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PRINCIPLES ON PARENTAL CO-PAYMENTS IN THE DEVELOPMENTAL DISABILITIES SERVICE SYSTEM

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INTRODUCTION

In 2003, the Legislature adopted a statute (W&I §4620.2) calling on the Department of Developmental Services (DDS) to develop a system of co-payments and/or enrollment fees to be assessed against parents of regional center consumers ages 3 to 17 *who live with their parents* and are “not otherwise eligible to receive services provided under the Medi-Cal program.” The assessments are to be applied only to parents whose adjusted gross family income is *more than 200% of the federal poverty level*. Already, regional centers can charge a fee to parents of children under 18 who receive 24-hour out-of-home care.¹

A “detailed plan” is to be developed by DDS “after consultation with stakeholder groups” and is to be submitted to the Legislature by April 1, 2004, but “may be subsequently modified during the legislative review process.” Section 4620.2(e) outlines a number of components that must be included in the plan, such as issues of privacy, potential safeguards regarding family income, cost sharing, hardship exemptions, appeal process, implementation timeframe and costs, etc.

Two bills have already been introduced this session, AB 1821 (Cohn) and AB 2775 (Richman), addressing the implementation date of the assessment system. AB 1821 calls for a plan to be implemented in FY 2004-05 (July 1, 2004) and AB 2775 calls for a January 1, 2005 start-up date.

This memo proposes a framework of general guidelines that PAI can apply to any co-payment plan that DDS develops and presents to the Legislature. At this stage, there have been a few public hearings, but no formal consultation. We understand that DDS will unveil a plan in early March, but there is no indication whether the Department will propose regulations to implement the plan; section 4620.2 is silent

on that point. Note that PAI has already adopted principles calling for the maintenance and strengthening of due process protections for Lanterman Act recipients of supports and services² (attached).

PRINCIPLES REGARDING PARENTAL CO-PAYMENTS

A Co-payment System Must Include Mandated Protections

A co-payment system will cause substantial harm to those families it will affect. While no fees or co-payments would be best, if a co-payment system³ is required, it must be implemented consistent with the principles of the Lanterman Act. The Legislature and/or DDS must set clear parameters that ensure a family's financial stability, privacy, right to the least restrictive environment, right to choose needed services, right to appeal a fee decision, and petition for an exemption. We suggest six specific principles regarding mandated protections. Many of these principles are included within the existing law.

First, any parental co-payment system must impose less of a burden on children living at home, than any fee system imposed on families with children in out-of-home living arrangements and institutions.

Second, a parental co-payment system should be on a sliding scale, based on family income and family size. The system needs to have, at a minimum, all of the income deductions that the institutional parental fee system currently allows. (*See* 17 Cal.CodeRegs. §§50231-50235).

Third, any parental co-payment system must contain safeguards that protect the privacy of the families' income records and the children's regional center clinical records, and otherwise considers and protects related privacy matters, including assurance that information will not be shared with other governmental entities.

Fourth, a parental co-payment system must have an exemption process for families who are experiencing financial hardships and may need to defer or waive co-payments.

Fifth, a parental co-payment system must have an appeal process for families who may dispute the co-payment or assessment amount. The hearing process in the Lanterman Act, (§4700 et seq.) should be the hearing process available to families, including adequate written notice and provisions that a co-payment will not be imposed during the pendency of the hearing.

Sixth, a parental co-payment system should have sufficient protections to minimize

the disruption of services when implemented. Among other things, a co-payment's implementation should not adversely affect the health and safety of an individual, or the person's right to the least restrictive environment within the context of any regional center services or supports.

Given the High Cost of Living in California, a Co-Payment System Must Be Equitable and Cannot Financially Burden Working Families

A co-payment system is equitable only if the State collects greater payments from families with substantially more disposable income than those families who are at or close to 200% of the federal poverty level.

The 200% of the federal poverty level established in Welf. & Inst. Code section 4620.2() is too low and will adversely affect working class families. Any co-pay system must operate in a way to ensure that families will not forego regional center services, consider institutionalization as an alternative, or suffer significant reductions in the family's financial well-being just to obtain regional center services.

In deciding on the co-pay floor (the income amount at which families would first be required to pay), the Legislature should require DDS to consider family size and the receipt or non-receipt of a true living wage for the geographic area where the family lives. A living wage is a wage amount that realistically meets the cost of living in a given area. For example, California families living in urban centers require a significantly higher wage than those living in communities that are more rural. Instead of minimum wage, a person in Los Angeles realistically needs to earn somewhere between 10 to 15 dollars per hour to adequately meet his/her cost of living needs. A co-payment system must therefore consider what a family's income is in direct relation to its expenditures. Therefore, a family's income is one factor that must be weighed differently based on the geographic area.

A Co-Payment System Should Not Harm Vulnerable Populations within the Regional Center System

A co-payment system should protect politically vulnerable populations within the regional center service system, such as undocumented immigrants, who tend to withstand reductions in services with little or no resistance, since they fear governmental intrusion.

DDS has always excluded individuals who are eligible for Medi-Cal services from its co-payment plan. Undocumented immigrants are not eligible for full-scope Medi-Cal, and can only receive "emergency" Medi-Cal. Therefore, this

commendable exception must also apply to individuals who receive any Medi-Cal benefit.

A Co-Payment System Should Be Uniform and Consistent

To eliminate the disparities in the administration of co-pays, DDS should centrally administer any co-payment system.

DDS should Develop a Co-Payment System that Reduces Administration Burdens on Families and the Agency

Any co-payment system should minimize the administrative actions necessary to process co-payments. A co-pay system can allow families to satisfy a co-payment requirement while lessening the financial affect on them and reducing the administrative burden it places on DDS.

For example, we understand that DDS has proposed a flexible program that would allow families to use alternative resources to meet their co-payment obligations. Under this proposal, a family's co-pay would be used to reduce the amount of services they receive from DDS. Families could use alternative resources (including non-vendored services) to meet this obligation. In addition, DDS is encouraged to consider alternative flexible programs such as allowing families to waive regional center case management as a way of meeting their co-payment obligation. The types of flexible systems that reduce administrative burdens and do not require families to make "cash" payments to regional centers should be encouraged.

¹ 17 Cal.Code Regs. §§ 50201-50241. These regulations provide some parameters for how to decide a family's adjusted gross income. We suggest that, at a minimum, any co-payment system use the same deductions set out in the regulations. DDS' notice requirements, and the appeal and exemption procedures in these regulations, however, are weak and unclear and should not be similarly used.

² "Principles for Addressing Amendments to the Lanterman Act..." ¶5, Adopted 4/18/98 and Amended 2/19/00 (App. O); "Developmental Disabilities Service System 2002 Budget Principles," ¶3, Adopted 2/23/02 (App. Y).

³ We use the term "co-payment system" here to refer to any system of enrollment fees or parental co-payments.