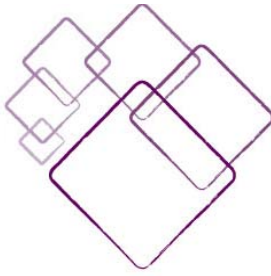


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## **Advocacy Tips for Responding to The Deficit Reduction Act of 2005**

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Training and Advocacy Support Center  
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National Disability Rights Network

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## Introduction

On February 8, 2006, President Bush signed the Deficit Reduction Act of 2005 (DRA). The legislation addresses deficit reduction across a wide range of issues, from housing and education to Medicare, Medicaid, and State Children's Health Insurance Programs (SCHIP). What is significant about the DRA of 2005 is that a large portion of the reductions in spending are attributable to provisions that make people ineligible for Medicaid or limit the benefits that are available to them through the program. This fact sheet will discuss selected major Medicaid provisions followed by specific tips for advocacy<sup>1</sup>.

## Background

The Deficit Reduction Act of 2005 moved through Congress as S. 1932. Once signed by the President, the legislation became Pub. L. No. 109-171. Legislative history for the DRA can be obtained from the Library of Congress and includes the text of the DRA; the Conference Committee Report, H. Rpt. No. 109-362; and Congressional Budget Office cost estimates. To access these resources, go to <http://thomas.loc>, and type in the bill number, S. 1932.

The Congressional Budget Office estimates that the DRA will reduce federal Medicaid spending by \$7 billion over the 2006-2010 period and \$28 billion over the 2006-2015 period<sup>2</sup>. The CBO estimates that 75 percent of the savings are due to provisions that make it more difficult for individuals to qualify for long term care, allow states to impose heightened cost sharing, permit states to restrict benefit packages, and require recipients to prove their citizenship using specified documentation. *Id.*

In addition, there is some question whether the DRA of 2005 is valid legislation. At least three lawsuits challenge the DRA as unconstitutional: *Zeigler v. Gonzales*, No. 1:06-CV-00080 (S.D. Ala. filed Feb. 13, 2006) (focusing on Medicaid transfer of asset provisions); *Public Citizen v. Clerk*, No. 1:06-cv-00523-JDB (D.D.C. filed March 21, 2006) (focusing on increased filing fees for federal district court); and the ongoing *Cookeville Regional Med. Ctr. v. Thompson*, No. Civ. A. 04-1053 JR (D.D.C.), *same case* 2005 WL 3276219 (D.D.C. Oct. 28, 2005) (focusing on Medicare disproportionate hospital provisions).

The plaintiffs in these cases point out that the version of the DRA passed by the House on February 1, 2006 differs from the version passed by the Senate on December 21, 2005 and signed by the President. *Compare* 151 Cong. Rec. S14346-47 (Dec. 21, 2005) *and* S. 1932 (stating that Medicare will pay for 13 months rental for certain types of durable medical equipment) *with* 151 Cong. Rec. H77 (Feb. 1, 2006) (stating that Medicare will pay for 36

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<sup>1</sup> The National Health Law Program and National Senior Citizens Law Center are publishing an in-depth assessment of all of the DRA's provisions on Medicaid, SCHIP, and health-related Katrina relief. The assessment will be available on our website, <http://www.healthlaw.org>, and in our quarterly magazine, *Health Advocate*.

<sup>2</sup> Congressional Budget Office, *Additional Information on CBO's Estimate for the Medicaid Provisions in the Conference Agreement for S. 1932, The Deficit Reduction Act of 2005* at 1 (Jan. 27, 2006).

months of medical equipment rental). They argue that, under Article I, section 7 of the U.S. Constitution, legislation becomes law only after it is passed in the same version by both the House and the Senate (the Bicameral requirement) and only after the same version passed by both chambers is signed by the President (the Presentment requirement).

## **The Medicaid provisions and implications for advocacy**

The DRA addresses numerous Medicaid topics, amending and adding provisions regarding, among other things, transfers of assets, provider-based taxes, outpatient prescription drug coverage, scope of benefits, cost sharing, home and community-based care waivers, documentation of U.S. citizenship, transportation, and case management. This fact sheet discusses the following:

- (1) cost sharing options (page 3)
- (2) benefit packages (page 9)
- (3) case management (page 14)
- (4) citizenship documentation (page 16)
- (5) the Family Opportunity Act (page 20) and
- (5) selected home and community-based care provisions (page 22).

As will become clear, many of the DRA provisions create *options* for states. For the most part, the options are elected through state plan amendments, as opposed to waiver programs. Thus, advocates in states considering these options will need to monitor developments closely and become familiar with how to participate in the state plan amendment process, which has no formal mechanism for consumer input<sup>3</sup>.

### **I. Premiums and Cost Sharing**

#### *a. Pre-DRA law*

The Medicaid Act already allows states to impose cost sharing on Medicaid beneficiaries. However, because cost sharing has been shown to cause beneficiaries to go without needed care, the Act has been fairly prescriptive.

Thus, with limited exceptions, the Act has prohibited: enrollment fees, premiums, or similar charges on categorically needy recipients, such as poverty-level children, recipients of SSI, and Qualified Medicare Beneficiaries. *See* 42 U.S.C. § 1396o(a). **Prior to the DRA, the limited exceptions included:**

- Congress has given states more flexibility to impose monthly premiums on individuals whose incomes exceed 150 percent of the federal poverty level (FPL) including qualified disabled and working individuals, employed individuals with a

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<sup>3</sup> The National Health Law Program's April Q&A, prepared for the Training and Advocacy Support Center will address the state plan amendment process. Posted at [www.ndrn.org](http://www.ndrn.org) under TASC – disability rights info.

medically improved disability, and individuals between the ages of 16 and 65 who would be receiving SSI except for excess earnings.<sup>4</sup> *See Id.* at §§ 1396o(c), (d), (g).

- Premiums and similar charges can also be imposed on non-categorical groups, such as the medically needy. *Id.* at § 1396o(b).
- States could also impose “nominal” copayments, defined by regulation and currently set between \$.50-\$3.00 depending on the cost of the underlying Medicaid service. Some groups and services have been excluded from copayments: services furnished to children under age 19 (at state option, under age 21 or 20), pregnancy-related services furnished to pregnant women (at state option, any services furnished to pregnant women), services furnished to institutionalized individuals with only a personal care allowance, emergency services, family planning services and supplies, and hospice services. *See Id.* §§ 1396o(a), 1396o(b); 42 C.F.R. § 447.54.
- Medicaid participating providers have been prohibited from denying care because of the individual’s inability to pay a copayment; however, the unpaid copayment amount could remain the legal liability of the individual to pay. *See Id.* § 1396o(e). This latter provision has recently been enforced by a number of courts. *See, e.g., Beeker v. Olszewski*, 2006 WL 334565 (E.D. Mich. Feb. 13, 2006); *Grier v. Goetz*, 402 F. Supp. 2d 876, 920 (M.D. Tenn 2005); *Newton-Nations v. Rodgers*, 316 F. Supp. 2d 883 (D. Ariz. 2005); *Spry v. Thompson*, 2004 WL 1146543 (D. Or. May 20, 2004); *Dahl v. Goodno*, No. C9-04-7537 (Ramsey Co. Minn. Dist. Ct. Aug. 15, 2005).<sup>5</sup>
- The Medicaid Act has allowed states to obtain a waiver from the Secretary of Health and Human Services (HHS) to charge up to twice the nominal amount when a beneficiary uses a hospital emergency room for non-emergency services. To obtain such a waiver, the state needed to establish that there are available and accessible alternative sources of non-emergency outpatient services. *See* 42 U.S.C. §§ 1396o(a)(3), 1396o(b)(3). If a state wanted to impose copayments that differed from the rules described above, it needed to meet tightly circumscribed requirements and obtain a waiver from the Secretary of HHS. *See Id.* § 1396o(f).

#### *b. Cost sharing options under the DRA*

The DRA of 2005 adds an entirely new section to the Medicaid Act, 42 U.S.C. § 1396oA that vastly expands the states’ options to impose cost sharing on Medicaid beneficiaries. *See* DRA, § 6041. This new provision leaves the existing premium and cost

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<sup>4</sup> The federal poverty level is \$9800 for an individual and \$13,200 for a couple.

<sup>5</sup> For additional background, *see* Jane Perkins, *February NAPAS [NDRN] Training and Advocacy Support Center Question and Answer* (Feb. 23, 2004).

sharing provision, § 1396o, on the books untouched, but, in effect, largely repealed. Children, the elderly, and persons with disabilities are all affected by the change.

The DRA allows states to increase beneficiary cost sharing generally and establishes separate options for prescription drugs and non-emergency use of the emergency room. These DRA provisions became effective on March 31, 2006, except for the emergency room provisions, which are effective on January 1, 2007.

*c. Services in general under the DRA*

The following tables summarize the options states now have to impose enrollment fees (e.g. premiums) and cost sharing (e.g. copayments). Keep in mind that *comparability is not required*: Through a state plan amendment, a state can impose premiums and copayments on any group of individuals and for any type of service and may vary such premiums and copayments among such groups or services, consistent with the limitations imposed by the DRA.

**Chart 1: DRA Maximums (other than Rx and ER)**

Income: < 100% of FPL cost sharing—not addressed*	No premiums
Income: 100%-150% of FPL Cost sharing, up to 10% of the service cost (option) family income	No premiums Capped at 5% of quarterly or monthly (at state option)
Income: >150% of FPL Cost sharing, up to 20% of the service cost (option) family income	Premiums allowed <i>Total</i> premiums and cost sharing capped at 5% of quarterly or monthly (at state option)

\* Section 1396oA is silent regarding limits on cost sharing for beneficiaries with incomes below the FPL. There has been some concern that this might authorize copayments *without limit*. Hopefully, this issue will be addressed in an upcoming guidance from CMS. Two congressional leaders have written to CMS to “reinforce Congressional intent” that the DRA “authority to change cost sharing does not apply to any beneficiary below 100% of FPL.” Letter from Charles Grassley, Chairman, Senate Committee on Finance, and Joe Barton, Chairman, House Committee on Energy and Commerce, to Honorable Michael O. Leavitt, Secretary, DHHS (Mar. 29, 2006).

### Chart 2: DRA cost sharing exclusions-premiums

States **cannot** impose **premiums** on:

- Children in mandatory coverage categories under age 18, including children in foster care/adoption assistance
- Persons in institutions who have only a personal needs allowance
- Women in treatment for breast or cervical cancer
- Pregnant women
- Terminally ill individuals receiving hospice care

### Chart 3: DRA cost sharing exclusions-cost sharing (copayments)

States **cannot** impose **cost sharing** on:

- Services for children in mandatory coverage categories under age 18, including children in foster care/adoption assistance
- Preventive services provided to children under age 18, regardless of family income
- Persons in institutions who have only a personal needs allowance
- Women in treatment for breast or cervical cancer
- Pregnancy-related services for pregnant women
- Services for terminally ill individuals receiving hospice care
- Emergency services
- Family planning services

Another huge change is that *States can now permit Medicaid-participating health care providers to condition the provision of care, items or services upon the payment of the cost sharing amount.*

#### *d. Prescription drugs under the DRA*

The DRA seeks to “encourage beneficiaries to use drugs ... identified by the State as the least (or less) costly effective drug.” *See* DRA, § 6042 (adding 42 U.S.C. § 1396oA(c)).

Separate copayment rules can apply to prescription drugs. *See* DRA, § 6042 (adding 42 U.S.C. § 1396oA(c)). States may select preferred and non-preferred prescription drugs, based on the cost of the drug. States can impose differing copayments based on the status of the drug and the poverty level status of the individual recipient, as shown by the following table:

#### Chart 4: DRA Cost sharing (copayments) – RX

##### Cost sharing limits for **non-preferred drugs**:

- Income < 150% of FPL: nominal cost sharing (currently \$3.00), subject to the 5% family income cap (see Chart 1)
- Income > 150% of the FPL: 20% of the cost of the drug, subject to the 5% family income cap (see Chart 1)
- Beneficiaries otherwise exempt: nominal cost sharing

##### Cost sharing limits for **preferred drugs**:

- State may waive or reduce the cost sharing
- State must exempt groups/services otherwise exempt

##### **Waiver process:**

- State must apply preferred drug cost sharing to a non-preferred drug if the prescribing doctor determines that preferred drug would not be as effective or would have adverse effects for the individual.

#### *e. Non-emergency use of the emergency room*

Separate rules authorize states to permit hospitals to impose cost sharing for non-emergency use of the emergency room (as determined by the ER doctors), if: (1) the individual is informed of the name and location of an actually available and accessible alternative that charges only a nominal copay; (2) the hospital refers the individual to the alternative; and (3) the hospital informs the individual of its copayment requirement. There are, however, limits for some individuals:

- Persons otherwise exempt from copayments can only be charged a nominal copayment (currently \$3.00).
- Persons with incomes from 100%-150% of FPL can be charged twice the nominal amount (currently \$6.00), up to 5% of family income.
- Note: No limits are placed on copayments for individuals with incomes *below* the FPL.

DRA, § 6043 (adding 42 U.S.C. § 1396oA(e)). A separate provision authorizes the Secretary of HHS to make payments to states for establishment of alternative non-emergency providers. The total amount of payments is limited to \$50 million during the 4-year period beginning with 2006. In providing these payments, the Secretary is to give preference to States that establish, or provide for, alternatives in rural or underserved areas or in partnership with local community hospitals. *Id.* (adding 42 U.S.C. § 1396b(y)).

The allowable “nominal” cost sharing under the current § 1396o and under the DRA’s provisions regarding prescription drugs and non-emergency room use must be adjusted annually by the Secretary of HHS. Specifically, the DRA requires the Secretary to increase the “nominal” cost sharing each year by the increase in the Medicaid Consumer Price Index (which is about double the overall consumer price index increase). DRA, § 6041(b) (adding § 1396oA(h)). Thus, the states will be able to increase maximum cost sharing annually on the affected services.

*f. Implications for advocacy related to cost sharing*

The DRA provisions are, for the most part, optional for states. Thus, advocates must monitor the situation closely and participate in any activity related to the imposition of cost sharing. Advocates should be ready to address the following:

1. *The effects of cost sharing.* It is not clear why Congress targeted this provision at beneficiaries, rather than to managed care companies and/or physicians, who are actually trained to and do control prescribing practices. Cost sharing is perhaps the most studied aspect of the Medicaid program, and a redundant body of research concludes that even small copayments and other forms of cost sharing can cause low income people to forego necessary health care or, in the case of premiums, to lose Medicaid eligibility altogether<sup>6</sup>. State officials considering premiums and copayments should be provided fact sheets and other information that discuss this literature. *See, e.g.,* Manju Kulkarni, National Health Law Program, *Q&A on Medicaid Cost-Sharing Requirements* (Apr. 2004), at <http://www.healthlaw.org>.

2. *Details of the cost sharing.* In a state that decides to impose premiums and/or cost sharing as a way to reduce eligibility and cut services, advocates must work to soften the blow to beneficiaries. The DRA provisions offer numerous options that can have extremely harmful effects on beneficiaries and applicants. For example,

- The DRA is silent with respect to the copayments that can be imposed on non-exempt individuals with incomes *below* the federal poverty level, including people with disabilities. Some advocates have expressed concern that states will want to use the provision to charge these individuals any size copayment the state chooses, not subject to any total limits. As noted above, however, Senator Grassley and Representative Barton, whose committees crafted the DRA, have notified CMS this was not Congress’ intent, stating: “Congress should not be presumed to have intended to have made so fundamental a change to the Medicaid program as allowing the imposition of unlimited cost sharing on the lowest income Medicaid beneficiaries while imposing clear limits on higher income beneficiaries, without expressly providing States with that authority in the legislative language.” *See* Letter from Charles Grassley, Chairman, Senate Committee on Finance, and Joe Barton, Chairman, House Committee on Energy and

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<sup>6</sup> *See, e.g.,* Leighton Ku and Victoria Wachino, *The Effect of Increased Cost Sharing in Medicaid: A Summary of Research Findings* (July 7, 2005), at <http://www.cbpp.org/5-31-05health2.htm>; Samantha Artiga & Molly O’Malley, *Increasing Premiums and Cost sharing in Medicaid and SCHIP: Recent State Experiences* (May 2005), at <http://www.kff.org/medicaid/7322.cfm>.

Commerce, to Honorable Michael O. Leavitt, Secretary, DHHS (Mar. 29, 2006). Guidance from CMS should be anticipated.

- The DRA authorizes each state to select its own definition of “family income” for cost sharing/premium purposes, including any disregards. Advocate for maximization of what can be disregarded.
- A state can allow health care providers to deny care, items and services to individual Medicaid beneficiaries—including those who have an inability to pay the copayment amount. Implementation of this provision by the state Medicaid agency and by individual health care providers will need to be watched closely. Based on NHeLP’s prior technical support, this option appears to be of particular interest with respect to pharmacy services.
- A state can decide to cut beneficiaries off of Medicaid for failing to pay a premium (if it has been unpaid for at least 60 days) and may waive the premium in a case of “undue hardship,” a phrase not defined in the statute. Advocate for states not to take advantage of this; but if they, to do use a low threshold for “undue hardship.”
- It could also be important that the special prescription drug provisions do *not* require the drug to be the “least costly, *equally* effective drug.” Advocates should ask the state to clarify in its plan amendment that “equally effective” be the standard used and that the state will not require prior authorization.

3. *Emergency room copayments and EMTALA.* The Emergency Medical Treatment and Active Labor Act (EMTALA) is a non-discrimination statute that requires each Medicare-participating hospital with an emergency room to provide an appropriate medical screening examination for any individual who comes to the ER and requests treatment or examination for a medical condition. *See* 42 U.S.C. § 1396dd(a). EMTALA prohibits hospitals from delaying the screening to inquire about the individual’s method of payment or insurance status. *Id.* at § 1395dd(h).

Unfortunately, the interplay between EMTALA and the DRA’s copayment provisions is not entirely clear. The DRA requires the hospital to inform the beneficiary of the hospital’s non-emergency room copayment policies *after* the individual receives an appropriate medical screening examination under EMTALA and *after* the determination is made that there is not an emergency. However, the DRA then defines the term “non-emergency service” to mean “any care or services furnished in an emergency department of a hospital that the *physician determines do not constitute an appropriate medical screening examination ... as required to be provided by the hospital under [EMTALA].*” DRA, § 6043 (adding 42 U.S.C. § 1396oA(e)(4) (Emphasis added). This definition could be read to authorize a physician to use her own determination of whether an emergency exists, rather than apply the hospital’s routine emergency examination protocol. The provision could also be read to authorize the physician to make that determination *before* the medical screening examination required under EMTALA is provided. While it is true that the DRA provides that the cost sharing provision is not to be construed to limit a hospital’s obligation under the EMTALA statute, important aspects of

EMTALA have been defined, not by statute, but by court cases. This includes what is an “appropriate” medical screening examination. There is the potential, then, that these requirements could change. Advocates should encourage states to clearly incorporate existing EMTALA screening requirements into any plan amendment.

4. *Slice and dice.* By eliminating the comparability requirement, the DRA allows states to carve up Medicaid populations into segments and either impose or exempt these segments from cost sharing. Advocates should make sure that the distribution of benefits using cost sharing does not become attached to the perceived worthiness of the beneficiary involved.

5. *Alternative provider funds.* Any state exercising the emergency room cost sharing option should be encouraged to take advantage of the DRA provision authorizing the Secretary of HHS to make payments to states for establishment of alternative non-emergency providers. The total amount of payments is limited to \$50 million during the 4-year period beginning with 2006. In providing these payments, the Secretary is to give preference to States that establish, or provide for, alternatives in rural or underserved areas or in partnership with local community hospitals.

## **II. Benefit Packages**

### *a. Pre-DRA law*

The Medicaid Act has required states to cover certain services and allowed states the option to cover others.

- Examples of mandatory Medicaid services for categorically needy recipients are: inpatient hospital services, physician services, nursing facility services, rural health clinic and federal qualified health center services, and Early and Periodic Screening, Diagnosis and Treatment (EPSDT) services. *See* 42 U.S.C. §§ 1396a(a)(10), 1396d(a).
- Optional Medicaid services for adults include prescription drugs, dental services, private duty nursing services, personal care services, and physical therapy. *Id.*
- States can offer a smaller set of services to individuals eligible through a medically needy program, but must include prenatal care and delivery, ambulatory services for children under age 18 and individuals entitled to institutional services, and home health services for those entitled to nursing facility care. *See Id.* § 1396a(a)(10)(C).

Although Congress defined the package of benefits, it did not explicitly set the minimum level of each service to be provided. The Medicaid rules have required states to assure that services are “sufficient in amount, duration, and scope to reasonably achieve their purpose.” *See Id.* at § 1396a(a)(10)(B); 42 C.F.R. § 440.230(b). Covered services (both mandatory and optional) must be offered to all beneficiaries statewide, 42 U.S.C. § 1396a(a)(1), and be comparable among eligibility groups, *id.* at § 1396a(a)(10)(B). For example, a state covering physical therapy must assure that the service is available statewide and covered in an equal amount, duration and scope for all categorically needy recipients.

Different rules apply to children and youth under age 21. EPSDT requires states to cover periodic and as-needed medical, vision, hearing and dental screening. EPSDT also requires states to cover any Medicaid service, whether mandatory or optional (*see* § 1396d(a) listing), if the service is needed to “correct or ameliorate” a child’s physical or mental condition. *See Id.* §§ 1396a(a)(10)(A), 1396a(a)(43), 1396d(a)(4)(B), 1396d(r). Thus, using the example above, a state could not limit a child to 12 physical therapy visits if additional therapy were needed to correct or ameliorate the child’s condition.

### *b. Benefit Packages under the DRA*

The DRA gives states the option to provide Medicaid to state-specified groups through enrollment in pre-existing health insurance plans. DRA, § 6044. In so doing, the state can ignore Medicaid’s traditional rules requiring coverage of mandatory and optional services, statewideness, freedom of choice, and comparability. The provision is effective March 31, 2006. According to CMS, state plan amendments submitted by June 30, 2006, may be approved retroactive to the first day of the quarter (April 1, 2006). *See CMS, Dear State Medicaid Director* (Mar. 31, 2006) (SMDL #06-008) (on file with author).

States are prohibited from requiring individuals to obtain benefits through this option if they are eligible for Medicaid because they are:

- pregnant women with incomes at or below 133 percent of the FPL,
- individuals who qualify under the state plan because they are blind or disabled without regard to whether the individual is eligible for SSI,
- dually eligible Medicare/Medicaid beneficiaries,
- terminally ill hospice patients,
- individuals eligible on the basis of institutionalization and receiving only a personal needs allowance,
- medically frail and special medical needs individuals, to be defined by the Secretary of HHS in regulations. In a March 31st letter, the Secretary designated these individuals as those groups defined in the managed care regulation, 42 C.F.R. §§ 438.50(d)(1) (dual eligibles) and (d)(3) (children under age 19 who are eligible for SSI, TEFRA children, or receiving care through a family-centered, community care system under title V), *id.*,
- beneficiaries qualifying for long term care services,
- children in foster care and receiving foster or adoption assistance,
- TANF and section 1931 parents,<sup>7</sup>

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<sup>7</sup> The provision apparently intends to exclude TANF and section 1931 parents from mandatory enrollment. However, it refers to individuals “who qualify for medical assistance on the basis of eligibility to receive assistance under a State plan funded under part A of title IV (as in effect *on or after* the welfare reform effective date ... [July 16, 1996].” DRA. § 6044 (Emphasis added). After July 16, 1996, AFDC was replaced by TANF in title IV-A, and no one automatically qualifies for Medicaid on the basis of title IV-A eligibility. *Cf.* 42 U.S.C. § 1396u-1 (treating individuals as automatically eligible for Medicaid if they meet the IV-A requirements in effect *as of* July 16, 1996). The CMS letter of March 31st exempts parents

- women receiving treatment for breast and cervical cancer,
- individuals who qualify due to TB-infection,
- non-qualified aliens receiving care for an emergency medical condition,
- medically needy.

See DRA, § 6044(a); CMS, *Dear State Medicaid Director* (Mar. 31, 2006) (SMDL #06-008). In addition, states can only exercise the option for an individual eligible under an eligibility category that had been established under the state plan on or before February 8, 2006 (the date of enactment of the provision)

Thus, mandatory enrollment is designed to have less effect on people with disabilities. However, mandatory enrollment will affect mostly children, working parents, and pregnant women with incomes over 133 percent of the FPL. These populations must have “access” to services provided by rural health and federally qualified health centers. It is not clear whether states will be required to maintain access to all such clinics or whether they can assure access by contracting with one or only a few clinics.

Section 6044 allows states to provide coverage to state-selected population groups through one or more “benchmark” or “benchmark equivalent” plans. The benchmark plans are: (1) the standard Blue Cross Blue Shield preferred provider option under the Federal Employee Health Benefit Plan, (2) the HMO plan with the largest commercial, non-Medicaid enrollment in the state; (3) any generally-available state employee plan (regardless of whether any state employees select the plan); and (3) any plan that the Secretary of HHS determines to be appropriate. To be considered benchmark-equivalent, the coverage must include inpatient and outpatient hospital services, physician services, laboratory and x-ray services, well baby and child care (including immunizations), and “other appropriate preventive services” designated by the Secretary of HHS. See DRA, § 6044. Thus, it is possible for services such as prescription drugs, dental, mental health, vision and hearing services to be excluded.

### *c. Implications for advocacy regarding benefit packages*

While many currently-eligible Medicaid recipients are exempt from mandatory participation in this option, advocates for individuals with disabilities will still want to pay close attention to whether and how their state implements § 6044.

*1. Determining eligible populations.* An individual is excluded from mandatory participation in this option according to the basis of their eligibility. Many individuals are eligible for Medicaid under more than one category. In states exercising this option, Medicaid applicants will want to select their eligibility category carefully if they want to avoid mandatory enrollment in a benchmark plan. See 42 C.F.R. § 435.404.

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who qualify for Medicaid “solely on the basis of qualification under the State’s TANF rules (e.g., the State links Medicaid eligibility to TANF eligibility).” However, parents cannot qualify for Medicaid solely on the basis of TANF. Thus, in practice, no one will qualify for the exemption from mandatory enrollment.

In addition, while the DRA prohibits states from requiring many populations from participating, it does not prohibit a state from offering voluntary enrollment in the option to otherwise excluded populations. So, activity in this area should be monitored. In recent years, there have been instances in the managed care context where states have sought to offer people with disabilities “voluntary” enrollment in a plan by enrolling them in the plan and then allowing them to select out. This type of process can be confusing to people with disabilities and disruptive of their care. Advocates should make sure that states exercising DRA benefit flexibility do so using systems that do not confuse or disrupt patient care.

Notably, the Secretary of HHS included language in the March 31st letter that appears to sanction such “voluntary” enrollment. In the letter, the Secretary requires states offering an individual the option to enroll in an alternative benefit package to: (1) inform the individuals that enrollment is voluntary and that the individual may opt out of the coverage at any time and regain immediate eligibility for the regular Medicaid program; (2) inform the individual of the benefits available under the alternative package and provide a comparison with regular Medicaid; and (3) document in the individual’s file that the individual was properly informed and voluntarily chose to enroll in the alternative benefit package. CMS, *Dear State Medicaid Director* (Mar. 31, 2006) (SMDL #06-008).

2. *Monitoring the limits placed on benefits.* If your state elects this option, it will result in a more limited benefit package, so the details will be important. Advocates should monitor not only the potential scope of benefits but also the delivery systems being considered (e.g. managed care, fee-for-service, vouchers). Notably, two of the benchmark options—a state employee plan generally available but not necessarily used and plans approved by the Secretary of HHS—lack facial standards and, thus, will raise additional questions. Moreover, it does not appear from the face of section 6044 that states will be required to apply the Medicaid Act’s managed care consumer protections (e.g. actuarial soundness). Thus, separate rules to mandate consumer protection and plan accountability may be needed.

3. *The effect on EPSDT.* There has been some confusion about how the provision affects EPSDT. No doubt, the provision could have been more artfully drafted. However, regardless of the benchmark selected, the DRA clearly provides that a state will provide “for any child under 19 years of age who is covered under section 1396a(a)(10)(A) [categorically needy coverage], *wrap-around benefits* to the benchmark coverage or benchmark equivalent coverage *consisting of early and periodic screening, diagnostic, and treatment services* defined in section 1905r [42 U.S.C. § 1396d(r)].” DRA, § 6044(a) (emphasis added). While another, later provision of § 6044(a) does give states the option of providing wrap-around benefits, this more general provision will not control EPSDT. According to the rules of statutory construction, this provision would apply to groups other than children under age 19, and the under 19 group is protected by the more specifically worded EPSDT language. The Secretary of HHS has recently confirmed this reading:

Individuals under age 19 who are covered under the State plan under section 1902(a)(10)(A) of the Act must receive wrap-around benefits to the benchmark, or benchmark-equivalent plan, consisting of early and periodic screening, diagnosis, and treatment (EPSDT) services defined in section 1905r. Wrap-around benefits must be

sufficient so that, in combination with the benchmark ... package, these individuals receive the full EPSDT benefit.

CMS, *Dear State Medicaid Director* (Mar. 31, 2006) (SMDL #06-008).<sup>8</sup> See also Letter from Charles Grassley, Chairman, Senate Committee on Finance, and Joe Barton, Chairman, House Committee on Energy and Commerce, to Hon. Michael O. Leavitt, Secretary, DHHS (Mar. 29, 2006) (on file with author) (“We insist that CMS reject any state plan amendment involving benchmark ... coverage that does not also provide for wraparound EPSDT services and benefits to individuals under age 19.... Congress intended to make no change to EPSDT coverage.”). See also Dep’t of Health & Human Services, *Statement by Mark B. McClellan, M.D., Ph.D., Administrator, Centers for Medicare & Medicaid Services* (undated) (on file with author) (“Children under age 19 will receive EPSDT benefits.”); 109 Cong. Rec. H46 (Feb. 1, 2006) (Statement of Rep. Joe Barton, R-TX, Chairman of the Committee on Energy and Commerce) (section 6044 “language reflects the clear legislative intent by both the House and Senate that all children should continue to receive access to coverage of early and periodic screening, diagnostic, and treatment services (“EPSDT”) services.... Congress clearly intended for all children under Medicaid to continue to receive EPSDT services and we will work with Administrator McClellan to ensure that all children continue to have access to these important services.”).

Nevertheless, there is cause for concern. Youth aged 19-21 can be enrolled in the benchmark coverage and, for them, the wrap-around benefit appears to be optional. The March 29, 2006 letter from the congressional leaders to the Secretary of HHS inaccurately states, “Consistent with section 1902(a)(43)(A) of the Social Security Act [42 U.S.C. § 1396a(a)(43)(A)] EPSDT remains a required benefit to all individual under the age of 19 who have been determined eligible for Medicaid and, if the state elects to provide coverage, up to the age of 21.” Letter from Charles Grassley, Chairman, Senate Committee on Finance, and Joe Barton, Chairman, House Committee on Energy and Commerce, to Hon. Michael O. Leavitt, Secretary, DHHS (Mar. 29, 2006). Section (a)(43)(A) explicitly extends EPSDT to all Medicaid-eligible persons in the state who are under age 21.

In addition, there is a great risk that services and administration between benchmark and wrap around EPSDT benefits could be uncoordinated, and advocates should work to assure clear guidelines and education regarding them. One place to look for a track record (good or bad) is how your state has coordinated the provision of services when contracting with managed care plans that do not provide the full scope of Medicaid benefits, for example carving out mental health, dental, or long term care services. Lessons learned from this past experience may inform the new debate.

4. *Recognizing a trend?* The benchmark options contained in section 6044 are the same as those provided to states for their SCHIPs. So, your state’s experiences with SCHIP contracting will be relevant. Moreover, these types of benchmark options may be applied to additional Medicaid populations in the future.

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<sup>8</sup> A State Plan Amendment pre-print that accompanied the letter required the state to assure, and describe how, EPSDT will be maintained. This pre-print has since been removed from the CMS website, and its status is unclear.

### III. Case management

#### a. *Pre-DRA law*

The Medicaid Act has defined “case management services” to mean “services which will assist individuals eligible under the plan in gaining access to needed medical, social, education, and other services.” 42 U.S.C. § 1396n(g)(2); § 1396d(a)(19). A state may target case management services to selected populations, such as people with AIDS/HIV or chronic mental illness. *See Id.* at § 1396n(g)(1).

#### b. *The DRA changes*

The DRA re-writes the Medicaid case management definition to more specifically define the services and to clarify the difference between case management and targeted case management. DRA, § 6052 (amending 42 U.S.C. § 1396n(g)(2)).

The term “case management service” includes: (1) assessment of a Medicaid-eligible individual to determine service needs (e.g. taking client history, gathering information from other sources such as family, providers, and educators), (2) development of a specific care plan, (3) referral and related activities to help the individual obtain needed services, and (4) monitoring and follow up activities, including those to insure that the service plan is effectively implemented.

Case management does *not* include the direct delivery of medical, education, social or other services to which the individual has been referred. With respect to foster care services, activities excluded from case management include, but are not limited to: research gathering and completion of paper work required by the foster care program, assessing adoption placements, recruiting or interviewing potential foster parents, serving legal papers, home investigations, providing transportation, administrating foster care subsidies, or making placement arrangements. *See* DRA, § 6052 (adding 42 U.S.C. § 1396n(g)(2)(A)(iii)).

The term “targeted case management services” means case management services that are provided to targeted populations without regard to statewideness and comparability requirements.

A newly added 42 U.S.C. § 1396n(g)(3) provides that contacts with individuals who are not eligible for Medicaid or in the case of targeted case management, with a Medicaid-eligible individual who is not in the target population, do not count as case management unless the purpose of the contact is directly related to managing the eligible individual’s care.

Finally, federal financial participation is only available for case management if there are no other third parties liable for the care, such as another medical, social, or educational program. Moreover, a state is required to allocate the cost of case management services between Medicaid and any other relevant federal program and only bill Medicaid for its portion, using an Office of Management and Budget accounting methodology.

The provision is effective January 1, 2006. The Secretary of HHS must promulgate regulations to carry out the section.

*c. Implications for advocacy*

Certain populations are particularly dependent on case management services, including children in foster care, people with mental illness or developmental, physical or sensory disabilities, and children with individualized family or educational plans. Depending on how services are provided in your county and/or state, the DRA could effect the case management of these populations.

In particular, the DRA could have an immediate, significant effect on children in the foster care system. For example, the Wisconsin Department of Health and Family Services recently notified county programs that the DRA “could be interpreted as prohibiting access to any MA [Medicaid] TCM funds for children receiving foster care services.” *See* Memorandum from Susan Reinardy, Deputy Secretary, Dep’t of Health and Family Services, to County Department (Mar. 9, 2006) (on file with author).

Moreover, the DRA’s provisions regarding federal financial participation for case management are confusing. As pointed out by the Wisconsin Medicaid officials, the DRA could be interpreted as possibly eliminating Medicaid as a funding source for case management if any other federal, state, or local funding stream includes case management as an allowable service without regarding to whether funds are actually available. Alternatively, the DRA could be interpreted to simply codify current federal policy regarding the submission of claims for federal funding. However, given that the Congressional Budget Office scored this provision as generating \$760 million in savings over five years, this could indicate the more significant change in policy. *Id.* at 2.

The DRA could also cause some confusion in households where two individuals can benefit from the same case management services but only one of them is eligible for Medicaid or where the parent plays a role in the activity (and the case management service could be labeled for the parent rather than the child).

TASC of NDRN will advise Protection & Advocacy agencies of regulations from the Secretary of HHS that address these potential areas of confusion.

#### **IV. Citizenship Documentation**

To be eligible for full Medicaid benefits, an individual must be a citizen or national of the United States or a qualified alien. *See* 42 U.S.C. § 1396 In most states, a U.S. citizen can generally attest, under penalty of perjury, to their citizenship for the purposes of establishing Medicaid eligibility. Most states’ policies require documentation of citizenship when there is any reason to question an applicant’s statement that he or she is a citizen.

*a. Documentation restrictions (§ 6036) under the DRA*

Using the potential denial of federal funding as the “stick,” the DRA requires states to document U.S. citizenship of program participants. Effective July 1, 2006, the provision applies to expenditures for new Medicaid applicants as well as current recipients (at the time of re-certification/determination).

Note: For eligibility purposes, it appears that the verification requirements of 42 U.S.C. § 1320b-7(d)(1)(A) continue to apply. *See* DRA, § 6063(a) (adding 42 U.S.C. § 1396b(i)(22)).<sup>9</sup>

The DRA provision only allows states to use certain documents to verify US citizenship:

- U.S. passport
- Certificate of Naturalization (Form N-550 or N-570)
- Certificate of U.S. Citizenship (Form N-560 or N-561)
- A valid state-issued driver’s license or identity document described in 8 U.S.C. § 274A(b)(1)(D) (Immigration and Nationality Act), *but only* if the state requires proof of U.S. citizenship prior to issuance or obtains and verifies the individual’s Social Security Number
- For individuals under age 16 or in a State which does not provide for issuance of an identification document (other than a driver’s license), documentation of personal identity of such other type as the U.S. Attorney General finds, by regulation, provides a reliable means of identification *but only* if the state requires proof of U.S. citizenship prior to issuance or obtains the individual’s Social Security Number and verifies its accuracy.
- Such other documentation as the Secretary of HHS may allow, by regulation, that provides proof of U.S. citizenship/nationality and “a reliable means of documentation of personal identity.”

DRA, § 6036 (adding 42 U.S.C. §§ 1396b(i)(22) and 1396b(x)).

If a person does not have one of the above documents, he/she must provide one document from each of the following columns:

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<sup>9</sup> The DRA adds subsection (22) to 42 U.S.C. § 1396b(i), but thereafter refers only to subsection (23), which does not exist. *See* DRA, § 6036 (adding § 1396b(x)). Also, the Conference Report discusses the provision at section 6082.

Column 1	Column 2
<ul style="list-style-type: none"> <li>• Birth certificate from U.S. birth</li> <li>• Certificate of birth abroad (Form FS-545 or DS-1350)</li> <li>• U.S. Citizen Identification Card (Form I-97)</li> <li>• Report of Birth Abroad of a Citizen of the U.S. (Form FS-240)</li> <li>• Such other document as the Secretary of HHS may specify that provides proof of citizenship or nationality</li> </ul>	<ul style="list-style-type: none"> <li>• A state driver’s license or similar identity document if it contains a photograph of the individual or identifying information found sufficient by the Attorney General, <i>but only</i> if the state requires proof of U.S. citizenship prior to issuance or obtains the individual’s Social Security Number and verifies its accuracy. <i>See</i> 8 U.S.C. 1324a(b)(1)(D); 8 C.F.R. §274a.2.</li> <li>• In the case of individuals under age 16 or in a State which does not issue identification documents (other than a driver’s license), documentation of personal identity as the Attorney General finds provides a reliable means of identification <i>but only</i> if the state requires proof of U.S. citizenship prior to issuance or obtains the individual’s Social Security Number and verifies its accuracy. <i>Id.</i></li> <li>• Other documentation specified by the Secretary of HHS that provides a reliable means of identification.</li> </ul>

Section 6036 also states that it does not apply to any “alien” eligible for Medicaid who is also:

- entitled to or enrolled for any Medicare benefits;
- receiving Medicaid because of receipt of SSI benefits; or
- eligible for Medicaid on another basis specified by the Secretary of HHS under which satisfactory proof of U.S. citizenship or nationality has been previously presented.

The reference to “alien” is inconsistent with the rest of the provision that applies to citizens and nationals. According to congressional sources, it was a drafting error and the reference should have been to citizens and nationals. Members of Congress have discussed introducing a bill to make technical fixes to address drafting errors, including this one. To date, no bill had been introduced.

Congress has required the Secretary of HHS, “as soon as practicable,” to establish an outreach program designed to educate individuals who are likely to be affected by the new requirements. DRA, § 6036(b). As the July 1 effective date approaches, no outreach program has been announced but early indications are that the Secretary may attempt to comply with this mandate by shifting responsibility for outreach to the states.

Notably, § 6036 was added to the DRA at the request of Georgia Republican Representatives Charlie Norwood and Nathan Deal who said they wanted to prevent undocumented immigrants from enrolling in Medicaid. However, a report by the HHS Office of the Inspector General found no substantial evidence that undocumented immigrants are fraudulently getting Medicaid coverage by claiming they are citizens. The report, thus, did not recommend requiring the documentation of citizenship. And, state officials interviewed for the report noted that such a requirement would add significant administrative costs and burdens, requiring the hiring of additional eligibility personnel. *See* HHS, OIG, *Self-Declaration of U.S. Citizenship for Medicaid* (July 2005), at <http://oig.hhs.gov/oei/reports/oei-02-03-00190.pdf>.

On February 16, 2006, Senator Akaka (D-Haw) and others introduced S. 2305, a bill to repeal these provisions.

*b. Implications for Advocacy regarding citizenship documentation*

1. *Enforcement.* The DRA implements the citizenship requirements through the Medicaid funding provision, 42 U.S.C. § 1396b. According to the DRA, federal financial participation will not be provided to states for individuals whose citizenship has not been properly documented. It is not clear whether these requirements can be affirmatively enforced by CMS against states or whether CMS must initiate funding denial/termination actions against non-complying states.

The requirements also create enforcement questions because they are at odds with another Medicaid provision, 42 USC § 1396b(a)(3), which states: “The Secretary ... shall not approve any plan which imposes, as a condition of eligibility for medical assistance under the plan ... (3) any citizenship requirement which excludes any citizen of the United States.” This provision is not amended or mentioned by the DRA or a draft CMS letter that, so far, has not been formally disseminated to the states. However, taken with the DRA, the provisions mean that the Secretary of HHS cannot approve a plan that excludes a citizen but will not give federal funding to a state that serves a citizen who has not produced the documentation required by the DRA.

Advocates have also raised questions with the Secretary of HHS about whether the DRA provisions are constitutional when applied to citizens who are eligible for Medicaid. The Secretary of HHS has drafted a guidance letter to states but, to date, not disseminated it.

2. *Monitor for adverse impact.* The DRA provision will likely lead to many citizens losing Medicaid eligibility or not seeking it in the first place. The Center on Budget and Policy Priorities conducted a survey to estimate the provision’s impact and found:

- About one in every twelve U.S.-born adults age 18 or older who have incomes below \$25,000 do not have a U.S. passport or U.S. birth certificate in their possession. This amounts to approximately 1.7 million U.S.-born Medicaid-eligible adults.
- More than 10 percent of U.S.-born adults with children who have incomes below \$25,000 do not have a birth certificate or passport for at least one of their

children. Between 1.4 and 2.9 million children enrolled in Medicaid likely do not have the required documentation.

*See Leighton Ku et al., Survey Indicates Deficit Reduction Act Jeopardizes Medicaid Coverage for 3 to 5 million U.S. Citizens* (Feb. 17, 2006), at <http://www.cbpp.org/1-26-06health.htm>.

Advocates must make clients aware of this provision and monitor its impact on them. Advocates may want to consider keeping their state and federal policy makers informed of the extent to which it is foreclosing eligibility for citizens.

Some populations are particularly vulnerable. Obtaining a birth certificate or passport is costly. Elderly persons and persons with disabilities who are in nursing care settings, with only a personal needs allowance, have no excess resources. A passport currently costs up to \$97.00. Copies of a birth certificate can cost from \$5 to \$23. As a result, native-born citizens poor enough to qualify for Medicaid will often be too poor to prove that they qualify for Medicaid.

The provision may also have a great impact on people with mental illness who may not be able to identify where they were born and cannot obtain a copy of their birth certificate.

Survivors of Hurricane Katrina and Rita who have lost all documentation may not be able to obtain replacement copies where county, parish and state records were also lost. It could affect foster children if Medicaid eligibility workers are not permitted access to these children's confidential, child welfare agency files.

Finally, the provision will likely have a disproportionate impact on people of color and the rural poor. For much of the 20th century, many hospitals in this country, especially in the South, would not admit African-Americans; and many other disadvantaged citizens, including Native Americans and rural Whites, simply could not afford, or did not have access to, a hospital birth (which provided a birth certificate). As a result, members of these groups were born at home and simply do not have birth certificates. For example, a 1950 study found that one in five African Americans lacked a birth registration. See Shapiro, S. "Development of Birth Registration and Birth Statistics in the United States," 4 *Population Studies* 86-111 (1950).

3. *Provide education.* Advocates should inform their clients of these provisions. In particular, clients should be made aware that the passport/documentation process can be time consuming and could result in delays in application and receipt of Medicaid if not initiated well ahead of time.

4. *Assure eligibility.* If a client needs immediate medical assistance and cannot immediately obtain the requested documents, advocates should remember that the documentation is not an eligibility requirement for the program, but merely something the state needs for purposes of federal financial participation for its expenditures. The eligibility requirement for Medicaid should remain the sworn statement of citizenship or nationality called for by 42 U.S.C. § 1320b-7(d)(1), and clients should not be denied coverage once they have provided that statement.

## V. Family Opportunity Act

### a. Current law

The Medicaid Act provides a number of options for children with disabilities to qualify. For example, children receiving SSI are automatically eligible for Medicaid in most states, as are children who qualify due to their poverty level status (regardless of disability). *See* 42 U.S.C. § 1396a(a)(10)(A)(i). The Act gives states the option to cover additional groups of children with disabilities, including non-institutionalized children (commonly called the “Katie Beckett” option). *See Id.* § 1396a(a)(10)(A)(ii). Regardless of the pathway used, the family income level must generally fall below 300 percent of the federal poverty level. *See* 109 Cong. Rec. H12724 (Conf. Rpt.).

### b. The Family Opportunity Act

The DRA creates a new state option, the Family Opportunity Act (FOA), which allows families to purchase Medicaid coverage for their children with disabilities. The DRA allows states to extend Medicaid coverage to children under age 19 who meet the SSI disability standards and whose income and/or assets exceed SSI limits but are less than 300 percent of the federal poverty level. DRA, §§ 6061-62 (adding 42 U.S.C. §§ 1396a(a)(10)(A)(ii)(XIX), 1396a(cc)). States can choose to cover children with higher family incomes, but will receive no federal matching dollars.

States taking up this option must require parents eligible for family coverage under a group health plan to apply for, enroll in, and pay premiums for the family coverage as a condition of FOA eligibility for the child. However, this requirement applies only if the employer contributes at least 50 percent of the total cost of the annual premium. DRA, § 6062 (adding 42 U.S.C. § 1396a(cc)(2)). Family health coverage will be treated as third party liability. In other words, the group health plan must pay for services for the FOA enrolled child first, before Medicaid will pay. Medicaid will pay only for those Medicaid services that the group health plan does not cover. *Id.* Moreover, if such coverage is obtained, the state must reduce the amount of premium paid under the FOA by an amount that reasonably reflects the premium amount paid by the parent to cover the child with the disability under the group health coverage plan. The state may choose to cover any portion of the premium payment that the parent otherwise would be required to pay for group health coverage. These state payments are considered “payments for medical assistance” for which it will receive federal Medicaid matching dollars, as long as the premium paid is for children whose family income does not exceed 300 percent of the federal poverty level. *Id.*

States are also allowed to impose income-related premiums on certain FOA children. *Id.* (amending 42 U.S.C. § 1396o(a) and newly codified 1396o(i)). For children whose family income is at or below 200 percent of the federal poverty level, aggregate out-of-pocket costs, including the FOA program premium, the premium paid for group health plan coverage, and other cost sharing charges, cannot exceed five percent of the family’s income. For children whose family income is between 200 and 300 percent of poverty, these aggregate out-of-

pocket costs cannot exceed 7.5 percent of the family's income. A state cannot require prepayment of a premium or terminate eligibility for nonpayment of a premium, until at least 60 days from the date on which the premium became past due. A state has the option to waive a premium in any cases in which it determines that the premium would create an undue hardship. *Id.*

States can begin using this option on January 1, 2007. DRA § 6062(d). However, groups of children will be phased in by age, starting with the youngest, between January 2007 and the end of the 2009 fiscal year. Children under age 19, but born on or after January 1, 2001 (ages 6 and below in 2007) will be phased in over the second, third and fourth quarters of fiscal year 2007. Those born on or after October 1, 1995 (ages 13 and below in 2008) would be phased in over the four quarters of fiscal year 2008; and those born on or after October 1, 1989 (ages 19 and below in 1989), over the four quarters of fiscal year 2009 and each quarter of any fiscal year thereafter. States can choose to phase in older children more quickly in fiscal years 2007 and 2009. *Id.*

### *c. Implications for advocacy regarding Family Opportunity Act*

It is important to note that some children already may be eligible for Medicaid under other Medicaid categories. For example, states currently are required to cover infants and children under age six up to 133% of the federal poverty level and children under age 19 up to 100% of the federal poverty level program. A number of states cover children with higher income levels within these groups. It will be important for advocates to compare the cost sharing and benefits requirements for children who fall within two or more categories to determine which option is more comprehensive.

Children enrolled through this option will be subject to the same benefit package as other categorically needy children, including EPSDT. However, as noted, Medicaid will be the secondary payer to any employer-sponsored family coverage that will have been purchased as a condition of FOA coverage. There may be challenges in coordination of benefits between Medicaid and the private health plan. A further layer of complication is posed in states that choose to enroll children under age 19 in "benchmark" plans with an EPSDT wrap-around. For children qualifying under the FOA, there potentially will be three plans to coordinate – the employer-sponsored health plan, the benchmark plan, and the Medicaid wrap-around.

## **VI. Home and community-based care provisions**

The DRA includes a number of provisions affecting long term care services. According to the Secretary of HHS, these options will allow states to modernize their Medicaid programs and "expand coverage for individuals with disabilities, increase access to community supports, and promote personal responsibility, independence, and choice[.]" *See* Letter from Michael O. Leavitt, Secretary of HHS, to Governors (Mar. 31, 2006). The options include:

*a. Home and Community Based Alternatives to Psychiatric Residential Treatment for Children (§ 6063)*

Since 1981, the Medicaid Act has allowed states to offer home and community-based waiver (HCBW) services to children under age 21 who need the level of care provided in a hospital, nursing facility, or intermediate care facility for people with mental retardation (ICF-MR). 42 U.S.C. § 1396n(c)(1). Children with serious emotional disturbances who did not qualify at this level of care might nevertheless be separated from the community and forced in psychiatric residential treatment facilities. The DRA, § 6063, provides that the Secretary of HHS will award grants “on a competitive basis” to as many as 10 states to conduct demonstration projects to test the effectiveness of providing HCBW services as an alternative to Psychiatric Residential Treatment Facilities (PRTF). PRTFs are non-hospital facilities that provide inpatient psychiatric services to individuals under age 21. 42 C.F.R. § 483.352.

The grants will be awarded in FY2007–FY2011. The projects will subject to the same terms and conditions that apply to HCBWs under § 1396n(c), including budget neutrality. Although each of the demonstrations will be limited to one year, if a child is enrolled in a such a project, the state may choose to continue to provide services to him in the same manner as it provides other services under § 1396n(c). The Secretary of HHS is required to conduct interim and final evaluations of these projects and report the results to the President and Congress. DRA, § 6063(e).

This provision will give selected states an additional means for providing mental health services to children and youth, without necessitating that they be institutionalized. It has historically been difficult for states to provide HCBW services to children with mental illness; thus, this option is welcome. The narrow scope of this program, however, means that only a limited number of children will have access to the benefit. Also, the short one-year duration of the projects allows an unreasonably short time to determine whether a particular child’s program is working, much less to measure the overall effectiveness of the program. This provision is another example of the reluctance of Congress to authorize broad expansions.

*b. Money Follows the Person (§ 6071)*

Section 6071 of the DRA directs the Secretary of HHS to award Money Follows the Person Rebalancing Demonstration (MFP) grants to states to increase the use of home and community-based services under the state’s waiver or regular Medicaid programs. The DRA gives the Secretary of HHS authority to waive Medicaid’s comparability, income, and statewideness requirements in MFP programs.

MFP focuses on individuals who are currently residing in inpatient settings and who, but for the home and community-based care, would continue to be kept there. DRA, § 6071(b)(2)(A). MFP is designed to give people with disabilities *choices*, in where they want to live, allow them greater accessibility to visit with family and friends and most importantly, to be a part of a community. DRA, § 6071(a)(2). Self-directed services, which allow the

individual to direct and control that planning and purchasing of home and community-based services, will be favored in MFP projects.

Individuals potentially eligible for these services, their families, providers and other interested parties must be included in developing the MFP project and evaluating its effectiveness throughout. The state will be allowed to specify the service area, the targeted groups of eligible individuals, and the number of individuals to be served. The state must also provide assurances that the quality of services provided to individuals under the MFP project will be adequate. Specifically, the state must assure that each eligible individual will be provided with enough information to make informed choices, that the choice of community setting will be determined by the individual, and that home and community-based services will be provided to the individual participant for as long as they remain eligible for such services. DRA, § 6071(c).

MFP will provide federal matching funds at the 75-90 percent rate during the first year of community based services for people who move out of a nursing home or institution. The formula to find the enhancement uses the state's existing federal medical assistance percentage (FMAP) plus one-half of the difference between 100 percent and the state's FMAP.

After the initial start up, the individual remains in the community, and the state will receive their regular federal Medicaid matching payment for their services. DRA, § 6071(e). While states will propose the length of the MFP project, it cannot be less than two fiscal years.

The MFP option becomes available to states on January 1, 2007. According to Congress, the Secretary of HHS is to give preference to states that propose multiple target groups and offer self-directed services. The Secretary is also to seek a national balance among geographic areas and eligible target groups. DRA, § 6071(d).

While the MFP option is a necessary step in the direction towards providing incentives for states to increase their home and community-based living opportunities for those in need of long term care, spending on these demonstrations will represent less than one-half of one percent of long-term services spending. *See Kaiser Commission of Medicaid and the Uninsured, Medicaid Long-Term Services Reforms in the Deficit Reduction Act 11* (Apr. 2006), at <http://www.kff.org/medicaid/upload/7486.pdf>.

*c. Expanded Access to Home and Community-Based Services for the Elderly and Disabled (§ 6086)*

Beginning January 1, 2007, § 6086 of the DRA allows states to offer home and community-based services as a state plan service—that is, without a waiver—to certain individuals whose incomes do not exceed 150 percent of the FPL. Such services may include any that may be offered under an HCBW pursuant to § 1396n(c). To participate, it will not be necessary for beneficiaries to show that they need an institutional level of care (i.e., the level of care provided in a hospital, nursing facility or ICF-MR.) In fact, under this option a state is required to have a more stringent level of care for eligibility for care in a hospital, nursing facility or ICF-MR. The option need not be offered statewide. Traditional comparability

requirements are also affected because states can limit the number of individuals who are eligible for services using waiting lists.

In general, states must establish eligibility criteria that include an assessment of an individual's support needs and capabilities, taking into account their ability to perform activities of daily living (ADLs), the need for significant assistance to perform ADLs, and such other risk factors as the state determines are appropriate. The independent assessment will determine the necessary level of services and supports based on the individual's physical and mental capacity, prevent the provision of unnecessary or inappropriate care, and establish an individualized care plan.

More specifically, eligibility must be determined by assessment, including at least: (1) an evaluation of the individual's capabilities in performing two or more activities of daily living (e.g. bathing, dressing, toileting) or the need for significant assistance to perform such activities; (2) a face-to-face evaluation by a trained individual; (3) consultation, if appropriate, with family or other responsible individual; (4) consultation with treating health care professionals; (5) an examination of the individual's history and records; and (6) if desired and covered by the state, the individual's or individual's representative's ability to self-direct care.

A written individualized plan of care must be developed pursuant to assessment in consultation with the individual, family, and health care and support professionals. Under this option, states may use presumptive eligibility for assessment. States must also ensure that quality assurance guidelines and conflict of interest standards are met.

This added option is positive in that it provides an additional means of providing home and community-based services to individuals who do not have needs as high as those who qualify for services under current HCBWs. However, it also continues the trend of creating limited service expansions instead of broader expansions of the Medicaid program. Moreover, it reflects the demands of state officials to make Medicaid more "flexible" to the point that it could introduce more instability and uncertainty for beneficiaries. States will no longer have to request permission to tighten eligibility criteria for this option and will have greater freedom to discontinue providing services to individuals when it does so.

Under this provision, states are to submit projections to the Secretary of HHS on how many individuals are expected to use home and community-based services. If actual numbers of individuals exceed these projections, the state may, without prior approval, tighten eligibility requirements for the services provided. If individuals already receiving home and community-based services under this option when eligibility requirements are tightened are deemed no longer eligible, those individuals must continue to receive services for at least 12 months from the time that their services began. A state may continue or discontinue services beyond that 12 month period.

*d. Implications for advocacy regarding home and community-based care provisions*

There are a number of steps advocates can take, among them:

- Prepare to develop comments for CMS when draft regulations are published. Regulations will impact how restrictive or broadly the law is interpreted at the state level and therefore how it is implemented.
- If a state is considering this option, advocate that there be legislative or other oversight by the P&A and consumer groups with particular emphasis on:
  - initial, and any future changes to, eligibility criteria,
  - ensuring that individuals who may lose eligibility for HCBS under adjusted eligibility criteria are grandfathered completely (as opposed to only a 12 month period),
  - ensuring that eligibility criteria developed are broad enough to include individuals with cognitive, neurological, and mental health disorders, and
  - ensuring that inappropriate care referred to in federal law includes care that is overly restrictive.
- Advocate to ensure that, if this option is taken up by a state, it is implemented statewide.
- Work to ensure that states do not terminate important optional Medicaid services, such as rehabilitative services, and offer them only to persons qualifying under the HCBS option (where the number of individuals receiving the service can be capped).

**VII. Self-Directed (Cash and Counseling) Personal Assistance Services  
(§ 6087)**

*a. Current law*

Currently, self-directed personal care services are provided through HCBWs and other Medicaid demonstration projects. Three states, New Jersey, Arkansas, and Florida, have operated demonstrations that allow beneficiaries to use monthly budgets to purchase the care and services of their choice, including from a family member. Beneficiaries would be counseled about how to manage their budgets and services.

*b. DRA provisions regarding Self-Directed Services*

Beginning in January 2007, states will be able to offer the option of self-directed personal care services for individuals who have been determined to require personal care services as a regular state plan or HCBW service. Individuals participating in this option would be allowed to: (1) choose as their paid service provider, any individual capable of

performing the needed task, including a relative; and (2) acquire items that would increase independence or substitute for human assistance (such as a microwave oven or accessibility ramp). Similar to an HCBW, states must assure that necessary safeguards have been taken to protect the health and welfare of individuals receiving these services and financial accountability for the services. States must provide a “support system” to ensure that program participants are appropriately counseled, assessed, and able to self-direct their services and service budgets.

*c. Implications for Advocacy regarding self-directed services*

The cash and counseling demonstrations have been monitored and studies and the lessons learned from them should be used by advocates in other states. For example, the Alliance for Health Reform has described five steps that should be assessed when getting started, and advocates work to assure these steps are taken as the option is implemented. For more information, see Alliance for Health Reform, *Cash & Counseling Moves into the Mainstream* (Apr. 2006) (<http://www.allhealth.org>) .

***Conclusion***

The National Health Law Program, National Disability Rights Network, and other consumer advocates will closely monitor legislative (federal and state) and judicial implementation of the DRA of 2005. Please consult our websites frequently. We are also available to provide technical support as issues arise in your state.