



Interim Report to the Barbara McDowell & Gerald S. Hartman Foundation

Background

Through years of investigations and legal advocacy for children with co-occurring conditions, Disability Rights North Carolina found that administration of the State's existing policies, procedures, and service delivery system for children with complex needs lacked effective case management, over-relied on institutional care, and failed to invest in effective community-based services and supports. These children were not being provided with appropriate medically necessary mental health services to treat their co-occurring conditions as required under the Early and Periodic Screening, Diagnostic, and Treatment (EPDST) provisions of Title XIX of the Social Security Act (Medicaid Act), 42 U.S.C. § 1396 *et. seq.* In North Carolina, children and adolescents with complex needs experienced cyclical hospitalizations (often stuck in emergency room beds for weeks because the hospital could not find a place for them), were shipped out-of-state for treatment, suffered trauma and over-medication in inappropriate placements, and either were unable to access adequate services or received no services at all.

Despite years of meetings with state policymakers and the direct legal representation of children with complex needs, the systemic denial of legally required Medicaid services continued. When we received notice of the grant award from the McDowell Foundation, we were just a few weeks away from filing a legal action in federal court to end the violations of the Medicaid Act.

Progress Report

In October 2016, we reached a settlement agreement with the NC Department of Health and Human Services (Department). The agreement included the understanding that a consent judgment would be filed simultaneously with a complaint in federal court which would allow us to go back to the federal judge immediately if the State did not adhere to the agreement. Experts we hired to consult and provide opinions in the context of the litigation were instrumental in helping the parties reach an agreement with specific systemic changes.

On October 14, 2016, Disability Rights NC filed a legal action in federal court. *Disability Rights North Carolina v. Brajer*, No. 5:16-cv-854 (E.D.N.C.). Simultaneously, the parties filed a Joint Motion to Dismiss without Prejudice and Retain Jurisdiction, agreeing that the court would retain jurisdiction to enforce the terms of the settlement agreement for the duration of the agreement. The court granted the Joint Motion on November 9, 2016.

The agreement covers "children with complex needs," defined as Medicaid eligible children ages 5 to 21 with a developmental disability and a mental health disorder who are at risk of not being able to enter or remain in a community setting because they exhibit acts or behaviors that present a substantial risk of harm to the child or to others. The agreement requires the Department to:

1. Develop and implement a statewide standard and process to identify children with complex needs;
2. Establish and implement a standardized process to conduct clinical assessments by properly licensed/credentialed professionals and clinicians who have experience in identifying and treating children with complex needs;
3. Secure adequate funding for statewide implementation of NC START crisis stabilization services;
4. Provide EPSDT training to case managers, provider organizations, and Local Management Entity/Managed Care Organization (LME/MCO) staff who are involved in the authorization or delivery of services for children with complex needs;
5. Publish a communication bulletin outlining the LME/MCOs' responsibilities and duties to implement the provisions of the agreement;
6. Seek approval and funding to create an administrator to oversee implementation of the settlement agreement;
7. Offer training to providers dedicated to serving children with complex needs; and
8. Begin operating an outpatient clinic dedicated to serving children with complex needs.

Disability Rights NC staff and its experts actively participated in preparing the Communication Bulletin sent to all LME/MCOs on December 30, 2016 that provided detailed instructions for implementation of the settlement agreement. Review the Communication Bulletin at <http://www.disabilityrightsn.org/sites/default/files/Joint%20Communication%20Bulletin%20J231%2012-30-16.pdf>. While the proposed Governor's budget includes funding for NC START required by the agreement, we have a long way to go before our state legislature adopts a final state budget.

Disability Rights NC notified all affected clients and given their families guidance on how to access the services, supports, and treatment outlined in the agreement.

Anticipated Future Activities

We will continue to meet quarterly with the Department and the LME/MCOs to monitor implementation of the terms of the agreement, identify barriers to implementation, and ensure continued progress on implementation. We will continue to consult with our experts throughout this implementation and monitoring phase until the Department meets all of the intended goals of the agreement. We will continue to monitor the progression of the budget through the state legislative process. Under the terms of the agreement, the court will maintain jurisdiction through June 30, 2018, unless either party petitions for a change in duration of the agreement or we dispute that the Department is making substantial progress toward implementation of the agreement.

Report submitted on March 30, 2017:

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