about half the number of nurses it says it needs to conduct the assessments. While the application process languishes, CCME seems to still find the necessary employees and time to identify cuts or elimination of services for current recipients. CCME's inability to hire or assign the necessary staff, DMA's failure to demand that CCME do so, and the refusal of both entities to create a workable alternative have unduly affected the rights and well-being of applicants and recipients.

The assessment and authorization process has caused undue delay, injury, and institutionalization yet the state has done little to address the problem. Of course, for every day CCME drags its feet and does

not authorize an eligible individual to receive services, NCDHHS saves money in the short term. The consequences of these delays are disastrous for those who need PCS to remain safely at home. Without the services necessary to remain in their homes, many individuals are forced into institutions like adult care homes, nursing homes, or hospitals. Others are endangering their health and safety by attempting to remain in their home without services in order to avoid an institutional placement. Thus, NCDHHS' myopic goal of cutting PCS and permitting these administrative delays to continue will ultimately cost the state and federal government more money and deprive individuals with disabilities the opportunity to remain in their communities.

The cost of community living through the use of in-home PCS is far less expensive than an adult care home placement. In addition to the per diem rate paid for adult care home PCS, adult care homes receive Special Assistance funds from the State. Typically, it costs three times as much to support an individual in an Adult Care Home than it does to support him in his own home. Individuals who try to live at home without needed services are more likely to be admitted to nursing homes or hospitals at a significantly higher cost than providing in-home PCS. North Carolina's proposed PCS changes, if approved, will result in increased costs for the North Carolina Medicaid programs and incur a much greater cost to the rights and independence of North Carolinians with disabilities.

In sum, NCDHHS has failed to hold its contractor, CCME, accountable for honoring the rights of applicants and recipients. For some time, the state has kept consumers and advocates in the dark regarding its intentions for its in-home and adult care home PCS programs, implementing tentative half-measures that have caused numerous problems with the PCS programs. The proposals currently under review do not address the current problems and are almost certain to make things far worse for people with disabilities in North Carolina.

If CMS approves North Carolina's pending applications, more individuals with disabilities will be forced to into institutional placements in order to receive needed services. Such a plan runs afoul of the *Olmstead* decision; is contrary to the current administration's Community Living Initiative; substantially affects current recipient's due process rights; and severely affects the rights of tens of thousands of North Carolinians with disabilities who have previously been able to maintain themselves in the community with limited assistance at a relatively minimal cost. We ask that CMS reject these proposals and that CMS and DOJ exercise their collective oversight and audit roles to investigate North Carolina's PCS program; ensure that North Carolina is in compliance with all applicable federal laws; and critically review any future proposals submitted by NCDHHS.

Sincerely,

Vicki Smith

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Executive Director

Enclosures: Disability Rights NC Complaint to the U.S. DOJ (July 2010)

cc: Renard Murray, CMS Regional Administrator for Dallas/Atlanta
Gil Silva, Deputy Regional Administrator, Atlanta Regional Office DOJ contacts