

SELF-DETERMINATION: INDIVIDUAL COSTS, SYSTEM COSTS AND QUALITY OF LIFE

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Self-Determination is a movement to change long term care by shifting power over resources directly to individuals and their family and allies. As such it requires fundamental structural changes (fiscal management agencies, independent brokering and highly personal budgets) and a leadership commitment that moves the present system from a highly paternalistic and costly one to a system that promotes both freedom and responsibility while achieving better value for the public dollars that are appropriated.

The original application to the Robert Wood Johnson Foundation in 1993 simply stated the premises:

- 1. If power shifts (carefully, gradually, responsibly, case-by-case) from paid professionals toward the people and their freely chosen allies,**
- 2. Then lives will improve,**
- 3. And costs will be the same or lower than they would be in the traditional professionally-dominated approach.**

What follows is a selection of data on changes in individual costs for projects in New Hampshire (the original Robert Wood Johnson Foundation pilot), Michigan and California. These projects reflect a reduction in per person costs or a smaller increase compared to others served in the same system. Two projects in Wayne and Allegan Counties in Michigan reflect the reduction in system-wide costs as well as per person costs when self-determination is well understood and adopted as a foundation for everyone served.

In conjunction with data for these first three projects, quality of life data was also collected and is reflected in statistically significant increases in overall quality of life. In addition, one project in Wayne County, Michigan tracked staff turnover (a reflection of one of the most important quality of life issues in human services) at the direct care level for a cohort of individuals served by Community Living Services—one of the largest system managers in Michigan under their version of managed care. The results are noteworthy

Finally, self-determination is beginning to become a foundation for re-thinking the notion of recovery in the field of mental health. The Substance Abuse and Mental Health division of the federal Department of Human Services convened a summit on self direction and self-determination and produced a report indicating that this approach might very well add a new and substantial foundation for both improving quality and advancing progressive notions of recovery. A small pilot carried out in Florida appears to support this notion. The link to the federal report is available as is all the original data sources on the self-determination website at www.self-determination.com.

INDIVIDUAL COST DATA

New Hampshire

The original pilot served 45 individuals over a three year period. These 45 individuals included those with developmental disabilities and brain injury. What was particularly significant was that it included those with the most significant disabilities (unlike most self direction projects). In other words it included individuals whose annual costs approached \$100,000 dollars. Depending on how one calculated the numbers, the average reduction in per person costs amounted to between 12 and 15 percent. Overall these 45 individuals saved about \$300,000 annually. As a result the Robert Wood Johnson Foundation committed over 7 million dollars to expand this concept to other states and to begin projects in both urban and rural settings.

Michigan

Michigan was one of the first states to pioneer self-determination in both rural and urban areas. The results of the initial investigation of 70 persons with disabilities (again including those with the most significant disabilities) revealed two things that are of primary significance: the higher the present cost in the traditional system the greater the reduction under self-determination; and, the average savings adjusted for inflation amounted to 16% or over \$10,000 per person. This analysis by Head and Conroy can be reviewed in its entirety at the self-determination website.

California

California was not a state funded by the Robert Wood Johnson Foundation. Rather, the state legislature mandated a pilot program on self-determination in four areas of the state. The fiscal results here were intriguing. The state opted to not use Medicaid dollars because they felt the traditional Medicaid rules would dampen creativity. The project was launched after a year's delay in a very complex system and the average per person costs increased slightly from pre to post analysis. However, this represented a smaller increase compared to those in the traditional system. The full California report is also available at www.self-determination.com.

SYSTEM COST DATA

Adopting a system wide approach to self-determination appears to have a significant positive impact on total system costs including those who exercise the option for self-determination and those who do not. It is primarily a reflection on some of the implications for moving personal planning and budgeting from professionally dominated teams to individuals and their close allies and friends. While conclusions drawn here have to be tentative, leaders in the following organizations subscribe to the belief that adopting

the principles of self-determination system-wide allowed them to utilize new tools in analyzing their present costs and redistribute income more efficiently as well as become more cost effective overall.

Community Living Services of Wayne County, Michigan

This large hundred and twenty three million dollar plus agency operates under a modified managed care plan in Michigan. They contract out all direct services but retain traditional case management/brokering and other professional services. As they began to implement self-determination for 500 individuals, these personal planning teams began to discriminate in important ways. Many individuals were no longer interested in purchasing services they did not need especially from psychologists, nurses and dieticians. Some of course still benefited from these services. Individuals then began to move from licensed congregate homes to personal homes and apartments.

CLS then began to look at what the costs of maintaining a cadre of these professionals on staff was costing and decided to simply make these particular supports available to individuals who did need them by having them purchase them independently by individual contractors on a person by person basis. By ridding itself of constant costs for a very large cadre of professionals CLS reduced its overall clinical costs among other system reductions. Today CLS serves 2,500 individuals at a total cost of \$123,952,000. In 2001 CLS served 1750 individuals at a total cost of \$123,532,000. During this same period their clinical costs moved from about 4 million dollars to about 3.4 million dollars.

Their average expenditure per person during this same time period moved from \$70,285 per person to \$49,200 per person—about a 30 percent reduction. This included all previous administrative and clinical costs. Average personal budgets decreased by approximately 4 % during this same time period. Most savings here came from newly enrolled individuals being served in their own homes together with those who moved from congregate to individual settings and those who eschewed clinical services that they didn't need.

Allegan County, Michigan

Allegan County Community Mental Health services (ACCMHS) in Allegan, Michigan was one of the first of four RWJ sites in Michigan. Allegan County is one of the largest counties geographically in Michigan and is mostly rural. ACCMHS serves about 380 people with developmental disabilities in any give year. ACCMHS started the SD process slowly, one person at a time.

In 2002, ACCMHS received a DD Council grant to further efforts in SD. At this time, it was decided to change the entire DD system into one that provided services based on the principles and values of SD. Every person receiving services participated in person-centered planning, as required by Michigan law, and additionally participated in the

development of an individual budget based on the plan. Each and every person decided how much control they wished to have over their budget. Some decided to continue with supports provided by ACCMHS while others decided to hire their own staff. Some decided to stay in the group home or day program while others decided to move in to their own place or get a job.

Overall, as person-centered planning improved, and people became more informed about the costs of their supports and services, there was a significant movement toward community supports. The number of people in congregate homes decreased from 55 to 38 while the number of people living in their own homes increased from 68 to 93. Some of the individuals moved into their own homes out of their parents' homes. As the number of people who lived in their own homes increased, the cost per person in residential settings decreased slightly from \$32,897 to \$32,610. While overall cost remained the same, the cost of supporting a person in their own home was less than supporting them in a congregate home. The average cost of a person in a congregate home was \$41,935 while the average cost of supporting a person in his or her own home was \$28,799.

As people were moving into their own homes, they were also making decisions to work in the community as opposed to segregated programs. In 2000, 182 people were participating in a day program, sheltered workshops, or crews while 175 people participated in job coaching or development. In 2006, 53 people participated in day program or crews, while 313 received support in job coaching, job development, or self-employment. While individuals chose to be supported in community work as opposed to day programs and sheltered workshops, the average cost of supporting a person decreased from \$6,180 to \$4,589.

At the same time, quality of life for these individuals increased significantly as analyzed by Dr. Jim Conroy. Quality of life was measured in 1998 and again in 2004. In all areas, including health and safety, there was a statistically significant increase.

IMPROVEMENTS IN QUALITY

The references above for New Hampshire, Michigan and California include extensive data on changes in the perceived and actual quality of life of those who participated in these self-determination projects. Based on an extensive Quality of Life Protocol developed by Conroy Outcome Analysis there are statistically significant increases in quality at all project sites. A limitation of this data, while it includes all who experienced self-determination as a new approach to supports, is that these changes are not necessarily linked directly with the provision of independent brokering, independent fiscal management and totally personal budgets. But, however this is interpreted, the data do, as the New Hampshire evaluation certainly did, include all those in the projects who benefited in partial and complete ways from the system change requirements for implementing self-determination.

One of the more interesting results of implementing self-determination that requires more research are the results obtained by Community Living Services on staff turnover. At the direct care level staff turnover is the bane of human services and contributes to high costs and constant jeopardy for individuals with disabilities—especially those with significant disabilities who cannot use traditional speech and need folks close to them for long periods who understand how they communicate. One provider study in the Community Living Services area of Michigan revealed that 96 jobs at 10 non self-determination sites experienced annual staff turnover of 87%. During this same year of 2006, 32 staff in self-determination arrangements at 12 sites experienced 38% staff turnover and for 42 individuals who worked more than a year at 18 self-determination sites in 2006 staff turnover was reduced to 18%.

What is most important to note is that this is considered *phase one* of the self-determination reform movement. With the exception of Allegan County most of the significant “savings” experienced by these individuals came about as a result of concentrating on residential supports and residential costs. If the Self-Determination Amendments were now made available to these individuals we could expect equally dramatic further positive effects both in housing and work related cost categories.