

## **Recommendations for System Level Changes**

The three self-determination pilot projects in California were developed and implemented by an extraordinary group of committed stakeholders. People with disabilities and their families agreed to try the program, even though many had years of negative experiences and broken promises in trying to organize support services. State and Regional Center administrators had the courage to assume leadership roles in a project designed to limit their own power and control. Fiscal policy makers and staff brought their expertise to the planning tables to help make the system more responsive to individual needs. Service coordinators, trainers, therapists, residential and vocational staff suspended disbelief in a desire to improve the quality of life for the people they support everyday. Provider agencies assumed new risks and agreed to share responsibilities.

The spirit of commitment exhibited in the California pilots is typical of self-determination initiatives across the country. All the people involved are stakeholders in the true meaning of the term. The people with disabilities and their families are the obvious beneficiaries of an improved service system but all the other players, the administrators, the accountants, the service brokers and coordinators have a vested interest as well. Their values, their aspirations, their daily routines, and their careers are enhanced through self-determination.

The three regional centers involved in the pilots have bravely followed through on their designs and gathered valuable qualitative and quantitative data on multiple strategies for facilitating self-determination. They have experienced delays, false starts, and even a few dead ends. But that is the nature of a pilot project and they are to be commended for their good will, energy and stamina.

Preliminary recommendations for systems change are primarily related to money; tapping into federal reimbursement, setting the amounts for individual

budgets, strategies for supporting individuals and families to allocate their resources, processes for managing accounts payable and receivable, and vendor contracts. Everyone knew from the beginning that moving the money was going to be one of the most difficult aspects of the pilot projects. Accountability and responsibility are important but it seems that many stakeholders have allowed the fiscal complexities to overwhelm the spirit of self-determination.

It is necessary to educate individuals and families and service coordinators about budgets but they do not have to become accountants. Many people who chose human services as a career have a strong aversion to spreadsheets and bookkeeping. The emphasis on the fiscal infrastructure across the various models has created unnecessary barriers to progress. It is our recommendation that the fiscal people concentrate on developing the internal systems that work best for them without bringing the dialogue to people who really have no interest or expertise in making such decisions. It is obvious from the time and energy devoted to the pilot strategies that the fiscal staff have a clear understanding of the principles and values of self determination and they can be trusted to develop a technical system that does not inhibit individual choice or freedom.

A second recommendation involves training. California is obviously committed to the principles of person centered planning. This can be dangerous if the plan is not joined with an individual budget. People who engage in person centered planning need the authority to allocate resources according to the plan. Otherwise, the circle of support and the planning team become stagnant, people become frustrated and stop participating and people with disabilities and their families are back where they started, maybe even a little worse off as they have been encouraged to envision a dream that is out of reach. The fear of budgets and money should not deter service brokers and coordinators from talking about money. It is not fair to let people assume that whatever they want is a possibility.

The amount of public funds available has to be part of the conversation from the first meeting.

A second training issue related to control and freedom. The qualitative data collected for this evaluation presented a disturbing thread. There were many comments about “taxpayer twinges” and concerns about what would happen if “others found out” etc. This kind of control is the antithesis of self-determination. This attitude is even more alarming when you consider that the majority of participants are receiving less than \$20,000 per year in public support. If the families had placed them in developmental centers the cost to California would be in excess of \$150,000 per year. In that light, it is hard to imagine concern about a father who needs to be reimbursed for a day’s wages to take his child to a specialist. The alternative would be to have a much higher paid service coordinator take the child, an alternative that would not benefit the child or the family. The best way to combat this attitude is to have people with disabilities and families present their stories at conferences, trainings etc. Service coordinators need to know that people can be trusted and that in the majority of cases, their solutions are cheaper and more beneficial than those presented by systems.

Another recommendation regards vendors. The provider agencies have not generally been included in the self-determination pilots. It is understandable that systems have to be developed that are primarily responsive to the needs of participants and funding sources, but it is more than time to invite the providers to the policy making table. Although provider agencies are concerned about the viability of their businesses, they are in most cases operated by caring professionals who share the commitment to improving life quality for people with disabilities. The excellent providers can lend their experience and imagination to families and regional centers to design new and improved ways of providing service.



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