

ANNUAL PROGRESS REPORT

Year 2 (Feb. 1, 1999 to Jan. 31, 2000)

Impact Assessment of the “Self-Determination
For Persons with Developmental Disabilities” Initiative

Contract Number 31891

1. What were the project's objectives and how has the project met them in this year?
(For an evaluation project, describe the evaluation methodology, the milestones to date in gathering and analyzing information, and preliminary findings to date from the evaluation.)

The methodology described in our original proposal was divided into seven areas of activity. These seven areas are described, and our progress summarized, below.

1. Measure the individual outcomes experienced as a result of the self-determination project; that is, qualities of life, power and control, health care, adaptive behavior, challenging behavior, work and earnings, family involvement, friendships, satisfaction, family satisfaction, and qualities of the home

All of the above outcomes have been measured for all the people interviewed to date. Individual project sites have received analyses of their baseline data. The sites that have post-interviews have received an analysis of the differences noted from the baseline interviews. We have also compiled various cross site tabulations such as the five highest and the five lowest areas in the personal decision control inventory. Finally we have produced several cross site and cross state comparisons.

2. Survey family members about their perceptions of the impacts of self determination

The family surveys will be distributed and analyzed in the final phase of this evaluation. We have devised a draft survey instrument, which will be reviewed and revised with the help of the National Advisory Panel for this impact assessment.

3. Survey paid staff about their perceptions of the impacts of self-determination

The PLQ includes questions of paid staff regarding job satisfaction, qualities of work life, length of employment, training received, and, most importantly, attitudes/knowledge concerning self-determination. The final project report will include a full analysis of this topic.

4. Conduct individual cost analysis over time associated with the self-determination initiative

This analysis cannot be conducted until the next data collection. (We have, however, completed our preliminary analysis of cost changes in Michigan.) The individual budget section of the PLQ records information regarding residential, day and other program costs.

5. *Summarize and compare five individual cases detailing the impact of self determination on individuals and their personal networks*

The five individual case studies are complete.¹ Updates on changes, progress and impressions since the last interviews will be incorporated in the final report.

6. *Summarize and compare five organizations, detailing the impact of self determination on paid staff, service provider agencies, and local government/administrative organizations;*

During the first two years of the work, focus groups and key informant interviews have been used to gather general impressions and to record information regarding barriers and successful strategies for implementation. The organizational analysis will be conducted in the final year of the project.

7. *Compare outcomes between individual and organizational levels, and between qualitative and quantitative collection methods.*

These comparisons will be completed after all data are analyzed and will be included in the final project report.

2. What internal challenges were encountered during this year that are related to the project's design, collaborations, staffing, operation, or other project factors?

Year 2 presented COA with some unique and unanticipated challenges. The qualitative component of this project proved to be much more labor intensive than originally projected. The independent qualitative consulting expenses almost doubled the initial projections. Likewise the travel associated with these consultants doubled. However, these two upward fiscal trends were offset by the extraordinary savings COA experienced in quantitative data collection. This was largely due to the contributions of Michigan and Ohio. These two states collected data free of charge to COA.

Another significant challenge was the resignation of Anita Yuskas, Ph.D., who had been in charge of the qualitative data collection and analysis for COA. She oversaw the work of a team of independent qualitative analysts, Susan O'Connor, Ph.D., Joan Bernotsky, M.A., Ellen

¹ Yuskas, A., O'Connor, S., Fisher, E., & Bernotsky, J. (April 1999, revised October 1999). *From Hawaii to Maryland: A Year One Status Brief of Qualitative Case Studies in Self-Determination*. Submitted to the Robert Wood Johnson Foundation, *Self-Determination Initiative* National Program Office. Ardmore, PA: The Center for Outcome Analysis.

Fisher, Esq., and Kathy Hulgín, M.A., who assisted in the individual case studies in Michigan, Hawaii, Ohio, Maryland and Minnesota.

In November of 1999, Dr. Yuskauskas accepted a position as the State Director of Developmental Disabilities in the State of Hawaii. (In her new position, she has already demonstrated her grasp of the issues related to self-determination, has brought in nationally renowned consultants, and is planning a conference for the Fall.)

In June of 1999, Marge Brown, M.S. joined the COA staff and was able to work with Dr. Yuskauskas for several months prior to her departure. Ms. Brown's 20 years of experience with service delivery systems and her interest in self-determination brought a new dimension to the COA team. Ms. Brown is now responsible for the completion of the individual case studies and the organizational analysis. Ms. Brown's C.V. is attached.

A special challenge for the qualitative consultants has been to organize immense amounts of data into a specially developed qualitative database, Folio. The process of getting this information into the database was one of the major accomplishments of Anita Yuskauskas this year. She coordinated the case studies, field notes, interviews, and transcripts of the qualitative consultants and supervised data transfer into the database. COA is now in the unique position of having a large qualitative database which enables us to access emerging themes in self-determination.

Building upon the strong and rigorous foundation of formal qualitative research methods, we are in a very strong position to extend our final year of work into more policy relevant and meaningful reports and recommendations. The extensive experience of current team members in direct service arenas will be valuable in this effort.

3. What challenges or successes were caused by factors external to the project?

The external factors that had the largest impact on COA's work were the actions of individual project sites. For example, Arizona and Utah never identified individuals to develop individual budgets and to participate in self-determination, and so we were unable to collect data in those states. The work was negatively affected by the withdrawal of Vermont and New Hampshire from the formal project impact assessment. Both states assured the Foundation that they would conduct their own internal rigorous evaluations. Still, they could not become part of

the National database maintained by COA because they decided to develop their own measurement instruments and methods.

Several other states focused their efforts on systems change and were therefore late in identifying individuals for participation. Interestingly, most of these states are now in the process of requesting COA's assistance in documenting the future impacts of self-determination on peoples' lives (e.g., Arizona, Oregon, Washington, Pennsylvania). Finally, one state was involved in another evaluation project (conducted by our partner in this impact assessment, HSRI), and felt that the RWJF impact assessment would impose too great a burden on respondents. This state, Texas, has now asked that COA return and begin outcome analysis with 90 participants. We are therefore developing a "post-only" outcome measurement package for that purpose. This package will rely on memory, rather than true pre-post measurement, but will still provide useful information.

4. If you are working in collaboration with other organizations, or depend on other organizations or institutions to meet the objectives of this project, how are those relationships working?

COA has developed excellent working relationships with colleagues at the National Program Office, federal, state and local government, and with key project site staff, self-advocates and family members, and HSRI researchers. In addition COA works closely with a variety of self-determination consultants and technical advisors. COA's field work is strengthened by this broad-based network of individuals, organizations and institutions involved with the principles of self-determination. We would rate our collaborative relationships as "excellent" at this time.

We also discern a significant trend toward demand for hard data on the impacts of self-determination. We receive dozens of requests each month for presentations of our early findings. More importantly for policy impact, perhaps, is the fact that large state and federal agencies have begun to show strong interest in what evidence is available so far. Dr. Conroy and NPO staff have begun dialogues with HCFA and Medicaid policy makers as well as with disability specific agencies such as ADD to address joint agendas for the consideration of self-determination for possible expansion. The COA research data are increasingly seen as a valuable resource for lawmakers, policy makers, advocates, and self-advocates.

5. What have been the project's key dissemination activities during the past year?

These articles and presentations were disseminated during Year 2 of this contract:

Article accepted for publication in professional journal:

Conroy, J., Yuskas, A., & Spreat, S. (In Press). Outcomes of self-determination in New Hampshire. *The Journal of the Association for Persons with Severe Handicaps*.

Professional presentations:

21. Conroy, J. (March 2000). Results of Research on the Outcomes of Self-Determination. Invited address to the Ohio Supported Living Association 2nd Annual Conference, Journey Beyond Possibilities: Back to the Future. Columbus, OH.

20. Conroy, J. (March 2000). Recent Advances in Self-Determination Across the States. Invited address to the Ohio Supported Living Association 2nd Annual Conference, Journey Beyond Possibilities: Back to the Future. Columbus, OH.

19. Conroy, J. & Agosta, J. (February 23, 2000). The State of the States in Self-Determination: Research on Practice, Policy, and Outcomes. Invited address to Pennsylvania's annual conference sponsored by the Office of Mental Retardation entitled "Everyday Lives." Hershey, PA.

18. Brown, M. (February 13, 2000). *Orientation to the Personal Life Quality Instrument*. Invited address to the North Carolina Developmental Disabilities Pilot Sites at the Southeast Regional Conference on Self-Determination. Winston-Salem, NC.

17. Conroy, J. (January 14, 2000). *Successful Outcomes of Self-Determination in Michigan*. Invited address to the management group of the Michigan Department of Community Health. Lansing, MI.

16. Conroy, J. (January 13, 2000). *How Can We Tell If Self-Determination Is Working?* Invited address to the Kickoff Conference of the Expansion of Self-Determination. Columbus, OH.

15. Brown, M., Conroy, J., Dorsey, S., and Miller, C. (January 4, 2000). *The Historical Context for Self-Determination in Delaware County*. Invited seminar to the biannual Case Management Conference of Delaware County, Pennsylvania. Media, PA.

14. Conroy, J. (December 21, 1999). *The Self-Determination Theory: Potential Applications in Indiana*. Invited presentation to the Quality Assurance and Person-Centered Planning Work Group. Indianapolis, IN.

13. Conroy, J. (December 8, 1999). *The Meaning and Outcomes of Self-Determination*. Invited presentation at the annual conference of the Tri-Counties Regional Center. Santa Barbara, CA.

12. Conroy, J., Yuskas, A., & Agosta, J. (November 1999). *Evaluating the Impact of the National Self-Determination Program*. Invited presentation to the 1999 Annual meeting of the National Association of State Directors of Developmental Disabilities Programs, entitled "Bringing Self-Determination into the Mainstream."

11. Conroy, J. (September 1999). *Self-Determination: The State of the Art in Supporting People with Developmental Disabilities in the United States*. Invited Presentation to the Second Moscow International Workshop entitled "XXI Century: The

World Is Open for Each of Us.” Conference jointly sponsored by the Ministry of Education and the Association for Down Syndrome. Moscow, Russia.

10. Conroy, J. (August 1999). *Why Self-Determination?* Invited speech to the annual retreat of the Delaware County Board on Mental Retardation and Developmental Disabilities. Delaware, Ohio.

9. Conroy, J. (August 1999). *Self-Determination: What’s All the Buzz About?* Invited presentation to the management staff of the TriCounties Regional Center, Santa Barbara, California.

8. Conroy, J. (June 1999). *The Design of the Evaluation of California’s Self-Determination Initiative.* Invited address and visual presentation to the California Self-Determination Steering Committee. Sacramento, CA

7. Conroy, J. (June, 1999). *What We Have Learned About the Impacts of Self-Determination.* Invited address to the first conference on self-determination organized entirely by self-advocates: The Speaking for Ourselves Northeast Regional 11 State Conference on Self-Determination. Valley Forge, PA.

6. Conroy, J. (June 1999). *Plenary Session: Outcomes from State Self-Determination Projects.* Invited Plenary presentation to conference entitled “Michigan’s Self-Determination Initiative: Building the Dream to Achieve Freedom and Authority. Ann Arbor, MI.

5. Conroy, J. (June 24, 1999). *Fiscally Conservative Supports for People with Developmental Disabilities: Self-Determination.* Interview by United States Congressman Robert Ehrlich of Maryland, for the weekly cable television program Bob Ehrlich’s Washington Update. Washington, D.C.

4. Conroy, J. (April 1999). *Self-Determination Seminar: Followup for Stakeholders and Family Care Council.* Invited address to Department of Children & Families, District 1, Developmental Services. Pensacola, FL.

3. Yuskas, A., & Conroy, J. (June 1999). *Individual Outcomes and Case Studies of the National Self-Determination Initiative.* Invited presentation to the Connecticut Self-Determination conference “With Choices, Life Changes – Join My Journey.” Waterbury, CT.

2. Conroy, J. (April 1999). *Self-Determination Seminar.* Invited presentation to District 1 Developmental Services and the Family Care Council. Pensacola, Florida.

1. Conroy, J. (April 1999). *The Past and Future of Self-Determination.* Invited keynote address to the Ohio Provider Resources Association. Columbus, OH.

A rough estimate of the number of people attending these 21 presentations is 3,000.

6. Does the project have other sources of support?

The answer to this question is “Yes,” and we anticipate continued and possibly increasing support from other sources. In addition to the funding contributed by The Robert Wood Johnson Foundation, COA has benefited from the direct support of other self-determination efforts. COA

is pleased to participate in these research projects that will continue beyond the scope of the Robert Wood Johnson initiative. To date these projects include:

STATE	COMMENTS	AMOUNT OF FUNDING
California	Three year contract (June, 1999 through March, 2002)	\$150,000.00
Florida	Dissemination efforts	\$5250.00
Michigan	Approximate contributions for consulting and dissemination efforts	\$15,000.00
North Carolina:		
Residential Support Services	Nine month contract	\$9634.00
North Carolina ARC	One year contract (June, 1999 through May, 2000)	\$25,655.00
North Carolina D.D. Council	One year contract (March, 2000 through February, 2001)	\$30,000.00
Pennsylvania:		
Blair County	One year contract for Baselines	\$10,000.00
Delaware County	Two and a half years (December, 1997 through July, 2000)	\$72,846.00
Delaware County Commissioners Association	One year contract (June, 1999 through May, 2000)	\$42,000.00
Ohio:		
Delaware County Board of Developmental Disabilities	Dissemination Efforts	\$1,700.00
Ohio Dept. of MR/DD	Technical Assistance	\$7,000.00
Ohio Dept. of MR/DD	One year contract (in process)	\$35,000.00
	TOTALS:	\$404,085.00

7. What are your plans for the project next year?

In the coming year, COA will finalize the quantitative and qualitative research.

Qualitative Component

We will conduct final follow-up with the five case study subjects to update their experiences and perceptions as self-determination participants. We will produce organizational descriptions detailing the major components of the local systems change that were necessary to

implement self-determination. This organizational summary will define essential resources, common barriers and challenges, and successful tools and methods as reported by local project site stakeholders.

Quantitative Component

In the summer or fall of 2000, we plan to conduct a mail survey of the families of the people in our baseline database. We will send out more than 2,000 surveys. We will be asking questions about attitudes, knowledge, experience, and hopes. We want to find out why people and their families chose to take part in self-determination efforts, what they expected to gain, and what they perceive has happened so far. The survey instrument will be designed to be maximally compatible with our databases that include more than 40,000 similar surveys of families. We anticipate response rate just above 40%. Since we have tested for non-respondent bias many times before, we believe that this response rate is quite acceptable.

During the next 10 months, we will conduct our most important activity: collecting the “post” data for the individual participants across the states. The following table shows the number of people, by state, for whom we have collected baseline data on our Personal Life Quality Protocol.

Original RWJF Grant Amount	State	# PLQs, Baseline	New Additions	2nd Round Scheduled	2nd Round Completed	Estimated Number of People Now With Individual Budgets as of 3/2000
200	AZ	0	60			0
0	CA	0	90			0
200	CT	59				20
100	FL	0				0
400	HI	115		50		2
200	IA	0				0
400	KS	10				10
100	MA	80				10
400	MD	21				10
400	MI	786			303	110
400	MN	30				15
0	NC	70	80			20
900	NH	74				60
0	NY	26	100			5
400	OH	74		75		37
200	OR	0				0
100	PA-BLAIR	600				50
	PA-DELCO	43				43
	PA-PHILA	12				6
400	TX	0	90			30
200	UT	50		50		10
400	VT	0				100
100	WA	0				0
400	WI	133		133		40
	TOTAL	2183	270	308	303	578

The Personal Life Quality Protocol gathers reliable information on power, choicemaking, control, independence, productivity, integration, satisfaction, health, health care, health care utilization, medication usage, individual planning, individual goal attainment, case manager interactions, day programs, environmental qualities, community activities, and friendships.

Our primary evaluative research design is “pre-post.” We are asking this simple question: *“Have the lives of the participants changed in any way(s)?”* There are dozens of subsidiary questions, the most important of which are: “If there have been any changes, in what

areas of life, how big are they, and what have been the costs or cost savings associated with the change from traditional services to self-determination?”

This final major data collection activity is the real core of the entire impact assessment by the Center for Outcome Analysis. It is here that we will finally answer the question of whether peoples’ lives improve when their supports are transformed via self-determination.

8. How do you see the Foundation’s role?

Our experience with the grantee states reveals that states have varied widely in the challenges they faced. Implementation of individual budgets was far more difficult in some states than in others. This meant that some states have made rapid and significant progress toward changing the lives of participants, while others are still grappling with “systems change” issues.

Some of the variables that have affected state progress have included state and local leadership, specifics of the state’s Waiver programs, organizational history, values base, the development of self-advocacy organizations, case management structure, and labor regulations. The Foundation’s immense prestige and continued support through training and technical assistance will be absolutely essential for the continued progress of this movement in many states, particularly those that have spent 1 to 3 years attempting to overcome some of these initial obstacles.

We perceive from our research thus far that self-determination is rapidly evolving away from a “demonstration” paradigm, toward a “best practice” model of public and private support and funding. We believe that the time is ripe for a media campaign. We have come to the opinion that major media sources of the magnitude of 60 Minutes could and should become interested in this movement. The notion of individual choice and control can never spread widely unless the availability of choices and controls is widely publicized. Therefore we see the future role of the Foundation as encompassing an effort to bring self-determination into wide public awareness.

Taxpayers, legislators, advocates, and funding agencies in the human services (including aging and mental health) need to know about this movement, including its scientifically documented (albeit preliminary) outcomes. They also deserve to know about the vision and the

hope offered by this cutting edge model of consumer control of public resources, at least in part because it is inherently fiscally conservative.

The self-determination movement also holds out hope for families on “waiting lists,” which is the most pressing single issue in the developmental disabilities field in this country. The relevance of self-determination to the Olmstead decision has not been publicized. The potential of self-determination for expanding and enhancing the involvement of people in supported and competitive work has not been disseminated.

Finally, the foundation is in a unique position to implement the basic tenet of self-determination: self-advocate and family control of resources. National and local self-advocacy groups have endorsed self-determination as their hope for the future. They need financial and technical assistance to continue their efforts. From our vantage point, we find this conclusion inescapable: the Foundation should direct its future training and technical assistance funds toward organizations that are responsible to, and controlled by, people with disabilities and their freely chosen allies.

The central point of self-determination has been the realization that control over one’s destiny is difficult without control of resources. We therefore urge the Foundation to consider ways to pass control of the Foundation’s self-determination training/technical assistance grant funds directly to people with disabilities.