

**Rosie D. Feature Article December 2011**

**The Number of Youth and Families Receiving
Intensive Care Coordination Services**

Intensive Care Coordination (ICC) Services are the central component of the Court's array of remedial services. ICC is not only the primary vehicle for offering wraparound services, but it is also the core program for organizing, coordinating, and integrating various other remedial services. ICC was envisioned, by both the parties and the Court, as the most effective intervention for youth with serious emotional disturbance (SED) and the most important support for families.

In documents obtained during trial, the Massachusetts Department of Mental Health (DMH) reported to the federal government that the number of Medicaid-eligible youth with SED exceeded 35,000, and the number of youth with SED and severe dysfunction exceeded 15,000. As a result, the Court noted in its decision that "at least" 15,000 class members would be eligible for ICC. Subsequently, MassHealth's consultant, Mercer Inc, estimated that the number of youth who would enroll in ICC was close to 12,000. The state's Request For Proposals for the new Community Service Agencies incorporated this projected demand. The plaintiffs' experts and family organizations assumed the number probably would be considerably higher.

Despite the national data on SED, the utilization of similar programs in other states, the broad eligibility criteria for ICC, and the projected demand by various executive and judicial officials, the actual utilization of ICC has been far lower and far more static than anyone expected. After an initial, steady increase in ICC enrollment during the first year of operation (July 2009-June 2010), the number of youth receiving ICC services has plateaued. In fact, during September 2011, the number of youth in ICC actually decreased. While October saw a slight rise, the number of youth receiving ICC services at any time - approximately 3,600 - has remained virtually unchanged for over a year.

The current utilization of ICC services is less than one-third of what the MassHealth's consultant projected, less than one-quarter of what the Court projected (as the minimum), and less than one-tenth of what the plaintiffs' experts projected. What explains this dramatically lower than expected use of ICC?

Unfortunately, there are no clear answers, but there are some strong indicators of what might be happening. First, the number of referrals from state agencies, other than the Department of Children & Families (DCF), is alarmingly low. Consistent with patterns that have stayed steady for over a year, in October 2011, the percentage of youth referred to ICC by DMH was less than 1%, by the Department of Youth Services, barely 1%, and by the Department of Developmental Services, 0%. Only 2% are referred by probation. Thus, the total referred by all state human service agencies - other than DCF - is 2%, and the total by judicial agencies only 2%.

Second, despite a huge (400%) increase in the number of youth screened by primary care clinicians, and a concomitant increase in the number of youth found to have a behavioral health condition, the number of youth referred to ICC by physicians is less than 1%. Finally, although tens of thousands of SED attend school and many receive special education services, only 7% of the referrals for ICC come from the entire local and state school system.

In addition to the paltry number of referrals from state human service agencies, judicial agencies, schools, and doctors, families consistently have had to wait for initial appointments, assessments, and services. According to family advocates, this persistent pattern of waiting has caused many families to forego ICC and look elsewhere for help. This, in turn, creates a negative view with families, stakeholders, clinicians, and state agency staff about the utility and appropriateness of ICC.

Moreover, of those youth who are referred and evaluated for ICC, 6% are found ineligible and 7% are referred elsewhere. Ten percent more are not engaged in the program and subsequently decline services. Thus, almost one-quarter of all youth who seek ICC do not enroll. And of those who do, 42% leave prematurely, either because they are deemed ineligible for Medicaid (4%), ineligible for ICC (6%), or simply withdraw consent (32%).

For those youth and families who find their way to ICC, are willing to wait, actually receive services, and remain enrolled until their goals are met (40%), they almost universally report successful outcomes and a positive experience. The challenge, therefore, is to substantially expand referrals to ICC, promptly enroll families, and continue to engage them for the duration of the youth's needs. If this could be accomplished, there is a significant likelihood that more youth will receive ICC Services, and that the utilization of ICC will begin to achieve the projections of state officials, the court, and national experts.