

RWJF Evaluation Report Abstract

Impact Assessment of the Self-Determination Initiative for People with Developmental Disabilities I.D. #32677

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I - Brief Description of the Project/Program Being Evaluated

In 1997, the Robert Wood Johnson Foundation invested in a broad range of demonstration activities around the country aimed at exploring the ways in which people with developmental disabilities can influence the character and configuration of the supports they receive through self-determination. The emphasis on the choices and preferences of people, a theme that was at the center of each of the 19 demonstrations, represented a significant departure from conventional practice.

The Foundation allocated over \$5 million in support of the demonstrations. Allocations for each project amounted to \$400,000 for a 3-year period, \$200,000 for a 2-year period, or \$100,000 for a 1-year period. While each local project was based on the same broad outline of values and objectives, there were significant differences given the variations in geography, socio-demographic factors, resources, service configuration, and economy. Further, the 19 states represented in the project also differed insofar as the history and evolution of publicly funded services, the extent of reliance on public institutions, the extent of provider acceptance of notions of self-determination, the extent of regulation, and the presence of supportive advocacy and professional/provider organizations.

II - Purpose of the Evaluation – What Were the Major Evaluative Questions?

The guiding questions for this impact assessment were:

- » Did the projects meet their goals?
- » What actions did the projects take?
- » What obstacles or constraints were encountered?
- » What were the results of the actions taken?
- » What national policy issues must be addressed?

Findings from the first year assessment were used to further shape the investigation. For example, based on themes that surfaced in the first year, an in-depth analysis of the link between self-determination and self-advocacy was conducted in the second year.

III - Summary of Methods

Given the diversity of the self determination projects, the HSRI evaluation team initially proposed an evaluation methodology that would document both the theory or model of how the program is supposed to work, as well as the process followed by the demonstration sites and the process outputs. The approach proposed for the evaluation involved two major components. The first was the development of a logic model, and the second involved the development of a “project data base” which would capture the variables associated with each project. Project staff developed a data collection protocol based on these variables and gathered information from the following activities: (1) records and literature review involving analysis of secondary data, (2) telephone interviews, and (3) on-site visits and interviews.

Constraints encountered during the first year suggested that a strict quantitative approach would not be appropriate for the final phase of the evaluation. As a result, the project team made the following revisions:

- » Selection of 10 states on which to concentrate data collection activities. The 10 states included New Hampshire, Massachusetts, Michigan, Vermont, Ohio, Wisconsin, Kansas, Oregon, Utah and Maryland. The criteria for selection included the momentum for change in those states, the length of the demonstration activity, and geographical distribution.
- » Revision of the interview protocol to reflect an emphasis on implementation issues and the change process rather than focusing on collection of quantitative data.

The impact assessment also included a separate analysis of financial management strategies within the demonstration sites. The evaluation of selected site consumer-managed/directed procurement methods was conducted through site visits and interviews with state and project staff along with the review of relevant documentation. Site interviews focused on understanding the flow of funds and documenting related procedures for tracking and controlling funds and payments.

IV - Major Findings from the Evaluation

Critical Factors for (or Barriers to) Success...

- » Flexibility is key – the ability of funding systems to accommodate individual budgets and to expand the pool of contracted providers. Where systematic approaches to budget development (e.g., based on costs, and/or individual characteristics) were already in place (e.g., in Utah and Kansas), the task of making these individual resource allocations was facilitated.
- » The success of the self-determination initiatives in certain states had to do with the fact that leaders there did not treat self-determination as a “project” but rather embedded the approach throughout the system.

- » Across the country, the ability to lead a self-determined life was significantly influenced by the availability of direct support professionals.

Self-determination's Impact...

- » The juxtaposition of the self-determination demonstrations with the emerging aspirations of people with developmental disabilities combined to spur the growth of organized self-advocacy.
- » The combination of person-centered planning and self-determination has sharpened the practice of person-centered planning in many states because it added person-centered "doing" to person-centered "thinking."

Future policy considerations...

- » Administrative aspects of budget and employee management systems can be extremely complex and may inadvertently give more power to families and brokers rather than to individuals. Many states/sites were able to find workable solutions to these challenges.
- » The entailments of supporting an individual in a person-centered process is, according to brokers interviewed, a highly labor intensive process. Given the turnover in case managers nationwide, attention must be paid to finding ways to separate administrative from other brokerage functions in order to ensure that adequate attention can be paid to both.

V - Summary of Dissemination

The Year One assessment report is currently available on HSRI's website: www.hsri.org . The Final Report will also be posted on the website. Numerous presentations have been made on the findings of this study (see list below). Selected presentations on this topic are also available for viewing or downloading in Powerpoint format on the website.

Publications to date:

Agosta, J., Bradley, V., Taub, S., Melda, K., Taylor, M., Kimmich, M., Semple, A., Kelsch, R. (July 1999). The Robert Wood Johnson Foundation Self-Determination Initiative: Year One Impact Assessment Report. Cambridge. Human Services Research Institute.

Bradley, V., Agosta, J., Smith, G., Taub, S., Ashbaugh, J., Silver, J., Heaviland, M. (November 2001). The Robert Wood Johnson Foundation Self-Determination Initiative: Final Impact Assessment Report. Cambridge. Human Services Research Institute.

Presentations to date:

Agosta, John (May 1998). Emerging Systems of Support for People with Developmental Disabilities. Everyday Lives Conference. Hershey, PA.

Agosta, J., Moseley, C. & Ward, M. (November 2000). Who is the "Self" in Self Determination. National Family Support Conference. San Antonio, Texas.

Agosta, J. (November 2000). The RWJ Self Determination Initiative: Year One Impact Assessment. Statewide Conference on Self Determination. Honolulu, Hawaii.

Agosta, J. (March 2000). The RWJ Self Determination Initiative: Year One Impact Assessment. CARF National Conference. Tucson, Arizona.

Agosta, J. (February 2001). The RWJ Self Determination Initiative: Year One Impact Assessment. CARF National Conference. Tucson, Arizona.

Agosta, J. (April 2001). The RWJ Self Determination Initiative: Year One Impact Assessment. NADDC National Conference. Kansas City, Kansas.

Agosta, J. (July 2001). The RWJ Self Determination Initiative: Year One Impact Assessment. National Conference on Self Determination. Seattle, Washington.

Agosta, J. (February 2002). The RWJ Self Determination Initiative: Final Impact Assessment. CARF National Conference. Tucson, Arizona. (planned)

Bradley, V. and Taub, S. (May 2001). A Systems-Level Look at Self-Determination in Nineteen States. The American Association on Mental Retardation Annual Meeting. Denver, CO.

Taub, S. (November 2001). Demonstrating Self-Determination: An Evaluation of Policy and Implementation Issues. Virginia DMHMRSAS Evaluation Conference. Richmond, Virginia.

VI - Recommended Next Steps

Prior to these RWJ demonstrations, antecedents to self determination can be found in innovations explored within family support, supported employment and independent living systems. One can argue that “self-determination” is less a revolutionary concept and more an evolutionary step that the field was already pushing toward. Based on the observations and data collection undertaken by the evaluators, it is clear that the presence of these demonstrations definitely hastened the progress toward a more person-driven system of supports – especially in those states/sites where there was already a glimmer of understanding and a hunger to go further.

This hastening process has permanently altered the developmental disabilities field. Even as RWJ funding for these demonstrations has ceased, the talk nationally about self-determination continues. Federal policy makers at the Centers for Medicare and Medicaid Services are exploring means for keeping Medicaid regulations from undermining efforts to adopt self determination practices. Self advocates in many states are focusing their efforts on teaching other self advocates about self-determination, and are becoming a greater presence at the policy making table.

The RWJ initiative has given great momentum to this cause -- the idea has been plainly set free across the country. Now, it is up to self-advocates, family members and other self-determination proponents to assure that the idea is put to practical application.

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