

Monitor's Commentary

Three questions help put this Addendum in context.

Why is it important for the Court to continue oversight of the Consent Decree?

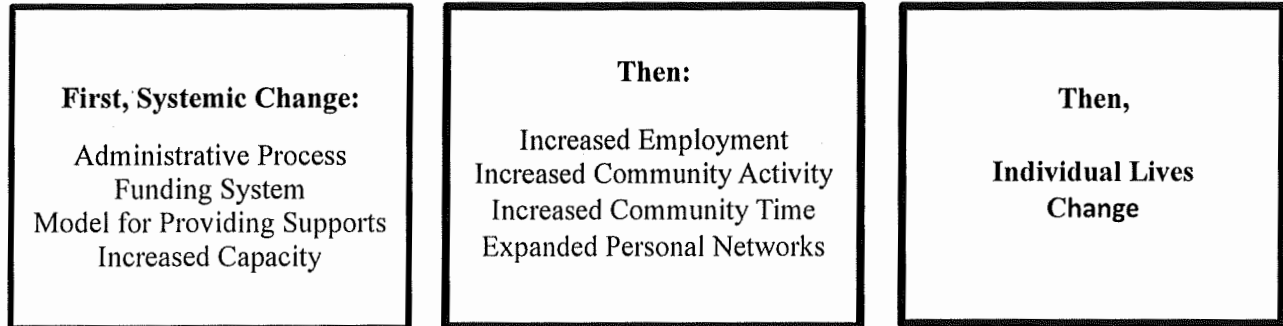
For the last seventy-five years the history of services and supports for individuals who have an intellectual or developmental disability has been marked by (a) increasing knowledge of the capacity of these individuals, (b) changing expectations, (c) developing practices that facilitate increased individual competence and participation in society and (d) developing and implementing systems that support those practices.

Rhode Island's history during the past fifty years has illustrated those trends. In 1970 Ladd Center was the primary source for services to children and adults with intellectual disabilities. Families' only choice was to institutionalize their family member or to maintain them at home with minimal public support. When *Iasimone v. Garrahy* was filed in federal court in 1976 there was a beginning understanding that a more qualitative life was possible, but there was minimal expectations that these individuals would gain meaningful employment. In 1982 Rhode Island became the first state in the country to close admissions to its institution. The 1982 Consent Decree opened the doors to building group homes and disability centers – the setting had changed, but the expectations had not. The last person left Ladd in 1992. The years between 1980-2010 were marked by rapidly changing understanding that individuals could have meaningful community lives and could be employed. Groups begin to be replaced by individuals. By the early 2000s Rhode Island (as documented by several national sources and experts) had one of the best systems in the country - **twenty-five years after *Iasimone v. Garrahy***. Then came several years of underfunding and decreasing services – a good system became significantly less so. This directly resulted in the Department of Justice investigation of RI in 2013 and the Consent Decree in 2014.

The Consent Decree was viewed as a national landmark event in that it mandated the presumption that **ALL** (not some) individuals were expected to be employed and participate in the community in integrated settings – not in groups, but as individuals who have preferences and can make choices. Once again, expectations needed to change. In his July, 2020 report the Monitor documented that less than half of families believed their family member should have a job and only about sixty percent believed their family member should participate in community activities. Once again, support models needed to be transformed – moving from group support in centers to individual support in the community. Once again, the systems and infrastructure necessary to support these changes needed to be developed and fully implemented.

In essence, the Consent Decree mandated the outcomes and the support infrastructure needed for implementation. The Consent Decree allowed ten years to achieve this. The first six years were more focused on addressing specific items in the Consent Decree, less on infrastructure and systems change. This was followed by two plus years of COVID that decimated the workforce. That left than two years to develop and fully implement the infrastructure needed to meet the goals of the Consent Decree.

The Monitor has repeatedly stated that compliance with the Consent Decree goals and benchmarks will occur in three stages. Ultimately, substantial compliance will be determined by whether individual lives change.



During the past year the State Team, in collaboration with multiple stakeholders, has done intensive, highly commendable, laudatory work to plan the components of the needed infrastructure. As was documented at the August 1, 2023 status conference, the majority of these plans **have not yet been fully implemented**. Thus, the impact on outcomes and individual lives has just begun.

Implementation Science is “the scientific study of methods and strategies that facilitate the uptake of evidence-based practice and research into regular use by practitioners and policy makers”.¹ Several implementation science studies document that it takes an average of 17 years (range of 10-20 years) for evidence to become practice.² Thus, two years is not a sufficient amount of time to expect that the impact of the new structures and practices associated with the Consent Decree will be felt in the lives of individuals. It took 25 years to move from an institutional model in Rhode Island to a fully functioning community model. The transformation associated with the Consent Decree is significantly more complex. The Addendum presumes (a) that the infrastructure (now in the final stages of planning) will be fully implemented by June, 2024 and (b) that infrastructure will be “firmly established” within two additional years and (c) that the impact of the transformed system will be experienced and documented in the majority of individual lives.

What have been the major accomplishments of the Consent Decree to date?

Section (I) of this Addendum provides a technical list of what sections of the Consent Decree are in substantial compliance. Interviews with the State Team and other stakeholders have documented several “big picture” outcomes. Because these are significant indicators of success, a few of them are highlighted here.

- There are no more sheltered workshops in Rhode Island.

¹ Fixsen, D., Naoom, S., Blase, K., Friedman, R., Wallace, F. (2005). *Implementation Research: A Synthesis of the Literature*. National Implementation Research Network.

² National Institutes of Health; 2016.

- Rhode Island was the first state in the country to eliminate sub-minimum wages.
- Rhode Island is an “Employment First” state.
- School districts report a significantly increased focus on transition-aged youth who have intellectual disabilities and on employment.
- There is a universal presumption across all state agencies that all individuals with IDD are capable of employment and activity in integrated community settings.
- Comprehensive rate review has been completed and is being implemented. The review resulted in a focus on individual budgets and services, significantly increased flexibility and choice and several new services.
- The budget to support the developmental disabilities system was increased by approximately \$75,000,000 for the coming fiscal year and approximately \$120,000,000 over the past three fiscal years.
- The starting hourly wage for direct support staff has increased from \$13.18 in June, 2021 to \$20.00 in July, 2023.
- There is significantly increased collaboration among the four state agencies (Developmental Disabilities, Rehabilitation Services, Education, Labor and Training) directly involved with employment of individuals with IDD.
- Self-employment has dramatically increased.
- There are several innovative models of support being piloted by provider organizations.
- The use of technology as a support strategy has significantly increased.
- Employer outreach and support has increased.
- Overall, the culture of Rhode Island has changed.

These are highly commendable outcomes for which all stakeholders should be commended.

What evidence and practices should guide efforts to increase employment of individuals who have intellectual and developmental disabilities?

There have been several studies that have documented the core “elements of high performing states”.³ The following table cites those elements and briefly summarizes Rhode Island’s current practice.

Core Elements	Status in Rhode Island
Leadership and Values	Leadership of the State and the State agencies directly involved are now actively engaged and supportive of the values of employment and community activity in integrated settings for all individuals with IDD.

³ Winsor et al (2023); *Pushing the Integrated Employment Agenda: Employment Systems Partners and the High-Performing States Model*; Intellectual and Developmental Disabilities. Hall, Butterworth, Winsor, Gilmore, Metzler (2007); *Pushing the Employment Agenda: Case Study Research of High-Performing States in Integrated Employment*; Intellectual and Developmental Disabilities. Several others.

Policy	Rhode Island is an Employment First state. Policies and practices have been established that promote employment and community activity.
Funding	The new rates and services, the court-ordered commitment to annual review of rates (not yet determined) and the inclusion of the developmental disabilities in caseload estimating provides a stable fiscal base which needs to continue.
Capacity Development	Capacity continues to be a challenge, both for provider organizations and individuals who self-direct. Although the State was slow in beginning the court-ordered statewide workforce infrastructure, the process is now underway.
Interagency Collaboration	As noted earlier, there is now significant collaboration among state agencies and between the State and stakeholders.
Innovation	The court-ordered transformation projects and other state initiatives have facilitated several innovations. There continues to be a need to broaden these efforts so that they approach scale.
Outcome Data	Although the State uses several data sources, there is inconsistency between these sources. There is need to develop a comprehensive system for collecting and reporting data on all pertinent elements.

Conclusions:

Several significant outcomes have been accomplished during the term of the Consent Decree. The efforts of the past year and the State’s increased capacity are noteworthy. However, most of the infrastructure changes have not yet been fully implemented. Thus, their impact on Consent Decree benchmarks and, most importantly, on individual lives is just beginning.

Implementation Science projects that it takes 10-20 years to fully implement new practices. In reality, the practices and infrastructure that facilitate the goals of the Consent Decree are in the “initial implementation”⁴ stage. More time is needed to ensure continuation and to assess impact on individual lives.

Rhode Island is actively addressing all seven core elements of high-performing states. Some are fully in place; others (taking innovations to scale, capacity, outcome data) are in early stages.

Thus, for all these reasons, continued oversight of implementation and impact has value.

⁴ Fixsen, op.cit.