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To: California Alliance for Inclusive Communities

From: Thomas Nerney

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RE: California Self-Directed Waiver Program

INTRODUCTION

At the request of Patricia Napoliello, President, California Alliance for Inclusive Communities, I have reviewed the draft Waiver submission that is being developed to expand self-determination in the State of California. In the interests of time and brevity I have addressed several issues that focus on clarification and provided a list of recommendations that I believe would strengthen this application.

The context for this analysis includes the gains we have made in understanding basic requirements necessary to implement self-determination after 10 years of demonstration and experimentation and a recognition that the world of Medicaid, and, indeed community services and supports, are in great jeopardy in many states. California is unique in that many years ago you established a basic right to supports and may not now be experiencing all of the problems that are surfacing in other states. But you will have your fair share.

In over a decade self-determination has built a coherent approach to serving and supporting individuals with disabilities especially those with developmental disabilities. From its inception the focus has always been on restoring basic freedoms to live a meaningful life in the community for individuals who experience disability and support for their families and close allies to provide assistance in this endeavor. This means of course that individuals/families/circles must have authority over a targeted amount of dollars and be given the flexibility to spend these dollars in life enhancing ways that will achieve personal objectives based on high expectations and the development of strong community connections and long term enduring relationships.

Next was the growing realization that there were personal consequences that resulted from the deliberate impoverishment of this entire class of individuals. And, finally, there was recognition that we had severely limited our understanding of what constitutes quality. This has led us to focus on the quality of the person's life and not just satisfaction with typical human services. In the

realm of health and safety it has forced a growing acknowledgement that without long term committed relationships individuals with intellectual and cognitive disabilities especially would always be at risk for health and safety issues.

Within the fiscal realm there was from the beginning a commitment to achieve better value for the dollars expended. This commitment resulted in the original demonstration project reducing total costs for 45 individuals by about \$300,000 a year. Even before we wrote and published the Principles of Self-Determination in 1996 (Nerney & Shumway, *Beyond Managed Care*, University of New Hampshire, Institute on Disabilities) we posited the necessity for cost effectiveness if we were ever to change the system of long term care and serve all of those who were in need of support. Today, the entire Medicaid system is both under scrutiny and vulnerable to massive re-structuring that may result in the loss of eligibility for many and increased restrictions on the use of these dollars. However, the ability to reduce average expenditures depended entirely on obtaining much greater flexibility in the use of public dollars, guidelines for expenditures that rested on high expectations for individuals with disabilities, and, simplifying the bureaucratic system that surrounded individuals and families.

Without much time left to re-design this system before it collapses in many states it might be helpful to consider the Florida Freedom Initiative as perhaps the best example of where the self-determination movement is leading. Beginning next month Florida will begin enrolling individuals with developmental disabilities into a dual Social Security and Medicaid 1115 demonstration Waiver. (Federal Register, Feb., 2004) These combined Waivers will allow individuals with disabilities to earn almost 5 times the amount of money now possible before their SSI begins to be reduced. They will be able to save without penalty thousands of dollars for potential down payments on homes, capitalizing very small businesses, purchasing the means of transportation, pursuing higher education and generally being able to, with both Medicaid and SSI, live in affordable housing, work in meaningful jobs or develop self employment, and become better connected with their communities. In other words this novel approach addresses in fundamentally important ways the loss of real freedom, the forced impoverishment of individuals with disabilities, the barriers to work and the restrictive nature of what passes for quality today. In the Florida Freedom Initiative (December, 2003) Florida State Developmental Disabilities Director, Shelly Brantley said:

It is our intent to create a prototype to transform health and human services as currently practiced in order to promote employment, home ownership, and provide incentives for all individuals with developmental disabilities served to generate income and assets without the current regulatory restrictions.

Two approaches here target housing in unique ways. Under the Medicaid Waiver dollars can be used to supplement SSI in order for individuals to be able to live in safe neighborhoods. More importantly, the Social Security Waiver encourages any dollars from employment that are saved to become Individual Development Accounts or matched savings accounts. Under this plan, for every dollar saved, from one to seven private dollars will be generated to match it. These are the dollars then that can be used for down payments, microenterprise developments and other “targeted” life goals. The rationale and genesis for this approach can be found in *The System of the Future* (Nerney, T., 2003 at www.self-determination.com)

Even more important are the series of recommendations sent to President Bush in December of 2003 by The President’s Committee for People with Intellectual Disability and contained in the report to the President entitled *A Charge We Have to Keep: A Road Map to Personal and Economic Freedom for Persons with Intellectual Disabilities in the 21st Century*. (www.acf.hhs.gov/programs/pcid/index.html) This report strongly endorses self-determination and the dual waivers cited above.

WAIVER APPLICATION

I would like to begin with outlining three issues that may benefit from greater clarification: the nature of this Waiver, the use of brokers and support coordinators, and the role of fiscal management agencies.

SELF-DETERMINATION

There are three paths that tend to become confused in many discussions of moving control of resources to individuals with disabilities and families: *provider choice, self direction and self-determination*. Provider choice is simply the Medicaid requirement to give Medicaid recipients a choice among qualified Medicaid providers. This includes not only typical services but also case management. This issue only plays a minor role in this discussion but I raise it because it may come into play with regard to some of the services offered in this Waiver application under self direction that appear to actually be provider choice. And, it should be pointed out that California is offering many more services in this application than are typically done in self directed Waiver submissions—including a strong array of technology related purchases. Parenthetically, it would be wonderful in the technology sections to emphasize computers and internet accessibility. With current breakthroughs in software this is becoming even more important than heretofore thought for this population.

Self direction is a strategy to move control of services, including the hiring and firing of key personnel, directly to people with disabilities and their

representatives. As such it constitutes an advance in our thinking but generally limits its overarching goal to “control of the services.” *Self-Determination* is a movement with deeper and more far-reaching goals. Control of personnel and, indeed, of all supports a person may require, is a bedrock-given here. However, self-determination sees this control as a means to an end not the end in itself.

The purpose of self-determination is to enable individuals with disabilities to fashion a meaningful life in the community, rich in relationships and community participation and crafted in such a way to enable individuals to pursue an economic future. In other words we address both the forced impoverishment of individuals and the limited view of quality represented by most human service systems. In this last respect we are committed to develop an approach to quality that is based on universal human aspirations for control over where and with whom one lives, being an integral part of one’s community, developing lasting long term relations and achieving at least modest economic goals. This is not to say that this application does not begin to address these issues but that much more could be done to solidify these objectives. This Waiver application then falls into the category more of a self directed Waiver (in fact that is what it is called) than a self-determination Waiver even though the principles of self-determination are incorporated within it as guiding principles. For this reason I have included below a list of recommendations that I hope would greatly strengthen this Waiver and move it closer to self-determination if there is a desire to do that.

BROKERS AND SUPPORT COORDINATORS

Brokers in the self-determination paradigm are one of the linchpins to success. As such their role needs to be clearly spelled out and their functions fully supported. They represent the critical need for unbiased and loyal support in navigating a very complex system. Simple standards adopted by the Center for Self-Determination may help clarify their importance:

- All of these individuals work directly for the person/family and are paid by them through a fiscal intermediary
- They can come from any walk of life or profession or possess any skill set desired by the person/family
- Their jobs are defined by the person/family/circle and can be re-negotiated as necessary
- They have the full support of the funding authority in order to truly and competently represent the person with a disability. In fact this representation requires that persons with disabilities and/or families and allies really control the resources in meaningful ways. (The New Broker, Center for Self-Determination, Ann Arbor, MI. In press)

The Center for Self-Determination recognizes and encourages two types of brokers—long term brokers and short term brokers. Long term brokers under the standards above have more responsibility for developing the individual/budget plan with the person and family. They tend to become real personal agents for persons with disabilities and carry a great deal of authority. Short term brokers are individuals or agencies hired for very specific and time-limited functions. These can range from assisting with securing safe and affordable housing to securing an agreement with a potential employer or helping to develop a viable business. Functions can of course overlap but short term brokers are frequently drawn from the world of business and typical community organizations. They are an express acknowledgement that long term brokers are not necessarily expert (just like case managers or support coordinators) in enough areas to assist in obtaining the desired outcomes a person may seek under this understanding of self-determination.

The introduction of brokering to the system of human services represents a fundamental shift away from typical case management and/or service coordination. Human service systems across the country are grappling with these issues not the least of which is whether or not case management/service coordination needs to be fundamentally re-thought. In any case their role is somewhat reversed. They become support to the broker and person with a disability/family as they develop their plans and budgets. Most systems will still require certain functions that they will perform from eligibility determination to a modified role in a new approach to quality assurance. With “caseloads” (sic) that are way too high to carry out the labor intensive work associated with self-determination their role needs to be re-defined as supporters rather than as individuals who can veto or steer individual plans and budgets.

FISCAL MANAGEMENT AGENCIES

Fiscal management agencies have always been simply defined by us as places where the dollars for an individual gets banked and the bills get paid, the taxes and benefits are addressed as well as all typical fiscal liability issues. This takes the obligation away from individuals with disabilities and families and makes it easier to function as well as insure great accountability for public funds. There are many ways this function can be carried out and there are many responsibilities that some agencies provide including employer of record in some instances. All of them, as in this application, provide timely reports to both the funding authority and to the person/family and circle.

The best of these across the country are simple arrangements that provide the basics necessary to satisfy both the funding source and the person with a disability. In some states, Connecticut for example, 6 or more fiscal agencies compete for the business of holding your individual budget. This has the effect

of making them more responsive to the person with a disability/family and many include 800 numbers and more intensive assistance. This role is moving in important new directions and Iowa is a case in point. In the self-determination transition program in Iowa all of the fiscal management agencies will be credit unions. This has the salutary effect of moving the person with a disability to “banked status” and the recognition that individuals with disabilities need to have savings and checking accounts, learn where appropriate basic fiscal skills, have ATM cards and eventually obtain credit.

This initiative along with the Florida Freedom Initiative is pushing the boundaries on our understanding of the negative effects of forced impoverishment and the Iowa project will also include a Social Security Waiver. As well, progressive systems allow changes within an individual budget not only within sub categories but within the entire budget. Only increases in budget requests need to go back to the funding authority. On another note it is also important to clarify the meaning of individual budget. In this application California adopts the terminology (understandable) of CMS using the term “individual budget” when they mean individual allocation. That is, we need to differentiate the amount of money available to the person (the allocation) versus the line by line item expenditure pattern which of course is an individual budget.

RECOMMENDATIONS

STRUCTURAL ELEMENTS

Self-Determination

It might be helpful for all stakeholders to carry out a more extensive discussion on the overarching goals of this Waiver application. It represents a lot of work by many people with a commitment to provide this new approach to support individuals with disabilities and families. But, it remains caught between traditional human service structures and the new structures that support self-determination. There is of necessity the need to operate a dual system. The question to be answered here is whether this relatively small group of potential enrollees can move more decisively to the new structures in a simple and consumer friendly way.

Brokering

The role of the service coordinator and the broker in this application appears at first glance to reverse the authority from the broker to the service coordinator and indeed the regional center as well. While it is clear that regional center service coordinators will play an important role here the distinctions made in function and authority are a little diffuse. Because the regional center still has certain legal responsibilities for the administration of the Waiver it is understandable that this conflict would arise. Without surrendering their oversight responsibilities it would be helpful to better describe the importance and significance and the authority of the broker for all major development

issues. For example, on page 18 the entire development of the individual budget rests in the hands of the regional center staff without even reference to the broker.

Consideration might be given to including the use of both long term and short term brokering as well as including more highly defined authority for the long term broker if this person is to be able to adequately represent the person with a disability or family.

Fiscal Management

The duties and requirements of the fiscal management agency appear to be extensive and difficult. This raises two issues: the cost of these services and the limitations inherent in who would be willing to perform them. Without prejudging the requirements that may be imposed by California laws and regulations there may be a way to simplify these functions and insure both that they are cost effective and accessible to any number of businesses or community organizations outside of typical human services, as well as create the possibility for competition among potential fiscal management groups. Fiscal management individuals or organizations, if they are community or business organizations, also represent another important possibility for individuals with disabilities to become better connected with their communities and more integrated into community life. Discussions around the use of credit unions and banks in the long term might have a beneficial effect as well.

RECOMMENDATIONS

SERVICE CATEGORIES

The following recommendations and questions for discussion are based on the service definitions coupled with the eligible services in this Waiver application. The issues cited below are only intended as examples of how this application might be strengthened over typical services offered in the regular Waiver.

Home Health Aide Services

The exclusion of homemaker services and the restrictions in this category point to the need individuals and families have for more authority in this area. For example, if this aide must be an employee of a licensed and Medi-Cal certified home health agency then the pool of potential aides is limited. There is as well always the potential for increased tension within these agencies when control over who gets hired is raised. As well, it is very difficult to alter their job descriptions and have real control over hours and times. Opening up this category and lessening these restrictions would be helpful in many instances.

Supported Employment

This category includes job development and placement as well as microenterprise development. It does not appear to allow for what will soon become one of the most cost effective ways to support individuals on the job: direct payments to employers for training and co-worker support. Consideration should be given to the long term positive economic consequences of changing these rules and also for allowing for start-up dollars for microenterprises.

Pre-Vocational services

These appear to be typical services provided by work activity centers and sheltered workshops. It is unclear if they can ever be truly "self-directed." In fact, if they occur in a congregate environment, there is very little opportunity to affect hiring and firing let alone the work to be performed. This is an issue that needs to be reexamined under this type of Waiver application.

Respite Services

There is an over reliance on congregate and licensed "places" where respite can take place. Aside from it occurring in one's own home there doesn't appear to be the possibility of using these dollars at the homes of friends or relatives. This could help immeasurably with both maintaining friendships and relationships and possibly be more cost effective as well. Consideration might also be given to the use of 16 and 17 year old teenagers in some instances.

Behavior Intervention Services

Calling behavior intervention a "self directed" service is a bit of an oxymoron.

Community Living Supports

This service is overly skill-based and may not be as useful to persons who intend to become vital members of their community. Instead, e.g., of concentrating so much on skill development, a push to help people join community organizations and providing the monetary resources to do so might go much further than what might otherwise amount to continual preparation to join the community.

Transportation

After lack of elementary freedom and poverty, the inability to have any control over transportation ranks as the biggest obstacle to controlling one's life. Consideration should be given to allowing Waiver participants the ability to purchase or lease their own cars or vans even if they can't drive. In one study the Center conducted it was actually more cost effective than typical human service transportation. Consideration should also be given to the development of job descriptions that require the availability of personal transportation for anyone hired by the individual or family.

RECOMMENDATIONS GENERAL

Guardianship and Representation

Guardianship of course represents a real barrier to self-determination. Many family members have sought guardianship with good reason. They wanted to protect their sons and daughters from the vagaries of the human service system and insure adequate medical attention to name just two. However, in the development of an individual plan and budget it is recommended that there be some objective evidence provided that this is really what the person with a disability truly wants. In addition, a good conversation on the pros and cons of guardians becoming representatives would be helpful as well. The potential for conflict of interest is very strong in this area.

Access

A much needed outreach to those currently served by typical Waivers and state funded programs would be helpful in opening up participation to those who do not have active family and advocates. There is always the danger that these individuals will be left out of what could clearly be a benefit to them if they had both the information and the right assistance.

Training

It is unclear what kind of training will take place for all stakeholders ranging from service coordinators to potential brokers and individuals and families. A good discussion of the overarching goals of this Waiver application will lead to a better understanding of the types of training and support that must be made available. There is always a tendency to focus on the technical requirements that everyone will need to meet (a danger also that certain “tests” will be developed for participation) at the expense of the issues surrounding how to achieve a meaningful life in the community.

Conclusions

This Waiver application attempts to shoehorn existing waiver services and categories into this self directed Waiver. Some of these services cannot easily or ever be self directed. It would be really advantageous if new “services” could be written and developed in key areas that are consistent with self-determination and easily managed and controlled by persons with disabilities, families and their allies and brokers. Negotiating more general and open supports with CMS is an art. These new waiver services could address the essential elements of a person’s life around home, community, relationships and the generation of private income.

Finally, in accord with the Principle of Confirmation endorsed by this application it is important for this and other system change plans to include those who will be most affected in both the development and the review of these changes. Too many projects of this kind simply pay lip service to the creation of equal partnerships with persons with disabilities and families. Knowing the progressive nature of California I am sure that this will be a primary feature of the review process that is now being launched.