

**HAND DELIVERY
AND VIA E-MAIL**

September 28, 2005

Tom Arnold, Deputy Secretary
for Medicaid Reform
Office of the Deputy Secretary for Medicaid
Agency for Health Care Administration
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Re: Comments on Florida's 1115 Demonstration Waiver Application

Dear Mr. Arnold,

The Advocacy Center for Persons with Disabilities (Advocacy Center), together with the Center for Public Representation and the Bazelon Center for Mental Health Law, appreciate the opportunity to submit comments on Florida's 1115 Demonstration Waiver Application (Waiver). Our comments focus on the impact and effect of the Waiver on persons with disabilities.

The Advocacy Center is a not-for profit corporation authorized by both federal law and Governor Jeb Bush's Executive Order 04-281, (extension, *inter alia*, Executive Orders 03-236 and 87-151). It is the Advocacy Center's mission to advocate the legal, human and civil rights of individuals with disabilities, and to advance the dignity, equality, self-determination and expressed choices of those individuals. The 1115 Demonstration Waiver affects persons with disabilities in seven of our eight current federal programs: Individuals with Developmental Disabilities, 42 U.S.C § 15043; Individual Rights, 29 U.S.C § 797e; Individuals with Mental Illness, 42 U.S.C § 10801 et seq.; Client Assistance Program, 29 U.S.C § 732; Assistive Technology, 29 U.S.C § 3002 et seq.; Beneficiaries of Social Security, 42 U.S.C § 1320b-21; and Persons with Traumatic Brain Injury, 42 U.S.C. § 300d-53.

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Medicaid is this country's single most important program for meeting the health and long-term service needs of people with disabilities. The Advocacy Center is committed to advocating the views and concerns of all people with disabilities to ensure their prompt access to medical services covered by this program. Over a half a million people in Florida who are on Medicaid are people with disabilities. Any change to the state's Medicaid programs will have a major impact on people with disabilities in this state.

Because the Waiver application, the fiscal neutrality calculations that support the Waiver, and the design of the program reflects the statewide implementation of the entire reform initiative, these comments address the consequences to persons with disabilities when the full program is implemented.

I. Overview

Although the Waiver is described as a demonstration or pilot to test certain delivery assumptions, as authorized by Congress in Section 1115 of the Medicaid Act, it really is a wholesale redesign of Florida's entire Medicaid program and a fundamental modification of the Medicaid entitlement to medically necessary treatment. While several populations and categories of disabilities will not be required to participate in the initial phases of the reform initiative ("voluntary populations"), when fully implemented in 2010, it will cover virtually all Medicaid populations throughout the state, including those currently covered by other waivers. But even in the initial phase, the Waiver will include significant disability populations, particularly adults with psychiatric and physical disabilities who receive Supplemental Security Income (SSI) benefits.

The Agency for Health Care Administration (AHCA) seeks approval of this statewide, fully implemented, and all encompassing Waiver, even though there are few details on how it will be expanded to the voluntary populations throughout the state, and most importantly, how it will address the specialized needs of persons with disabilities and the benefit design necessary to ensure that these individuals receive medically necessary services. Moreover, AHCA does not need any further review or approval from Centers for Medicare and Medicaid Services (CMS) to proceed with Phase II or III, or to expand coverage to voluntary populations. It appears that mere notice to CMS, without the opportunity for public comment or legislative review, is sufficient to move to the next phase of the Waiver. Given the substantial level of ambiguity concerning Phase II and III of the program, and particularly its expansion to the most challenging disability populations, we believe further public, legislative, and federal review of these phases is needed, once additional operational and implementation details are determined.

II. The Needs of Persons with Disabilities

Persons with disabilities, and particularly those with severe or chronic disabilities, have significant medical needs. Because of their intensive and long term needs, they often consume a disproportionate share of Medicaid services and incur high per person costs.¹ Establishing standard premiums and benefit packages for managed care health plans usually disadvantages persons with disabilities because of their unique needs and costs. Efforts at risk adjustment to reflect these special needs are commendable, but usually result in benefit limitations that fall far short of what is medically necessary treatment. States have struggled, with some success, to incorporate persons with profound, chronic, or multiple disabilities into managed care programs in a manner that reasonably meets their needs for medical assistance. Most have found that this is possible only through specialized benefit packages or carve-out plans.

Limitations on certain optional services, like rehabilitative services, impose a singular burden on children with serious emotional disturbance and adults with psychiatric, cognitive, and/or physical disabilities. For persons with severe disabilities, and perhaps others, restricting access to optional services, limiting the amount and duration of mandatory services, and establishing a cap on all services is likely to result in one of three unacceptable outcomes: (1) an increased reliance on public institutions and segregated facilities; (2) a shift in costs to state or locally funded programs and hospitals; or (3) simply, no care at all. The first of these is expensive and inconsistent with the President's New Freedom Initiative and the Supreme Court's mandate in *Olmstead v. L.C.* The second is expensive and patently inconsistent with the cost-containment goals of the Waiver. The third is contrary to Congress' command in enacting the Medicaid Act.

¹ In Florida, approximately 19% of the Medicaid population is considered disabled. This group accounts for 48% of all of Florida's Medicaid expenditures. See Policy Brief: What Could a Waiver to Restructure Medicaid Mean for Florida, Winter Park Health Foundation (April 2004). This disparity is not only understandable, but quite reasonable, given the substantial medical needs and corollary costs of persons with disabilities, and particularly those with severe, chronic, and multiple disabilities. These figures are also consistent with national data.

According to a recent Kaiser Foundation report on Medicaid programs in all states, although persons with disabilities are only 11% of the Medicaid optional populations, they account for 31% of Medicaid expenditures. Moreover, these figures mask an even higher disparity for adults with severe or long term disabilities. Significantly, almost two-thirds of these costs involve optional, as opposed to mandatory, Medicaid services. See Issue Paper: Medicaid: An Overview of Spending on "Mandatory" vs. "Optional" Populations and Services, Kaiser Commission on Medicaid and the Uninsured (June 2005) at 6-7.

Our comments, although applicable to all persons who will be included in the Waiver, are informed by the unique needs of persons with disabilities. In short, we are deeply concerned that several of the central tenets of the Waiver will result in grave harm to citizens with disabilities, by limiting access, restricting services, and, in some cases simply abandoning individuals with severe, chronic, or multiple disabilities. This possibility is aggravated by the use of pre-existing condition clauses, which, for persons with disabilities, poses an ominous threat to continued coverage. Moreover, while the negative impact of the Waiver may be less draconian for individuals with less challenging disabilities, the problems described below still deeply threaten their ability to obtain medically necessary care. Within the mandatory group included in the first phase of the program, we are particularly concerned with adults with serious psychiatric disabilities, persons with significant physical challenges that require durable medical equipment,² individuals with multiple disabilities or complicated medical conditions, and children with serious emotional disturbance. These are the most vulnerable and dependent Medicaid recipients who are at the greatest risk under the Waiver, precisely because they are high end users of Medicaid services.

Finally, it is virtually impossible to determine how persons with profound disabilities who already are covered by specialty waivers, such as individuals on the Developmental Services Home and Community-Based Services (DSHCBS) waiver, would fare under this program. The Waiver application offers no guidance or assurance that all currently provided services, at current service levels, would be maintained. If the private insurance model, or some undefined specialty plan, is the method for serving them, it is highly likely that DSHCBS recipients would lose many of their critically needed, but optional services.

III. The Scope of the Waiver

As noted above, the “voluntary” groups not required to join a plan during the initial phase of the program predominantly include certain persons with disabilities, specifically individuals with developmental disabilities, persons in nursing facilities and other institutions (including sub-acute psychiatric facilities), persons with HIV, children in foster care, children with medical needs, and dual eligibles. However, the initially-covered populations also include many persons with disabilities, specifically noninstitutionalized adults with chronic psychiatric conditions and persons with severe physical disabilities who

² It appears that the Waiver may contravene existing judicial orders or settlement agreements in several DME cases, including *Esteban v. Cook*, 77 F.Supp. 2d 1256 (S.D. Fla. 1999) and *Hunter v. Chiles*, 944 F.Supp. 914 (S.D. Fla. 1996). This may subject the entire program, or a portion thereof, to further injunctions or at least judicial review.

are eligible for SSI or SSI-related benefits. For the reason set forth below, these groups are at significant risk of losing current benefits and being denied needed treatment because of their unique medical needs, high costs and the lack of specialized benefit packages at this time.

The Waiver waives numerous provisions of the Medicaid Act, including, among others, reasonable promptness; amount, duration, and scope; statewideness; comparability; freedom of choice; and various eligibility criteria. While many other states have submitted and obtained waivers that modify certain of these provisions, a waiver of reasonable promptness is rare, if not unique. This waiver allows the state to deny medical assistance, other than emergency treatment, to any recipient who does not chose a reform plan or is not automatically enrolled in a plan. Thus, a recipient is forced to sacrifice all Medicaid benefits -- other than emergency services -- unless and until she is enrolled in the new program. It also permits the State to totally deny necessary care once a cap on inpatient days or total expenditures is reached. *See* section IV(C), *infra*. These constraints are particularly onerous for those persons with disabilities who will have difficulty selecting an appropriate plan in a timely manner (see section VII, *infra*), and/or are likely to exceed the cap. If that occurs, they will be at grave risk if their benefits -- like psychiatric medication, inpatient treatment, or medical equipment, are drastically limited or totally suspended.

IV. The Benefit Design

Ironically, the most serious problems with the Waiver for persons with disabilities are its key features: (1) restrictions in the treatment and services available that will result from allowing plans the flexibility to set limits on the amount, duration, and scope of services offered; and (2) the uncertainties and risks of tiered care (comprehensive and catastrophic); and (3) the maximum benefit level set for all persons and all treatment.³

A. Flexibility in Benefit Design

Flexibility in benefit design is a central element of the Waiver. The flexibility is achieved by allowing plans to tailor services, allegedly to reflect local needs and provider capacity, which traditionally benefits larger, less needy populations. The Waiver allows plans to tailor (limit) mandatory services that otherwise must be provided to all recipients when medically necessary, and to eliminate altogether, or offer any combination of, optional

³ Whether extended benefits (incentives for healthy behavior) will have any impact or utility for most recipients is speculative. It appears likely that most persons with disabilities will not qualify for or benefit from most extended benefits, like child immunizations, exercise, or smoking cessation programs.

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services. Unfortunately, flexibility by private insurers and managed care plans tends to discriminate against certain disabling conditions, and particularly psychiatric disabilities, in benefit design, service options, and access restrictions. This tendency is aggravated by the fiscal reality that private insurers and managed care plans do not pay the cost of long term care, including institutionalization, thereby eliminating all incentives to cover critically important but potentially expensive preventive services, like Assertive Community Treatment (ACT teams), psychosocial rehabilitation, intensive home-based services, intensive case management, other forms of home-based supports, and innovative durable medical equipment. As a result, persons with disabilities may have a limited array of services that create an increased risk of institutionalization. Ironically, the State will incur the cost of institutionalizing individuals with disabilities, which typically is greater than the cost of preventive home-based services.

The Waiver's two key safeguards to ensure that this flexibility does not result in a significant reduction of benefits are sufficiency and equivalency. Plans must demonstrate that they offer a sufficient array of benefits to meet the needs of members, and also must demonstrate that the plan's benefit package is equivalent to that currently provided by the Medicaid program. But there is little guidance, criteria, or analysis of how the state will measure sufficiency and equivalency. For instance, it appears that both comparisons are based upon historical fee-for-service expenditures, which presumably would not include various specialty waiver costs, such as targeted case management, or non-Medicaid costs, such as inpatient IMD days. Thus, it is impossible to determine if these alleged safeguards will be effective in constraining restrictive modifications of the current Medicaid benefit or unreasonable limitations on the amount, duration, and scope of medical assistance. What is clear is that both safeguards are based upon the average member in the target population, as well as total expenditures for the entire population, without any method to ensure that the most needy – and consequently the most expensive – members will receive equivalent and sufficient services. If sufficiency and equivalency are determined by the average member and average cost of serving Medicaid recipients, these alleged safeguards will be of little relevance to high end users of medical care, like many people with disabilities. Moreover, the sufficiency standard is based upon an arbitrarily determined and undefined percentage of the total benefit package currently provided to recipients. Therefore, there is no meaningful assurance that persons with the most challenging and complex disabilities will continue to receive all medically necessary care.

Flexibility supposedly will allow plans to design specialized benefits for specialized populations.⁴ The Waiver envisions that any specialized benefit packages will take several

⁴ Specialized benefit packages are particularly critical to smaller, higher need populations, like many types of profound or long-term disabilities. In recognition of this reality, the Legislature required

years to develop. There are no incentives to develop such specialized packages and no strategy to facilitate their adoption. In fact, the most effective strategy to date – behavioral health carve-outs – is not even mentioned, and, by omission, disfavored. Instead, the Waiver relies on market forces and competition to generate specialized benefit designs. For persons with severe disabilities, these factors tend to operate in precisely the wrong direction.

Given the high cost of serving many persons with disabilities, the unique needs (low incidence interventions) of discrete disability groups (HIV, persons with long term psychiatric conditions, dually diagnosed individuals, persons with mental retardation and medical conditions), and the lack of incentives to develop specialized benefit packages for disability populations, there is little likelihood that the flexibility in the Waiver will benefit persons with disabilities. There is little market competition for these clients and little reason to develop specialized benefit designs. While the Waiver may encourage plans to meet the needs of the vast majority of Medicaid recipients, persons with severe, chronic, or multiple disabilities are likely to be in minority.

B. Tiered Benefits: Comprehensive and Catastrophic Care

The Waiver is vague and unclear about how the two key categories (comprehensive and catastrophic) will be calculated and what happens when a recipient shifts into the latter. Although the Waiver claims this will be invisible to the recipient, plans will not be required to cover catastrophic care; in fact, the Waiver envisions that most will not. As a result, many recipients presumably will have to go (if they are able to) out of network to receive this care. Where and how they do this is a bit of a mystery. Similarly, how the state -- which will be responsible for funding catastrophic care -- will arrange this care, guarantee its adequacy, and ensure timely access to providers is never mentioned.⁵ But it is undeniable that the distinction between comprehensive (most health expenditures) and catastrophic (the most expensive users and treatments) will primarily impact persons with disabilities and others with chronic or unusual conditions. This is decidedly true for persons with severe psychiatric disabilities or chronic serious illnesses, many of whom will exceed the inpatient

that specialized plans or benefits be developed for certain special populations (children with serious medical conditions, children in foster care, persons with developmental disabilities). But the Waiver envisions this will not happen until Phase III (2009), has virtually no description of how this will occur, and contains no incentives or even descriptions of how to make this happen.

⁵ Since this level of care will be provided and compensated by entities other than the plan, it is critical to understand the methods for accessing, managing, coordinating, and compensating this level of care. It is difficult to evaluate either the adequacy or the cost-neutrality of the Waiver in the absence of this information.

bed threshold of forty-five days. Moreover, local and national data suggests that these individuals, and their associated medical expenditures, are significantly greater than the 10% projected in the Waiver.

C. Maximum Benefit Level

The maximum benefit level is the element of the Waiver that transforms Medicaid from an entitlement program to a capped expenditure private health plan. Since it is also a key element to ensuring cost neutrality and achieving the program's purpose of controlling expenditures, it is potentially the most important to the state and most dangerous for recipients. Nevertheless, it is completely undefined, and not even linked to a discernible standard. The Waiver does not describe how it is determined, how the dollar limit intersects with the bed limit, how care is accessed and managed when it is exceeded, and, perhaps most importantly, how care is ensured once the maximum level is exceeded.

The Waiver simply notes, without more, that the state will establish this level, and that once it is reached, further care will be provided through the uncompensated care pool. But this pool primarily is delivered through hospitals. This could well result in the wholesale denial of most outpatient medical care, mental health treatment, durable medical equipment, personal care assistance, and other community services and supports, other than inpatient treatment. In effect, the maximum benefit level either will result in institutionalization or denial of care for most persons with disabilities, as is currently the case in many private insurance programs when total benefit caps are reached. Moreover, the maximum benefit is likely to disproportionately impact persons with disabilities and others with chronic or unusual conditions. How, where, and most importantly, whether recipients will obtain needed care when the maximum level is reached is entirely unaddressed.

V. The Service Delivery System

All plans that meet very minimal standards will be allowed to participate.⁶ The Waiver envisions that choice and marketplace competition, rather than state standards and oversight, will be the primary determinants of quality and effectiveness. This clearly advantages large plans and core populations. There is little incentive to develop specialty networks or providers. This clearly disadvantages small or boutique plans and special populations.

⁶ For instance, there are no minimal travel distance or time standards for ensuring accessible treatment, which is critical issue in providing meaningful services for persons with mobility or psychiatric impairments.

The Waiver suggests that premiums will be risk-adjusted to reflect actual costs and potential utilization. It is unclear if the adjustment is specific to each recipient, to categories of recipients, or to each plan. If the former, this seems like a huge bureaucratic undertaking that is almost impossible to do reliably and promptly for every recipient. Even the Waiver acknowledges that it is not possible to do individualized adjustments at the present time. If the latter, this is likely to have little impact on the inequity, unless an entire plan focuses on a special population of disability group. While many states have adopted the middle alternative (risk categories or populations), the Waiver does not appear to adopt this approach, or, at the very least, does not describe how it would be operationalized. Finally, the risk adjustment process does not include certain critical expenditures, such as hospitalization in an IMD, thereby further undermining the reliability of this methodology.

As noted above, a significant portion of Medicaid expenditures has increasingly been spent on a relatively small portion of recipients who have high costs. This phenomenon particularly affects persons with disabilities, persons with serious and chronic conditions, and the institutionalized elderly. Choice and marketplace factors have traditionally disadvantaged and constrained health care for the most needy populations, including persons with disabilities. Managed care and traditional health care delivery systems shun persons with disabilities and other high cost users because standard premiums rarely are sufficient to serve these individuals. While risk-adjusted premiums can reflect the high needs and costs of these special populations, they rarely allow as generous and broad coverage as publicly-financed programs like Medicaid or VA care. There are no incentives or even factors to make it likely that the open competition and the premium-based structure of this reform initiative will provide adequate coverage for these special populations.

VI. Cost Neutrality

The cost neutrality calculations are based entirely on the statewide, full implementation of the reform initiative. It is unclear what is the fiscal impact of gradually implementing the initiative, whether costs under the Waiver will exceed costs without the Waiver during the phase-in (probably), and how costs can or will be compared during 2006-2010. Since the enabling legislation (SB 838) specifically requires legislative approval to move beyond the two county demonstration in the first year, it is difficult to understand how CMS can evaluate the cost neutrality of the Waiver given this contingency. Conversely, if the Waiver is approved and implemented in two counties, the legislature is in a perilous position if it fails to approve the expansion to other locations. Theoretically, it could put the entire Waiver in peril, and subject Florida to recoupment of huge sums of FFP.

VII. The Alleged Opportunity for Choice

Choice is a central element of the Waiver, and a major argument for its approval. But meaningful choice appears illusive at best. First, recipients are only required to be offered a choice of two plans, or, even worse, one plan and MediPass. While some recipients in some counties may be offered more, this is not required, and is probably not likely in rural counties or areas that do not have sophisticated managed care options and provider networks.

Second, recipients must make a choice within thirty days. Given the complexity of health care plans, and the options or factors that distinguish the plans, this is an unrealistic time period for anyone to render an informed choice. If recipients do not or cannot chose a plan within thirty days, the state will make the choice for them. This "auto-enroll" process virtually eliminates any semblance of choice.

Third, the Waiver indicates that recipients may elect to forego participation in any plan and, instead, choose to join an employer-sponsored plan or opt out of Medicaid altogether. But there is no assurance that these private plans will offer even remotely adequate benefits, will avoid traditional caps on certain benefits, and will not discriminate against certain disabling conditions. At a minimum, it is clear that the private plans are not subject to Medicaid standards and provisions that can be critical to – but unknown by -- persons with disabilities. The Waiver implies that the only real and ongoing choice available to all recipients is to opt out of Medicaid. It appears that the choice process is constructed to encourage this outcome.

Finally, in addition to the constraints and fiction of choice for most recipients, selecting a plan will be especially challenging for persons with psychiatric, cognitive, and developmental disabilities. There appears to be no consideration of how to make choice meaningful, or even available, to persons with limited ability to comprehend complex issues. Choice counselors would have to be specially trained, would have to be able to meet with persons in their homes, and would have to be able to make complicated benefit options understandable to individuals with limited intellectual abilities – a challenge even for sophisticated consumers. As a result, it is doubtful that persons with disabilities will have any real choice. Conversely, it is likely that most persons with mental or emotional disabilities will have the choice of plans made for them by the state, through the auto-enroll process. Given the vague and unpredictable auto-enrollment process, most persons with mental disabilities may be placed in plans that are favored by AHCA for various reasons, from cost-efficiency to limited coverage of expensive treatment like psychiatric medication.

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VIII. Evaluation

There are several concerns with the proposed evaluation process. Most importantly, implementation of Phase II should not begin until a full assessment of Phase I is completed for each vulnerable population. AHCA should gather adequate data to assess the impact of the pilot on adults with serious mental illness, children with serious emotional disturbance, persons with significant physical disabilities, and individuals with complex medical conditions. A general, non-stratified evaluation will ignore population specific problems, particularly ones affecting recipients with severe disabilities.

The evaluation should be done by independent clinical and health care researchers, such as universities or qualified contractors. All of the evaluation objectives should include reference to the issues faced by vulnerable populations, such as persons with psychiatric and cognitive disabilities. In particular, there should be several evaluation questions concerning the number, type and effectiveness of the specialty health plans. Enrollee satisfaction measures should also be focused on specific populations, to prevent under-reporting from recipients with disabilities. Finally, the evaluation should include a study of any cost-shifting to other state/local systems that has occurred over the period of these pilots, including state and local mental health, developmental disabilities, and correctional agencies.

IX. Conclusion

The Advocacy Center, on behalf of thousands of Floridians with disabilities who will be significantly impacted by the Waiver, request that AHCA substantially revise the Waiver before submitting it to CMS, to address the concerns discussed above.

Thank you for the opportunity to provide these comments. We look forward to working with you in drafting revisions to the Waiver.

Sincerely,

Gary J. Weston

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