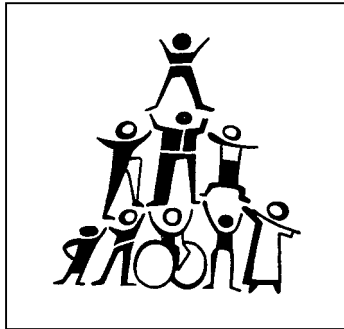


The History and Development of Family Support in NH



The following article written by Bonnie Shoultz and Pam Walker from the Center on Human Policy describes the history of the family support movement in New Hampshire, how the Family Support Act was passed, and the initial implementation of family support in the regions.

New Hampshire's Family Support Network

by Bonnie Shoultz and Pam Walker

Family Activism in New Hampshire: A Brief History

New Hampshire's family organizations have been unusually successfully in their efforts to achieve lasting change for people with disabilities and their families. Their accomplishments were a result of a tremendous amount of work, including an unusual degree of collaboration with professionals and non family advocates.

The Task Force on Family Support

In the mid-1980's, a major gap in services in many parts of the state was the lack of concrete support to families living with a family member with a disability. Families who had not institutionalized a family member felt as though their needs were left out of planning. When they needed community services, their family members were placed on waiting lists.

In 1987, a bill written during the previous year by the State Division of Mental Health and Developmental Services was introduced by freshman legislator Frank Tupper. The bill, signed into law on April 3, 1987, by Governor John Sununu, was "An Act establishing a Task Force to study support services for families with developmentally disabled children."

The Task Force became a strategic force for change on many different levels. By the end of its 16-month existence, many transformations had taken place. The Task Force and its constituent bodies had reached a consensus about what must be done, and that agreement was documented in the Task Force Report and summary. Family members all over the state had organized and were poised to get legislation passed, had learned how to be effective advocates, and had many allies within state government. These transformations occurred because the Task Force process encompassed four critical components, inclusiveness, study, creative thinking, and organizing.

Inclusiveness

From the beginning, the Task Force declared that its meetings were open to anyone who wanted to attend and participate. The Task Force meetings became a place where people

with an interest could speak their thoughts and work together, and where the major players in the state were included in the decision-making. Another form of inclusiveness had to do with definitions. The legislation had used the term, “families with children who are developmentally impaired or multiply handicapped,” which the Task Force interpreted as applying to families living with a family member of any age who had a developmental disability. Inclusiveness continues to be an issue today. A current debate over whether family support services should include families of people with other disabilities is pushing families and state officials to deal with the many implications of that concept.

Studying- What was Needed and What was Possible

Another early Task Force decision was that they must learn what New Hampshire’s families need and want, and what was being thought and one elsewhere about family support. They gathered information from research centers, other states’ developmental disabilities programs, and national disability advocacy organizations. The Division also sponsored conferences that brought in nationally known speakers to address family support issues. The other area of study was to examine, within the state, the current lives, needs, and wants of families whose members had disabilities. In order to do this, the Task Force organized numerous regional public forums. In addition, the Institute on Disability conducted a parent survey. Early on, two things became apparent: respite care services, while appreciated, were not enough; and families needed more than just services that money could buy.

The Creative Process

While they did consider the different ways family support is organized and provided in other states, the Task Force developed ideas that took New Hampshire’s political, economical, cultural, and social environment into consideration. Perhaps the most creative idea was the recommendation that there be legislation to establish a comprehensive family support network, not just services in New Hampshire. The network’s structure would include statewide and regional family support councils made up of family members of people with developmental disabilities; these councils would be represented by a state coordinator and 12 regional coordinators, and would have funds specifically designated for flexible use by councils for the benefit of families. The Task Force made 23 recommendations in all, only two of which required legislative action. They felt strongly that no priority should be given to any recommendation over another, and therefore did not number their recommendations in the report.

Organizing for Change

While the Task Force worked, a number of other parties also prepared families to organize for legislative and executive action. The New Hampshire Challenge, the widely circulated new newspaper of Special Families United, became a vehicle to inform people of the Task Force’s progress. The institute on Disability at the University of New Hampshire held the first Family Leadership Series in June, November, and December of 1988. This series had two days on developing a vision of what could be, two days on community organizing, and two days on advocacy through the legislative process, in which family members learned how to organize to get legislation passed. All over the

state, people were talking to each other and preparing to push for passage of legislation for family support. The Task Force process was therefore an organizing mechanism as well as the fact-finding and recommending process the legislature was accustomed to in authorizing such studies.

Passing the Legislation

In early 1989, family support legislation was being drafted. It was based on Task Force recommendations, and called for a network of family support councils and family support coordinators throughout the state. Bill 195 was introduced, which requested \$3 million for the biennium (2 –year period for which the legislature sets a budget) to establish family support services throughout the state. A second bill, the Waiting List bill, requested \$5 million for the biennium. The decision to have two bills was critical. First, it acknowledged that there was great need for both family support and services for people waiting in the community. Second, having two bills made it clear that there were differences between the two concepts, and most critically, permitted family support services to be administered differently than the waiting list services. This separation allowed the concept of family support councils and the Family support network to stay intact.

Over 200 family members and other bill supporters had received training on the legislative process and had made personal commitments to seeing the legislation through, to testifying, meeting with their local legislator, writing letters, and appearing in public. These people went back home, trained others, set up telephone trees, and invited their legislators into their homes to meet their families. Then, after the Family Support bill was introduced, they began attending every committee hearing.

The Family Support bill, which became Chapter 255, survived a threatened veto by the governor and was enacted into law on May 26, 1989, to take effect July 1, 1989. The appropriation was set at \$500,000 per fiscal year. The Waiting List bill, which became Chapter 280, was enacted into law 3 days later. The appropriation for this bill was set at \$1.5 million in FY'90 and \$2 million in FY'91

The Family Support Act laid out a number of principles for family support, recognized families as “the greatest resource available to individuals who are disabled,” and created “a comprehensive statewide family support network” to support families, especially those living with family members with disabilities. Conceptually-and in its implementation-it represents a different way of doing things in the state. It puts families into a new position, at least in regard to the services for families.

Implementation of the Family Support Act

One of the Division’s first acts was development of a rationale for dividing the money between regions. Each region’s allocation is based on its percentage of the state’s population. Family support councils, made up entirely of family members, were formed in each of the regions. The Division asked the councils to work with the area agencies, which would be receiving the monies, to develop a family support plan for each region.

The Family Support Plans

The Division developed broad guidelines for how the plans should look, and reserved the right to disapprove a plan or send it back to be reworked. Plan developers were asked to use a “whatever it takes” philosophy and were given latitude in how the plan could look. The plans were to specify what staff would be hired, the qualifications of the family support coordinator, whether extra money or resources would be added to the allocation and from where this would come, where the program would be housed, how much money would be set aside to purchase goods and services for families, and in what general categories money would be spent (indirect services, vouchers, medical assistance, emergencies, etc.)

The Councils

There are many similarities and differences in how councils function across regions. For example, every council provides information and referral; every program has some cash to pay for family requests; and they all adopt a flexible approach as to what can be purchased.

In each area, the family support coordinators have the latitude to make decisions on expenditures per family up to a certain amount, and can simply report these decisions to the council. Beyond that amount, they get permission from the council. No area received enough money to meet the anticipated need, however. Partly as a result, coordinators and councils across the state have seen “going to the community” as part of their job from the beginning. That is, they have identified existing resources such as social services, benefit programs, civic organizations, and political organizations, and helped families to access them.

Across the state, councils and coordinators make use of their network to share ideas about supporting families. The bimonthly meetings of the family support coordinators and of the state advisory council, which is made up of representatives of the local councils and of the Division of Developmental Services, allow people to get acquainted and describe what they are doing.

Conclusion and Implications for Other States

New Hampshire’s family support network, comprising the statewide and local councils and coordinators and their linkages to other families within the local communities, offers many lessons for family activists and policymakers elsewhere.

- They developed a clear vision and principles by which they measured all their efforts and ideas. The Task Force’s vision and principles guided the family support councils in setting up their programs. From beginning to end, the vision and principles pervaded all their efforts.
- They built a constituency. The legislation would not have passed if they had not realized the importance of using all their early efforts to involve people, giving people training on legislative effectiveness, and guiding them to develop their own councils.

- They took into account the political and social context in New Hampshire as they developed their ideas, rather than adopting another state's program. This undoubtedly boosted their creativity and helped them to get the legislation passed and the councils underway.
- State administrators had a history of collaboration with parents, encouraging their active involvement in and advocacy regarding policy issues. This history played its part in their success, as the trust and knowledge of each other that were displayed could only come through ongoing relationships.
- Parents were in positions of leadership, probably because of this history of collaboration. Both in the Task Force, and in their ideas for how the family support program should operate, parents were put in positions of leadership.
- They didn't compromise on important issues, such as whether to merge two separate concepts and whether to take money from other families' allocations (e.g., WIC). In spite on the fiscal constraints that made success less likely, they held fast.
- They pursued their goal when the constituency was ready for it. Although they were advised to wait, they knew they were ready and should not wait for a better fiscal climate. At the same time, they did not proceed before the constituency had been organized.
- Inclusiveness was valued. From the beginning, when they broadened the Task Force mandate to include families of adults, until the time of the site visit, when they were designing ways of meeting the needs of new groups of families, inclusiveness was explicitly discussed and embraced.
- Their research was careful. By the time the Task Force was ready to report, they knew well the needs in their own state and the approaches used in other states. Their research helped them to frame their ideas and then became an instrument of persuasion.
- State flexibility allows for regional differences. In New Hampshire, regional and local differences are assumed and accounted for. At the state level, flexibility is built in so that these differences can exist comfortably.
- The community can be a rich resource. Even though there are dangers in having low levels of funding, there can be benefits, if community resources are involved and developed. The family support councils in New Hampshire have discovered countless new ways of mining (and replenishing) the community's resources on behalf of families.
- They built a family network around what could have been just a new or expanded category of service. From early on, they wanted a network, and there is good evidence that the parent leadership uses that network to strengthen their local programs and to connect families with each other.

The family leaders and policymakers in New Hampshire are people with concern for others, creativity, and energy. Their successful organizing efforts in bringing about their vision of support for every family living with someone with a developmental disability can be studied by people elsewhere who desire that same, or who wish to develop other programs that affect families.

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