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Pushing the Integrated Employment Agenda: Case Study Research in New Hampshire

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Introduction

Employment for people with severe disabilities was legitimized in P.L. 99457. However, some states have made more progress than others in helping individuals with disabilities achieve successful employment outcomes. This is the first in a series of publications highlighting the findings from the case studies in three states--New Hampshire, Washington, and Colorado--that have been recognized as high performers in integrated employment. These products are intended to be a practical resource for other states as they work to help people with disabilities obtain and maintain gainful employment.

New Hampshire was identified as a "high-performing" state based on criteria aimed at assessing overall commitment to community inclusion: the percentage of citizens served by the state's mental retardation/developmental disabilities (MR/DD) agency that are in integrated employment and the rate of growth in state provision of integrated employment (Prouty & Lakin, 2000).

From June 2002 through December 2003, a team of ICI researchers conducted face-to-face interviews with state and local key informants, including parents and service providers, who had been recommended as being knowledgeable about New Hampshire's system of integrated employment. With permission, interviews were tape-recorded and transcribed. State policy documents and New Hampshire's state website also contributed to data collection.

Deinstitutionalization in New Hampshire

Moral outrage over the situation of people with disabilities was nationwide during the late 1970s and early 1980s. There was a strong reaction to the segregation of people with disabilities and the failure of many institutions to provide care or treatment. Despite an increase in state spending for MR/DD services that elevated New Hampshire from 44th place in 1974 to 5th place in 1979, parents of the residents of the Laconia State School brought forward a class action suit, *Garrity v. Gallen*, in 1978. In 1981 Judge Shane Devine issued a court order for the state to deliver services in the least restrictive environment (Racino, 1999).

Devine did not specifically order the closing of the school, but he embraced a plan to develop alternatives to institutional care that became the cornerstone on which the current community service system was built. "The state never appealed," Devine said. "It was clear from the beginning of the trial that it was time to give these residents some dignity, something better." (Helm, 1999)

While the lawsuit did not specifically mandate the closure of Laconia, the settlement did require the development of a comprehensive set of services in the community (Covert, Macintosh, & Shumway, 1994).

Credit for the satisfactory transition from Laconia to "something better," the development of the community-based support system, has been given to several parties in the implementation of Judge Devine's ruling. These include administrators at the state Division of Mental Health and Developmental Disabilities Services, regional MR/DD officials, independent service providers, and families (Helm, 1999; Racino, 1999). While leadership during this time of change cannot be attributed to one particular individual, it was clear that upper-level staff in the MR/DD agency transmitted values that were linked with the start of the closing of the Laconia State School and the development of the community-based support system. The upper-level management hired a new superintendent of Laconia whose mission was to close the school. As the new system solidified, in January 1991 New Hampshire became the first state in the nation to shut the doors of its institution.

New Hampshire's history shows that the community was clearly the intended setting for services and supports for people with developmental disabilities. This has laid the groundwork for continued emphasis on inclusion and meaningful daytime experiences in the community.

Findings

Our research suggests that three themes framed the success of integrated employment in New Hampshire:

1. Redirection and continued refinement of fundamental values through investment in training and technical assistance
2. Restructuring Developmental Disabilities Services to emphasize local control and innovation
3. The shift to quality outcomes

Theme 1: Redirection and Continued Refinement of Fundamental Values Through Investment in Training and

Technical Assistance

Driven by the Laconia State School class action lawsuit, the state invested heavily in values-based training as the transformation to a community-based service system began. This remained the primary focus of state-level training initiatives, reflecting a belief that the primary goal was a quality life and full participation in the community. Community inclusion was described as the driving value for the service system.

Deinstitutionalization and the principles of normalization

Early values change efforts sprang from the coinciding forces of deinstitutionalization and the principles of normalization in the 1970s. These values were instilled through training on normalization (referred to as "social role valorization" since the late 1980s) and the integration of people with MR/DD into their communities. Informants related how early training, specifically Wolfenberger's teachings on normalization, ultimately led to a shared understanding about the importance of community involvement. Values-based training was mentioned consistently as the foundation for redirected MR/DD service policies and practice, though there was resistance by some state employees in the early days. The superintendent of Laconia sent staff to values training in the 1970s.

A lot of people who were administrators at the state school were forced, kind of kicking and screaming, by their boss to attend [values-based trainings]. However, a number of people from the state facility attended and came away with the notion that *this needs to change* [emphasis added].

Values-based trainings occurred physically at the Laconia State School from 1985 until the school closed in 1991.

This training secured commitment to the new values that was sustained by the longevity of key staff. Some area agency directors have worked in the field for over twenty years; in fact, the Division has employed a small number of program specialists since the early 1980s. The values-based training was also instrumental in fostering strong working relationships through shared commitment to deinstitutionalization and the principles of normalization. One informant commented,

The way things develop[ed] can be based on a handful of people and a handful of personalities that share the same values.... You have these relationships that have developed over the years of the shared values, the historical perspective of having watched and helped close the institution and helped develop the community system.

Important state and local staff have stayed through the development of the community system and "have made sure that it continues to work."

The Role of Families in New Hampshire

According to one respondent, "Families have done more to change what's happened in New Hampshire than anything else." Through legislation, the state facilitated the creation of the Family Support Council. This council has played a key role in helping the state define what

type of supports it must provide to families, though these supports were not specifically targeted to employment issues. One informant noted that the family movement in New Hampshire has been one of the most important components of the evolution of the service system. He believed that there was a genuine intent on the part of the state to see families become empowered and have input on the lives of their family members. This seemed to be in line with the state's emphasis on employment as one vehicle for community integration.

Self-determination and person-centered planning

During the 1990s, the second wave of value transformation concentrated more specifically on community integration. Self-determination was the new value, which reflected growing emphasis on individual preferences and control. This led to a shift in emphasis from quantity outcomes (e.g., number of people receiving services) to quality outcomes on an individual basis.

As programs began to shift to individual consumer-focused services in the 1990s, experts from outside New Hampshire, such as John O'Brien, Michael Kendrick, Beth Mount, and John McKnight, and experts from the state of New Hampshire but outside the MR/DD system, such as John Vance, were hired by the state to conduct training. Sponsored by the state MR/DD agency, this training sent an unambiguous message that this was the new service philosophy. Most of the informants acknowledged the importance given to the new values by the state.

I think a number of people came together and recognized the value and that group of people became the leaders and those leaders really pushed for it. So there wasn't a mandate, it was just sort of a natural thing. This is where we're all going. If you want to keep up, you're going to have to do this.

It is important to note that the training focused on principles that were meant to underpin all service and support delivery. These goals were not designed to provide a template for all community integration, but were designed to help MR/DD representatives and service providers understand the importance of individualization, and to foster flexibility and innovation.

The use of state resources, particularly during the late 1970s and early 1980s, was highlighted by a number of informants. Both MR/DD and provider staff felt that the University Center for Excellence in Developmental Disabilities at the University of New Hampshire was, and continued to be, a regularly used resource for consumer-focused training related to supported employment. In 1998, the Division encouraged the development of the Northern and Southern Training Collaborative rather than providing training through the Division's central office. Through this collaborative, six Southern and six Northern regions met periodically to identify their training needs for the fiscal year and determine regional priorities. Funding from the Division enabled area agencies to bring in national trainers that they would be unable to pay for otherwise.

Several informants stressed that the Division clearly recognized that people did not live their lives in categorically funded "residential" or "vocational" services. The concept of self-determination, which emphasized an individual's preferences, needs, and control of services and support, was implemented through the strategy of person-centered planning. According to an MR/DD administrator, "Certainly employment is an important part of that, but it hasn't been the primary mission of the various area agencies as much as making somebody's life

meaningful."

Personal budgets and self-directed funding were other ways that allowed individuals to use funds in nontraditional ways to support goals and needs. For integrated employment, self-determination and person-centered planning meant that:

People can go out and hire their own job supports... anybody can go to any vendor they want. We are seeing a lot of training in how to help people make choices and gain control of their budgets. It's happening.

What continued to be noteworthy was the ongoing refinement of services and supports based on the individual, and the gradual reduction of congregate services and supports, with investment in cultural change preceding the structural change.

Relationships with the Community

Early in the supported employment movement, area agency staff and provider agencies were noticeably present in their communities. New provider agencies that had few spare financial resources were often forced to meet in public settings or borrow office space from other businesses. This allowed providers to make close connections with other firms that later were used to identify potential employment opportunities. One provider shared,

When we first started with this organization... it was really hard going and the people that we were connected to were all like people in businesses and stuff-- you know, we'd have a meeting at their office and they would give us a couple of pads of paper or something at the end of the meeting. And we'd always have our meetings in different place in the community because we didn't have an office to go hide out in and that was great. It forces you to be out in part of the community, which I think is a really good thing. The more you're kind of bricks and mortared away, the more funding you have, the more insulated you are from what you really need [in the community].

According to the Division director, "[Community relationships] are probably the single biggest key to employment." Successful outcomes in integrated employment could in part be attributed to these local relationships.

Theme 2: Restructuring Developmental Disabilities Services to Emphasize Local Control and Innovation

Notably, the restructuring of the state system occurred concurrently with the values change movement, allowing the Division to organize to better achieve its new goals. One informant described the reorganization:

Part of the strength of our system in the state, I think, has a lot to do with the fact that the area agency system was also sort of conceptualized under a Wolfenberger's model.... They all came back [from trainings] and I think that served as a basis for putting together the community development services system, the area agency system.

Minimal bureaucracy

Changes in structure of the Division were concurrent with the downsizing of Laconia in the early 1980s. As people left Laconia, the Division realized that community-based agencies would be necessary to coordinate people's return to their home communities. The structural change created a streamlined state MR/DD entity. Prior to the formation of the community-based Division, the only public services were provided at the Laconia State School. The new system shaped an agency with state program specialists and twelve regional administrative offices, with each regional office administered by an "area agency."

Three existing nonprofits were initially chosen to do this, but by 1983 there were a total of twelve area agencies (Racino, 1999). At the time of this research, the agencies demonstrated the variety of ways New Hampshire provided services. Approximately one-third of these agencies provided their own services. Others contracted with other nonprofit agencies for local service provision, while the remaining agencies used a combination of these approaches. Unique to New Hampshire, these agencies were nonprofits, governed by a board that must include at least one-third consumers or family members. Local consumer and family board membership was intended to support local control and innovation.

As service providers contracted by the Division, the area agencies were held responsible for service and support delivery. "The state-level staff hold [the area agencies] accountable for all services... regardless of whether they provide them... or [whether they] subcontract with another agency."

Flexibility

Informants characterized the New Hampshire MR/DD system, at both state and local levels, as "flexible," which was linked to the minimal state structure and the perception of minimal regulations as well as integrated funding processes.

Minimal state structure

One informant indicated that the majority of area agency program staff members' time was spent working with local providers. Staff took a consultant role, recommending training options and helping problem-solve rather than overseeing providers in a punitive or threatening way. This simple structure also allowed state staff to be directly involved "with families and individuals when there are issues, when things fall apart.... We are working closely with them to try and make sure that things are going well for people."

The reality and perception of minimal constraining regulations

Residents perceived New Hampshire as a state based on small towns and local control, and the Division tried to operate in this vein. Said one state MR/DD official, "We have a couple of general regulations, you know, which... set out the parameters for how the system should be run. But we really delegate all the decision-making to the local area agencies."

It is significant that the state provided few formal rules about how day services could be provided. Facility-based, congregate services and programs were discouraged not by formal regulations but by significantly limiting funding for facility-based services, including sheltered employment. Since 1984, New Hampshire had not provided any funding to open

new sheltered employment programs, and in 1985 a systems change grant with the state Vocational Rehabilitation system helped to spur the closure of sheltered workshops. This change was gradual and came about as services became more consumer-directed. For a time funding guidelines required that individuals participate in the community in groups of no more than three individuals with disabilities. These guidelines were not formal regulations at the time of this research but were understood as expectations for service delivery.

The belief in limited regulation, contract restrictions, and bureaucratic processes reduced complications in changing services and supports. Due to the flexibility of the state system, providers felt that they were not constrained and that they could manage services in a manner that they felt best met individuals' needs. One provider commented, "The state doesn't really tell us. They ask us. Honest to God, they sometimes ask us... so the state doesn't dictate what we do, which is really nice." Another person said, "There isn't that much that the state says 'Learn it this way,' or 'Be here now, do that.'"

Some felt that there was less emphasis on discrete programs and more emphasis on comprehensive supports and services, including natural supports. One provider did comment on regulations positively:

I think statewide our regulations have changed to support the types of things we have. They even stepped out of the box away from the traditional Medicaid slots.... What we have here is called a "consolidated developmental services" category, which is a whole class of funding we can use to define ourselves. So the Division rules have given us good ways to do that.

Funding

The New Hampshire approach to funding allowed a high degree of flexibility in program implementation. At a contract level, residential and day service funds could be combined to integrate resources across major life areas. One respondent commented, "This policy, if you look through it, people can be funded in any way." The integration of funding streams allowed the state to overcome the typical barriers that arose when services needed cross-categorical funding. The ability to integrate funding with ease signaled the state's commitment to providing and supporting comprehensive services.

Informants noted that the Medicaid Waiver was developed with as much built-in flexibility as possible. According to a Division representative, "We're always looking at ways to make the funding more flexible and to be able to allow providers of area agencies to be able to apply the available Medicaid funding to meet the needs of that individual person." Providers expressed the benefits of the discretion to use Medicaid funds flexibly to meet the needs of the individual. One provider commented upon their experience with using funds fluidly.

I get this impression that where other people may be saying, "Oh gee, Medicaid waiver doesn't fund sufficiently for the supports needed and all that." **We just kept looking at the individual and figured it out [emphasis added].** They are individuals by our values and the money has always followed for us because of that. Again, you have to know the intent of the waiver and use it to support that person and the shifting that can happen.

Most informants did not identify new sources of funding as a key factor that tied directly to New Hampshire's integrated employment initiative, although one person noted that "I'm

pretty sure there was [specific funding]," for integrated employment but could not isolate it as a factor in the systems change.

There was an informal understanding that the state allocated additional resources to providers that were more effective at meeting the broad goals of community inclusion and employment. One provider commented, "[The state] has allowed us probably extra money because they like our performance, but it isn't formalized."

Monies from the systems change grant were used exclusively to pay for trainings and conferences at the national, state, and regional levels for area agency and state administrations staff as well as for providers. These trainings commingled the staff members from different agencies and from different levels of government, increasing the opportunities for various agency staff to build relationships between groups and reduce the bureaucracy of planning and service provision. Additionally, family members of people with disabilities were invited to attend evening meetings with agency staff to discuss ideas for developing a more comprehensive employment support system.

Attendance at national conferences by local case managers and Vocational Rehabilitation counselors exposed these groups to innovative supported employment strategies and allowed staff to identify new types of training they would like to bring to New Hampshire. One respondent specifically highlighted the experience of meeting an advocate from Montana who was an expert in developing and providing supported employment in rural areas. New Hampshire was able to use systems change monies to pay for training by the Montana advocate on rural issues and best practices for supported employment to meet the training needs of the more remote regions of the state.

Most importantly, the trainings were where staff learned how other state agencies operated and how funding from the different groups could come together and be used to fund non-duplicative services for successful short- and long-term supported employment outcomes. One person noted that the comprehensive use of funds was only possible because of the support of the various state-level agency directors. These directors were personally invested in the success of the systems change and worked together to frame the way the funding streams would come together to provide employment supports. The directors then personally worked with all levels of their staff to ensure that the funds were integrated at the local level.

Cross-Agency Funding

In 1986 New Hampshire applied for a five-year systems change grant through the federal Rehabilitation Services Administration. While New Hampshire's Vocational Rehabilitation department was the sponsoring agency, the grant was a consortium effort between the Department of Vocational Rehabilitation, the Division of Developmental Disabilities, the Department of Mental Health, the Job Training Council, and the Developmental Disabilities Council. State directors of these agencies collectively developed a funding policy that would allow their organizations to work together at the local level to fund supported employment. At the local level, short-term support funds from Vocational Rehabilitation were used in conjunction with funds from the Division of Developmental Disabilities and/or other long-term funding agencies to meet specific individuals' supported employment needs. One respondent commented that this "created a 'synergy' of money that was more effective at meeting individuals' needs than if each agency had tried to solely fund supported employment services."

Theme 3: The Shift to Quality Outcomes

Role of the state program specialists

Informants indicated that the state structure and its size (approximately 22 state personnel worked for the Division) made state leaders very accessible. Six of the 22 staff at the central Division office were program specialists who worked with the 12 regions. Program specialists had always been responsible for ensuring program compliance; however, their jobs evolved as the system has matured. "It's a misnomer. We no longer talk programs and we certainly aren't specialists. We are much more generalists."

Because program specialists spent so much time with the area agencies, the state was able to work through issues with a particular region. In the spirit of local autonomy, one administrator noted,

We would prefer that if an area agency identifies a particular issue that they're dealing with, and if we don't have the expertise to help them with it, we would help them fund local resources.... We don't dictate very much.

She added, "It's more of a negotiation, an offer of support."

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