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California's protection and advocacy system

January 10, 2012

Toby Douglas, Director
Department of Health Care Services
1501 Capitol Avenue, MS0000, P.O. Box 997413
Sacramento, CA 95899-7413

Transmitted to: OMCPRFP9@dhcs.ca.gov

Dear Mr. Douglas,

Disability Rights California appreciates the opportunity to comment on the draft RFS. We have been advocating for an integrated long term care budget for several years, based on civil rights and prudent fiscal policy. We agree with the underlying assumption: the current non-system of acute and long term care is not the best California can do. Public dollars and human resources are wasted, not only by lack of coordination and duplication of efforts, but by sending and keeping people in nursing homes who do not want and do not need to be there. We know there are people who need assistance in finding, keeping and managing services. We want to see fiscal and program policy which gives people with disabilities a true choice in what services to receive, and where and how to receive them.

We have appreciated the opportunities to participate in the stakeholder process, both in the large meetings and at smaller meetings, and the professionalism of the employees and consultants of the state throughout the process.

Any pilot project must be designed with input from those most affected, whose voice has been largely absent from the stakeholder process, despite the representation in the cover letter and the RFS. Any pilot project must build on, and not undermine, the success of the PACE program, the IHSS program, the Public Authorities, the MSSP program.

We have had serious concerns about some aspects of the RFS and the stakeholder process. The state seems to be asking the plans what they want to do, rather than telling them what will be required. Although the plans may respond with good intentions and good ideas, those cannot constitute or substitute for public policy.

Although SB 208 and the RFS were for four pilots, the context has changed with the release of the Governor's Budget and the proposal to increase the pilots to ten and then statewide within three years; with so much at stake, our concerns are even deeper. We would support the idea of a small number of carefully conceived pilot programs, which would meet this definition: "A pilot project is generally a project which is designed as a test or trial to demonstrate the effectiveness of a full program."¹

Some stakeholders have been asking what was being tested in the 4-county Demonstration, and whether more than one model was to be tested, and what defines a successful or unsuccessful test. If Los Angeles were to be selected among the four sites, the "test" would experiment with the lives of half the seniors and persons with disabilities who are dual eligible in California. Now the scope has very possibly changed to an even bigger number of dual eligibles, with a timetable which precludes any course changes based on any true "test or trial." Successful outcomes are in danger of being sacrificed to a "full speed ahead" devolution of historically public responsibilities to private entities, without input from the people most affected, and without a close examination of the fiscal assumptions (of savings) which are, in part, setting the speed.

California has historic and recent experience mandating managed care for people on Medi-Cal; it is not clear how that experience is informing the current push to make managed care the only care. In 2005, the Robert Wood Johnson Foundation announced the findings of a study of an earlier wave of mandatory managed care in California, with this summary: California's Shift to Medicaid Managed Care Doesn't Save Money or Improve Outcomes.²

¹ From the http://www.philanthropywiki.org.au/index.php/Pilot_Project

Over the last year, the state has forced over 200,000 seniors and persons with disabilities who have Medi-Cal only, into managed care. Advocates and consumers fought hard to slow the process down and to build sturdy protections and readiness standards, to prevent disruptions to the health and well-being of the population. Advocates, including physicians, have documented widespread problems including disruptions of crucial care, including cancer and AIDS treatment, surgeries and dialysis. At the joint Senate and Assembly Health Committee hearing on December 7, 2011, legal services attorney Katie Murphy testified that “These problems exist because of uneven and incomplete implementation by DHCS, and often a refusal to fix problems as systemic and a focus only on individual circumstances, dismissed as aberrations.”

Among the concerns of DRC and other advocates was that managed care plans were not familiar with the medical needs of people with disabilities, much less with their access and accommodations needs, and were unlikely to be in compliance with the state and federal laws which guarantee the rights of people with disabilities to accessible programs, buildings and services. Despite the three decades which have passed since the first federal access laws, managed care providers were not required to demonstrate compliance before they received a monthly influx of tens of thousands of new patients with disabilities.

Now the Governor’s Budget proposes to move another population, which is described as having even higher health needs, into managed care, and give managed care providers even more responsibilities and even more control over the medical and social services for beneficiaries.

2 <http://www.rwjf.org/reports/grr/049006.htm>. Key findings: Following the shift from fee-for-service to managed care:

- ⤴ Medicaid spending increased an average of 17 percent, an effect that lasted well after the shift, suggesting that startup costs were not the cause of the increase.
- ⤴ Counties with only one managed care plan experienced significantly greater spending increases than those with multiple plans, suggesting a benefit to competition.
- ⤴ Significant improvements in health outcomes did not result.
- ⤴ Infant health outcomes showed little change.
- ⤴ Although the study did not produce administrative cost data, anecdotal evidence suggests that the shift to managed care may result in increased state administrative costs.

Our comments on the RFS follow, in order of their appearance in the document:

Key Attributes:

On the question of excluding beneficiaries with certain disabilities: We now understand that the motivation was to protect people. This raises two questions:

a) If people with these disabilities need protection from managed care, don't other people with other disabilities? There are people with all sorts of disabilities, some common and some rare, who have the same need for good acute and long term care as those with the named diagnoses. If people are to be exempted because they cannot get the services they need, and do not want to lose their current providers, those people should be able to self-identify and be exempted.

b) If people with these disabilities are in nursing homes, they will be denied an equal chance to return to the community if they are exempted. This raises the specter of disability-based discrimination, even though the exemption idea was well-motivated.

Our response is NO.

On exempting people who have been institutionalized for longer than 90 days.

Now we understand that only the first year of the project was being discussed. If the duals project will have a benefit for people in institutions, and we think it can, that benefit should be available to everyone, regardless of the length of institutionalization.

Our response is NO.

Enrollment:

We object to passive enrollment, as interfering with consumer control. If the managed care project is as beneficial as is hoped, people should want to enroll and not be forced to enroll.

We object to the lock-in, which was never discussed at any stakeholder meeting. Locking in consumers is always problematic and the problems are magnified by the newness of this experiment: we don't know if or how the

service goals will be met, or whether, as seems likely, we will see a repetition of the problems in the SPD enrollment.

How will the enrollment of duals work out better than has the enrollment of seniors and persons with disabilities?

Are people who are on Medi-Cal waivers or waiver waiting lists to be exempted from the project?

Geographic coverage:

Why must a site be capable of covering the county's entire population of dual eligibles? This is especially worrisome in Los Angeles, whose duals population is probably greater than that of most states.

Integrated financing:

The rate and fiscal incentives are crucial, but the RFS provides minimal information. If the rate is based on current baseline spending, where is the funding for the improvements such as case management and transition services and a whole range of services which are not now provided or widely provided?

What is the basis for savings assumptions, and how do they square with the experience of California and other states?

Benefits:

General principles

Services should be provided consistent with the federal Balancing Incentive Program. The Balancing Incentive Program requires the state to make the following structural changes:

1. A No Wrong Door–Single Entry Point system (NWD/SEP);
2. Conflict-free case management services; and
3. A core standardized assessment instrument.

Although California is not participating in the Balancing Incentive Program, this program is the direction in which provision of Medicaid services is moving. California should be moving in this direction now rather than later.

Expanded benefits:

If the projects are to improve acute and long term care coordination and keep people at home, they cannot be limited to providing existing benefits. Housing, transportation, home modifications, case management, supported employment, habilitation, independent living skills and transition services are among the many services, lack of which are consistently identified as barriers to living at home. Assistance in accessing these services is consistent with the “no wrong door” approach.

Sites must be required to provide or coordinate these, and to contract with community-based providers, such as Public Authorities, independent living centers, MSSP sites and supported living providers, who know how to work with people with disabilities and have track records in delivering services. Again, this is consistent with the “no wrong door” approach.

People who are in nursing homes, with Medi-Cal payment, should be able to use any monthly income to retain their homes in the community rather than paying it towards share of cost in the facility. When housing is retained, people can go home if they so choose and save the state money on their care. When housing is lost, the chances for leaving a facility are greatly diminished.

IHSS:

IHSS is regarded as a model of person-centered personal care because it reflects these values: disability is not a medical condition needing a cure, people with disabilities are not patients, people with disabilities have the same rights over their bodies and lives as anyone without a disability, the medical world does not know more than people with disabilities about disability. In IHSS, “consumer choice” is not just a slogan – it is fully realized. In IHSS, “assessment” does not mean a blood pressure reading or a diagnosis – it means looking at the functions and needs of a person with a disability, including a senior, and how those needs can be met with the assistance of non-medical personal care attendants. This is the social model. It is largely unknown to the medical community, which providers readily admit.

IHSS should be coordinated with other services, but the social model together with consumer self-direction and control should be maintained. The

Public Authorities for IHSS have played and should continue to play a crucial role as an organized voice for IHSS consumers, including dual eligibles. Their advisory boards, statutorily required to be consumer-dominated, are a model worth retaining and replicating.

Any core standardized assessment instrument should be one that the counties can use to make IHSS needs assessments in accordance with current uniform, statewide needs assessment standards. Counties should continue to perform needs assessments for IHSS. This will help to insure “conflict free” case management services.

Care coordination: while all enrollees must be offered this service, any enrollee must be able to refuse this – and any other – service or treatment. Enrollees must be free to make the same mistakes as anyone else, and to make decisions based on whatever information they request, delivered in whatever format they need.

Supplementary benefits: We appreciate the encouragement to Sites to provide supplementary benefits. If the Sites do not provide the listed supplementary benefits, it must be clear to Sites that the Sites are required to coordinate benefits. This will help to insure that beneficiaries actually receive the benefits. In addition, it must be made clear to Sites the Sites have an obligation to arrange for non-medical transportation, even if the Sites are not required to provide it.

Beneficiary notification: We appreciate the Department’s requirements.

Appeals: We understand that appeals will be covered by another document. We urge the Department to use the Medi-Cal appeals process so that there will be a seamless appeals process for all of Medi-Cal managed care as well as Medi-Cal LTSS.

Monitoring and evaluation: There is no role mentioned for beneficiaries or other stakeholders in the design or implementation of monitoring or evaluation, nor any information about what constitutes quality. Will it include personal interviews with beneficiaries, and assessments of how many people were diverted from or were assisted to leave institutions?

Monitoring and evaluation must start before the first person is enrolled, and must include quick course correction when problems are spotted.

Will plans be required to show compliance with state and federal disability laws? We would be happy to see DHCS accept responsibility for oversight on this.

Medical loss ratio:

There should be a medical loss ratio consistent with the federal Affordable Care Act.

Ongoing stakeholder involvement:

Beneficiaries and other stakeholders must have a designated and substantive role in the design, operation, oversight and evaluation of programs. They must not be brought in after decisions are already made, and must be equal members of decision-making bodies.

For the Timeline and subsequent sections of the RFS, we fully support the comments and recommendations of the National Senior Citizens Law Center.

Again, thank you for the opportunity to comment on the RFS. We look forward to continuing to work with you and your team.

Sincerely,

A handwritten signature in black ink that reads "Deborah Doctor". The signature is written in a cursive style with a large, sweeping initial "D".

Deborah Doctor
Legislative Advocate
Disability Rights California