# Understanding Changes in Prescription Drug Coverage for People with Disabilities on Medicare

A Guide for People with Disabilities, Benefits Counselors, Disability Organizations and Others On Transitioning to the Medicare Part D Prescription Drug Benefit

A project of Advancing Independence

**Prepared by** 

Jeffrey S. Crowley
Health Policy Institute, Georgetown University

With

Bob Williams

Advancing Independence

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Please direct questions to robert.willliams@gmail.com.

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#### Introduction

Beginning on January 1<sup>st</sup>, all Medicare beneficiaries will have the opportunity to purchase prescription drug coverage from among a choice of competing private plans (individuals can enroll in the new program starting on November 15<sup>th</sup>). For many Medicare beneficiaries who previously did not have prescription drug coverage, this represents an important updating of the Medicare benefits package. Literally millions of people will have prescription drug coverage for the first time.

Many Medicare beneficiaries with disabilities also receive Medicaid. These individuals, called dual eligibles, already have drug coverage through Medicaid. This will change, however. Medicaid prescription drug coverage of dual eligibles will end at the end of 2005 and they will receive prescription drug coverage through Medicare starting in 2006. These individuals will continue to receive Medicaid for other services. Several steps are being taken to assure that this transition is smooth and does not lead to any gaps or interruptions in drug coverage. But problems will almost certainly arise for certain individuals, including some with potentially serious consequences.

# Medicare beneficiaries with disabilities, whether or not they are dually eligible, have an important role to play in ensuring that they have access to the drugs they need.

This guide was developed for people with disabilities who receive Medicare, friends and family members, benefits counselors, disability organizations, and others who will assist individuals in taking advantage of the new Medicare drug coverage option. Reading it should enable individuals to better understand the changes in their prescription drug coverage and what key steps they can take to ensure that their prescription drug needs are met. While this guide will focus in on issues of particular importance to people who are dually eligible, much of the information is critical for all Medicare beneficiaries with disabilities.

# What makes some people with disabilities under age 65 eligible for Medicare coverage?

Medicare is a program of the federal government that primarily provides retirement health insurance to Americans once they turn age 65. However, people younger than 65 can also qualify for Medicare if they meet the Social Security Administration's standard for long-term, serious disability, including End Stage Renal Disease.

There are 3 basic ways that people with disabilities under age 65 qualify for Medicare:

- Most people with disabilities under age 65 that have Medicare are individuals who have worked, but have become disabled and now receive SSDI payments.
- About 10% are eligible for Medicare because they are the "Disabled Adult Children" of parents that are already covered by Medicare or are deceased.
- Others are eligible because they have End Stage Renal Disease.

#### What is the Medicare waiting period?

Most people with disabilities under age 65 generally must wait two years from when they are determined to be eligible before their Medicare coverage actually becomes effective. But there are two exceptions to this: Individuals with End Stage Renal Disease only wait three months for such coverage to begin and people with amyotrophic lateral sclerosis (ALS, or Lou Gehrig's disease) can enroll in Medicare as soon as they are diagnosed. Individuals in the waiting period are not yet Medicare beneficiaries. Thus, if they qualify for Medicaid, they can receive prescription drugs from Medicaid during the waiting period.

#### What does it mean to be "dually eligible"?

Roughly 7 million Americans – including about two million people with disabilities under age 65 – are dually eligible for both Medicare and Medicaid because they have very low incomes and few other resources.

Medicaid is a federal and state government program that provides health care coverage to certain low income persons, including children and families, pregnant women, seniors (persons 65 or older) and people with disabilities. Persons in these categories qualify if they meet state-established income and resource standards and other eligibility requirements.

As a general rule, Medicare payment levels for providers are higher than for Medicaid. This can mean that Medicare beneficiaries may have a broader choice of providers than Medicaid beneficiaries. On the other hand, Medicaid often covers services that Medicare does not cover. Therefore, for many people with disabilities, the ideal arrangement is to be dually eligible which enables them to access the benefits of both programs. For dual eligibles, Medicare is the primary payer and Medicaid fills in for gaps in Medicare coverage. This includes paying for benefits that Medicare does not cover such as long-term services and supports – this will not change. Medicaid also has and will continue to pay Medicare cost-sharing, including the Part B premium and the cost-sharing associated with physician, hospital, and other services received under Medicare Parts A and B—traditional Medicare. Until now, Medicaid has provided prescription drug coverage for these individuals. As discussed, this coverage will change in January, 2006.

#### What makes some Medicare beneficiaries with disabilities dually eligible?

As a general rule, an individual whom the Social Security Administration has determined has a serious long-term disability—the basis for receiving Medicare—also falls into a Medicaid eligibility category (except for a limited number of states with a more strict definition of disability for Medicaid). But, for any of these individuals to qualify for Medicaid they must also satisfy income and resource standards.

*Income Limits:* Most states provide Medicaid to persons who receive Supplemental Security Income (SSI) which provides income support up to 74% of the federal poverty level. A limited number of other states set slightly different income eligibility rules.

States also are permitted to cover people with disabilities and seniors up to the poverty level, but fewer than half of the states do so. The average SSDI payment for a disabled worker, however, is roughly 113% of the poverty level. Therefore, depending on where one lives, a significant number of people with disabilities on Medicare can be quite poor, but have too much income to qualify for Medicaid.

**Resource Limits:** Additionally, some people are ineligible because they have resources (*i.e. financial assets such as money in the bank or property other than their primary home or primary vehicle*) in excess of Medicaid's resource standard which, in most states is \$2,000 for a single individual or \$3,000 for a couple.

Other Ways to Qualify: For Medicare beneficiaries who do not currently receive Medicaid, there may be additional opportunities in their state to qualify for Medicaid. Many states have chosen to take advantage of a special income rule to make nursing home care available to persons with income up to 300% of the SSI payment level. In 2005, this comes to \$1,737 a month. States that take advantage of this rule are also permitted to apply the same income standard to permit people with disabilities to qualify for Medicaid in order to receive community-based long-term services and supports. Additionally, individuals may qualify for Medicaid if their state has a medically needy program which permits individuals to "spenddown" to coverage by incurring medical expenses so that their income minus their medical expenses is below a state established medically needy income limit.

In certain instances, people with disabilities that work can obtain Medicaid coverage. Medicaid eligibility rules can vary dramatically from one state to another. The best way to find out the specific eligibility requirements is to contact the Medicaid office in a specific state. Medicare beneficiaries who are dually eligible receive special treatment in the Part D program, so if individuals think that they may be eligible for Medicaid, but are not currently enrolled in it, they should contact a benefits counselor for assistance or contact Medicaid in their state and ask to be screened for Medicaid eligibility.

Medicaid programs also provide financial assistance with Medicare cost-sharing (*i.e. such as paying the Part B premium*) for low-income Medicare beneficiaries with too much income and resources to qualify for full Medicaid coverage. These programs are collectively called the Medicare Saving Programs (MSP) and will be discussed further later in this guide.

#### How is the Medicare program structured?

Medicare consists of several program components, or parts, and each provides different benefits:

Part A	Hospital insurance, including skilled nursing, some home health, and hospice services
Part B	Physician and outpatient services, some home health care, durable medical equipment, and ambulance services
Part C	Alternative to receiving traditional Medicare. Beneficiaries enroll in a Medicare Advantage health plan instead of participating in the other parts of Medicare
Part D	Prescription drug coverage program (beginning 01/01/2006)

All Medicare beneficiaries participate in the Part A program. Medicare Part A pays for hospital expenses, including hospitalizations in specialty psychiatric hospitals. Medicare Part A also pays for up to 100 days in a skilled nursing facility and for skilled home health services; for persons with a life expectancy of six months or less, it pays for hospice services.

The Part B program is voluntary. The Part B program provides medical insurance that pays for doctors' visits/services, skilled home health services, durable medical equipment, outpatient hospital services, ambulance services, and lab tests. The Part B program also covers certain preventive health care services.

#### Parts A and B are sometimes referred to as "traditional Medicare."

The Part C program is a voluntary program providing options to enroll in a Medicare managed care program. The Part C program operates Medicare Advantage health plans that provide an alternative to participating in Parts A and B (and in January 2006, Part D). Medicare Advantage plans combine the benefits of the other parts of Medicare into a health plan that takes responsibility for providing all Medicare benefits.

The Part D program is a voluntary program affording individuals the opportunity to purchase Medicare prescription drug coverage. This new program begins in January 2006 and is the focus of this guide.

#### What are some key considerations regarding Part D for dual eligibles with disabilities?

Dual eligibles have poorer health status and more extensive prescription drug needs than most other Medicare beneficiaries because the majority of dual eligibles are people with disabilities. Dual eligibles also differ from many other Medicare beneficiaries in that they are generally quite poor, and have limited capacity to pay cost-sharing or to pay out-of-pocket for non-covered drugs.

Therefore, the stakes will often be higher for dual eligibles with disabilities to ensure that they enroll in a prescription drug plan that meets their needs—and to ensure that they take advantage of all of the financial assistance that is available to them. But it is important to note that most people with disabilities under age 65 who have Medicare coverage only also tend to have very limited incomes and resources. In August 2005, for example, the average SSDI payment for a disabled worker was \$898/month. In some states, an individual on SSDI that receives this level of income may be eligible for Medicaid; in others they would not.

Understanding how Part D works is important to all Medicare beneficiaries with disabilities. The following section is intended to provide such a basic understanding of the Part D program.

#### **Overview of Medicare Part D Drug Coverage Program**

The Medicare Part D program is the new part of Medicare that provides prescription drug coverage. The law that created the Part D program was called the Medicare Prescription Drug, Improvement, and Modernization Act of 2003. This is sometimes abbreviated as the Medicare Modernization Act or the MMA. If people refer to MMA prescription drug coverage, they are talking about the Part D program.

Extra Help is a component of the Medicare Part D program that provides financial assistance to dual eligibles and other low-income Medicare beneficiaries (with countable income up to 150% of the federal poverty level, \$1,196 in monthly income for a single individual in 2005) to assist with the costs of obtaining prescription drug coverage. The benefits of the Extra Help program—and how to apply—will be described in greater detail later in the guide.

Key aspects of the Part D program relate to who can purchase coverage, what the program covers, and whether individuals can be guaranteed that their plan will cover the drugs their health care providers prescribe.

#### Who can purchase Part D prescription drug coverage?

All Medicare beneficiaries are eligible to participate in the Part D program. This includes persons entitled to Medicare Part A coverage and anyone enrolled in the Part B program.

#### What benefits does the Part D program provide?

Part D prescription drug coverage provides coverage for prescription drugs and biologicals (such as insulin). Part D drug coverage generally cannot cover over-the-counter drugs (drugs that can be purchased without a prescription), drugs already covered by other parts of the Medicare program, and "Medicaid excludable drugs", except for products used to help people quit smoking. While the cost-sharing responsibilities of Medicare beneficiaries changes as their annual drug costs rise, there is no upper limit on the amount of drug coverage an individual has—no Medicare beneficiary can be told that they have exceeded the coverage limit for prescription drugs under the Part D program.

#### What drugs are covered by other parts of the Medicare program?

Part D prescription drug plans are prohibited from covering drugs covered by other parts of Medicare. As a general rule, drugs that are covered by other parts of Medicare include prescription medications provided during a stay in a hospital or skilled nursing facility which are paid for by the Part A program and limited circumstances when the Part B program covers prescription drugs. In general, the Part B program can pay for outpatient prescription drugs in the following circumstances:

- 1. Drugs billed by physicians and typically provided in physicians offices (such as chemotherapy drugs);
- 2. Drugs billed by pharmacy suppliers and administered through durable medical equipment (DME), such as respiratory drugs given through a nebulizer;
- 3. Drugs billed by pharmacy suppliers and self-administered by the patient (such as immunosuppressive drugs and some oral anti-cancer drugs);
- 4. Separately billable drugs provided in Hospital Outpatient Departments; and,
- 5. Separately billable End Stage Renal Disease (ESRD) drugs such as erythropoietin (EPO).

# What happens if there is confusion over whether Part D or another part of Medicare should pay?

There may be some cases when there is confusion over whether Parts A or B will pay for a drug or whether Part D should provide coverage for the drug. Part D cannot pay for drugs when Part A or B should pay, even if an individual is unable to get Part A or B coverage for the drug. In cases where there is a dispute over which part of Medicare is responsible for coverage of a specific drug, see the following document from the Centers for Medicare and Medicaid Services (CMS) which provides guidance and scenarios for deciding which Part of Medicare is responsible for coverage: http://www.cms.hhs.gov/pdps/PartBandPartDdoc-revised7-27-05.pdf.

#### What are the "Medicaid excludable drugs"?

Part D prescription drug plans are prohibited from covering Medicaid excludable drugs under standard coverage plans, with the exception of smoking cessation products. Medicare plan sponsors that offer standard coverage plans, however, can offer enhanced coverage plans for a higher premium, and these plans are permitted to cover the Medicaid excludable drugs.

The following are Medicaid excludable drugs:

- 1. drugs when used for anorexia, weight loss, or weight gain;
- 2. drugs when used to promote fertility;
- 3. drugs when used for cosmetic purposes or hair growth;
- 4. drugs when used for the symptomatic relief of coughs and colds;
- 5. drugs when used to promote smoking cessation (can be covered by Part D plans);
- 6. prescription vitamins and mineral products, except prenatal vitamins and fluoride preparations;
- 7. nonprescription drugs;
- 8. covered outpatient drugs which the manufacturer seeks to require as a condition of sale that associated tests or monitoring services be purchased exclusively from the manufacturer or its designee;
- 9. barbiturates; and,
- 10. benzodiazepines.

These listed exclusions were enacted into law in the Omnibus Budget Reconciliation Act of 1990 and are sometimes referred to as "OBRA exclusions" or "OBRA-90" exclusions.

Although Medicaid generally cannot receive federal funding for prescription drugs for Medicare beneficiaries, this prohibition does not apply to excludable drugs. Indeed, if a state covers these excludable drugs for other Medicaid beneficiaries, then they must cover them for dual eligibles, when they are medically necessary.

#### What types of plans will provide Part D prescription drug coverage?

The Medicare Part D program does not provide a Medicare benefit directly. Rather, it creates a right for Medicare beneficiaries to purchase prescription drug coverage from a Medicare prescription drug plan. Prescription drug plans can be stand alone plans or individuals can enroll in a Medicare Part C managed care plan (now called Medicare Advantage health plans).

#### What are prescription drug stand alone plans?

Stand-alone plans are programs offered by insurers or other entities that provide coverage for <u>only</u> prescription drugs, and no other health care services. For Medicare beneficiaries wishing to participate in the traditional Medicare program, they should select a stand-alone plan to receive their prescription drug coverage.

#### What are Medicare Advantage plans?

Medicare Advantage plans combine the benefits of the other parts of Medicare into a health plan that takes responsibility for providing all Medicare benefits.

There are important trade-offs to think about when considering enrolling in a Medicare Advantage plan. Some plans offer premiums and cost-sharing that is lower than in traditional Medicare. Some plans offer expanded benefits. Typically, plans are able to do this, in part, by tightly managing the benefits. This could mean that if an individual enrolls in a Medicare Advantage plan they will not be permitted to see all of the doctors they want.

While deciding whether to enroll in a Medicare Advantage plan is a personal choice, the program's history serving people with disabilities and chronic conditions has produced mixed results. Individuals with disabilities considering enrolling in a Medicare Advantage plan should weigh this decision with care.

#### Will Medicare beneficiaries be able to get their drugs from the pharmacy they choose?

As a general rule, any pharmacy could decide to participate in a Part D plan's network, but plans can offer favorable terms for individuals to use a preferred pharmacy. It is also possible that an individual's regular pharmacy is not in the network of a particular plan. For some individuals, this may be an important criterion in selecting a Part D plan. This may be especially true for people with mobility limitations as well as those living in rural communities or other areas where pharmacies are few and far between. In some instances, even these types of difficulties can lessened if a Part D plan allows for mail-order delivery of prescription drugs.

#### What is a drug formulary and how is it used?

Part D prescription drug plans are permitted to operate formularies, which are lists of drugs covered by a plan. This means that plans can choose to cover some, but not all FDA approved prescription drugs. Part D plans can also have tiered formularies where preferred drugs have a lower level of cost-sharing and drugs the plan considers non-preferred can have a higher level of cost-sharing. In some cases, plans can charge very high levels of cost sharing for non-preferred drugs.

Some beneficiaries, however, are not required to pay high cost sharing. Dual eligibles and low-income people receiving *Extra Help* (i.e. financial assistance with cost-sharing for dual eligibles and people below 150% of the poverty level) are generally protected from this higher cost-sharing.

To get all of the drugs they need, Medicare beneficiaries with disabilities need to know the plan rules and know how to ask for an exception or appeal if drugs are denied or if the cost-sharing makes the drugs unaffordable.

#### What must a Part D formulary cover?

In developing a formulary, drugs are grouped into classes of drugs which work in the same way or which are used to treat the same condition. As a general rule, Part D plans are only required to cover two drugs in each class. For example, there are at least 14 drugs in the antihistamine class (*i.e. drugs used to treat allergies*), and plan formularies, at a minimum, must only cover two of these.

#### What happens when a drug is not on a Part D plan's formulary?

A Part D plan may not have a drug prescribed by an individual's physician on the formulary—or they may charge a high level of cost-sharing. In some cases, the drug on the formulary that is used to treat the same condition (or the preferred drug with a lower level of cost-sharing) is perfectly acceptable. In others, substituted drugs on the formulary may have interactions with other drugs an individual is taking, they may not work effectively, they may produce unacceptable side-effects, or they may pose safety risks. Therefore, individuals, alone, should not try to make these determinations. If an individual is told that a drug prescribed by their physician is not on the formulary—of if they are told that the cost-sharing is at a high level, they should ask their pharmacist for options and recommendations, and they should check with their physician.

If an individual needs a drug they are denied—or to request that a non-preferred drug be provided at the preferred level of cost-sharing, individuals can request an "exception" to the plan's formulary or cost-sharing policy. To be successful at an exception, though, the physician or other provider who prescribed the drug must agree that the specific drug is necessary and that a substituted drug is not appropriate. Exceptions and appeals procedures will be described in more detail later in this guide.

#### Which classes of drugs are given special treatment under the Part D program?

As previously stated, the MMA generally requires prescription drug plans that operate formularies to cover at least two drugs in each drug class. Federal officials have established a higher standard of coverage, however, for six specific classes. Plans are required to cover "all or substantially all" of the drugs in the following classes:

- Anticonvulsants;
- Antidepressants;
- Anticancer drugs (i.e., antineoplastics);
- Antipsychotics;
- Immunosuppressants; and
- HIV/AIDS drugs (i.e., antiretrovirals).

For drugs other than HIV/AIDS drugs, Part D plans are permitted to use utilization management tools such as prior authorization (requiring a patient to provide clinical evidence or other justification before a specific drug is covered) and step therapy (requiring a patient to try certain drugs or therapies in a particular order) with new users, but not with patients who already are using the drugs. For HIV/AIDS drugs, with one exception (*enfuvirtide*, also known as Fuzeon), Part D plans may not subject any users to prior authorization or step therapy requirements. New Fuzeon users may be subject to prior authorization (but not step therapy) requirements.

Although Federal officials have not articulated explicit coverage requirements for other classes, a plan typically will cover more than two drugs in a number of categories in order to provide a suitable range of drugs currently used to treat various disorders.

#### Can a Part D plan change the drugs available on their formulary?

Part D plans are permitted to change the drugs on the formulary at any time, but except for emergency circumstances, they must give their enrollees notice 60 days before removing a drug. For enrollees taking a drug, the notice must be in writing. In the notice, plans must include information on the exception and appeals processes. Beneficiaries may appeal to continue to receive coverage for the drug. In addition, Part D plans are limited in the changes they can make between September 15, 2005 and January 1, 2006. In general, plans may not remove drugs during this period, although they may add drugs that are newly available.

#### Can a dual eligible do anything to retain Medicaid drug coverage?

No. It is not possible for a Medicare beneficiary to continue to receive their prescription drugs from Medicaid, except for the limited number of "Medicaid excludable" drugs discussed earlier.

### If an individual is currently on a treatment regimen, can they continue getting the same drugs under a Part D plan?

Part D plans are required to establish an appropriate transition process in order to address the needs of individuals who are stabilized on certain drug regimens. Federal officials have recommended, but have not required plans to provide a temporary "first fill" supply of a drug so that they can access their drugs and be given a certain amount of time to make any necessary switches in treatment regimens.

Federal officials are <u>requiring</u> that Part D plans dispense a temporary supply of non-formulary drugs for residents of nursing homes and other long-term care facilities.

#### When can individuals switch plans?

As a general rule, Medicare beneficiaries can switch plans once per year during an *annual coordinated election period*. This will run from November 15 – December 31<sup>st</sup> for enrollment changes for the next calendar year. There are certain circumstances when individuals have a right to change their enrollment during the year at a time other than the annual coordinated election period. These circumstances are called *special enrollment periods*. They include circumstances such as when an individual moves to another region and they need to enroll in a plan operating in their new region, or if they had creditable retiree coverage that stops providing them coverage.

Dual eligibles have a special protection in that they always qualify for a special enrollment period. This means that dual eligibles can switch plans at any time throughout the year.

### Are there special issues for people with disabilities in nursing homes or other long-term care facilities?

It is essential that Medicare beneficiaries residing in nursing homes or other long-term care facilities, such as skilled nursing facilities and intermediate care facilities for persons with mental retardation (ICF-MRs), select a plan that includes a long-term pharmacy (a specialized pharmacy that provides drugs to residents of long-term care facilities) serving the institution where they reside. The Part D program has special provisions that allow individuals to access a non-network pharmacy, such as in case an individual travels outside of their region. It is important to note that these out-of-network provisions cannot be used by residents of long-term care facilities to access a non-network long-term care pharmacy.

#### **Paying for Medicare Drug Coverage**

A key aspect of the Medicare Part D program is the amount of money that Medicare beneficiaries are charged to receive the drugs they need. There are three main elements of the cost: the premium, the deductible, and the cost-sharing. This is complicated because the cost of some of these elements can change within a year as a person's annual drug spending increases; costs can also vary depending on where in the country one lives. Dual eligibles and other low-income Medicare beneficiaries are eligible for *Extra Help* which protects individuals from many of these costs.

#### What are premiums?

The premium is the monthly fee that individuals must pay to have Part D prescription drug coverage. Plans set their own premium and premiums vary with the level of coverage offered or with the level of cost-sharing—some plans have no premium, and others have very substantial premiums. In 2006, the national average Part D premium is \$32.20 per month.

For an individual to retain prescription drug coverage, they must pay the premium each month. Individuals are given the choice of paying the premium by check or having it deducted from their Social Security payment. For persons receiving *Extra Help*, some or all of the premium is paid by the federal government.

#### What is the deductible?

The deductible is the amount that Medicare beneficiaries must spend on prescription drugs each year before Part D drug coverage starts to provide assistance. The deductible is established by the federal government and is adjusted each year based on the growth in Part D costs. In 2006, the standard Part D deductible is \$250. A number of plans throughout the country are offering coverage with either a reduced deductible or no deductible. Additionally, most persons receiving *Extra Help* have no deductible even if they select a plan that charges other beneficiaries a deductible.

#### What is cost-sharing?

Cost-sharing is the amount that individuals must pay at the pharmacy counter to get their prescription drugs. In some cases, the cost-sharing could be a flat dollar amount per prescription, such as \$5 per prescription, or it could be a percentage of the drug's total cost.

#### What is the basic structure of the Part D benefit in 2006?

While the precise structure of the prescription drug benefit can vary from plan to plan, under the standard drug coverage plan, beneficiaries will be responsible for the following prescription drug costs in 2006:

- Pay the monthly premium of the plan in which they enroll;
- Pay the first \$250 in drug costs (deductible);
- Pay 25% of total drug costs between \$250 and \$2,250 (this is called the *initial coverage period*)
- Pay 100% of drug costs between \$2,250 and \$5,100 in total drug costs per year (this is called the *coverage gap* and has also been described in the media as the *doughnut hole*);
- Pay either \$2 for generics and \$5 for brand drugs or 5 percent of total drug spending (whichever is greatest) for all drug spending greater than \$5,100 in drug spending per year (Once individuals have drug spending greater than \$5,100 in 2006, this extra coverage is called *catastrophic coverage*).

Part D plans are also permitted to offer higher coverage options by charging a higher premium, as long as they offer a standard coverage plan. Part D plans are also permitted to offer plans with different levels of cost-sharing and either a smaller or larger coverage gap, as long as the total value of the coverage is equivalent to the level of coverage offered by a standard coverage plan described above. For example, a plan may charge a higher premium and charge cost-sharing of 30% for drugs, but eliminate or reduce the coverage gap. Additionally, plans are permitted to establish cost-sharing tiers, such that preferred drugs may have a low level of cost-sharing and non-preferred drugs would have a higher level of cost-sharing.

#### How can the cost of Part D drug coverage change from year to year?

As costs grow, the federal government will adjust every year both the deductible and the level of drug spending needed to reach catastrophic coverage. Plans will also adjust their premiums each year, and they may adjust other features of coverage, such as the level of cost-sharing for specific types of drugs, and which drugs are given preferred or non-preferred treatment.

#### What is meant by "True-Out-of-Pocket" or TrOOP?

True out-of-pocket spending (TrOOP) refers to spending by individuals and other sources that counts toward meeting the catastrophic level of coverage.

A philosophical principle underpinning the MMA is that all beneficiaries should be responsible for a share of the cost of the prescription drugs they receive. Dual eligibles residing in institutions are exempt from cost-sharing because, as a condition of eligibility for institutional care, they have already

contributed all of their personal resources to the cost of their care. Dual eligibles and others residing in the community are required to pay some level of cost-sharing.

The cost of drugs covered by a Part D plan (including cost-sharing) count toward TrOOP as long as any applicable cost-sharing was paid by:

- The beneficiary
- Another individual (e.g. family or friends)
- Certain charities, including some pharmaceutical patient assistance programs
- A State Pharmacy Assistance Program (SPAP)
- A personal health savings vehicle (Flexible Spending Accounts, Health Savings Accounts, and Medical Savings Accounts)
- Co-pays waived by a pharmacy
- CMS payment to Part D plans as low income subsidies

If an individual receives assistance with purchasing prescription drugs by a government entity that is not a state pharmacy assistance program, then the cost of the drugs provided do not count toward TrOOP. Additionally, if individuals purchase drugs on their own because their plan tells them the drug is not on the formulary, then this spending also do not count toward TrOOP.

#### What is Extra Help?

Extra Help is a component of the Medicare Part D program that provides financial assistance to dual eligibles and other low-income Medicare beneficiaries to assist with the costs of obtaining prescription drug coverage.

#### Who is eligible for Extra Help?

Extra Help is available to dual eligibles and individuals with income below 150% of the poverty level (monthly income of \$1,196 for a single individual in 2005, with higher limits for larger households) and with limited assets. Due to rules for counting income where some income is not counted, some individuals may qualify for Extra Help even if they think they have too much income. Most people on SSDI will qualify for Extra Help, so they are especially urged to apply.

People with disabilities with income even close to income cut-off should be encouraged to apply for Extra Help.

#### How can someone apply for Extra Help?

Dual eligibles, SSI recipients, and Medicare Savings Program (QMBs, SLMBs, and QI-1s) are automatically eligible for *Extra Help* and do not need to do anything to get this assistance.

To apply for *Extra Help*, individuals should contact the Social Security Administration or the Medicaid office. While Social Security will be set up to handle the large volume of *Extra Help* applications, if individuals apply through their Medicaid office, they should also be screened for Medicaid eligibility and for the Medicare Savings Programs.

To help individuals find their local Social Security office, go online to: http://s3abaca.ssa.gov/pro/fol/fol-home.html. Individuals can also call toll-free 1-800-772-1213. For people who are deaf or hard of hearing, the toll-free TTY line is 1-800-325-0778.

Since each state operates its own program, there is not a central number that everyone can call nationwide to get information about Medicaid in each state. Therefore, to get information individuals should call their state Medicaid agency. The number can be found by looking in the phone book in the State Government pages (often blue pages). Some states refer to Medicaid as "Medical Assistance". In California, for example, Medicaid is called "Medi-Cal".

#### How much must assistance does Extra Help provide a dual eligible in an institution?

Dual eligibles in institutions are fairly well protected from Medicare Part D cost-sharing. This is essential as these individuals have already pledged all of their financial resources, except for a personal needs allowance, to the cost of their care. The following rules apply:

**Premium:** Dual eligibles in institutions receive a full premium subsidy up to the average cost premium in their region. Therefore, as long as they select a standard coverage plan (or equivalent basic coverage plan) with a premium below the regional average, they do not need to pay a monthly premium. If they select a plan with a premium above the regional average, they are responsible for the premium cost above the regional average.

Deductible: Dual eligibles in institutions have no deductible.

Coverage Gap: There is no coverage gap for dual eligibles in institutions.

Cost-sharing: Dual eligibles in institutions have no cost-sharing.

#### How much must assistance does Extra Help provide a dual eligible in the community?

With one important exception, the same basic rules outlined above apply to dual eligibles living in the community. The exception is that someone that is a dual eligible living in their community is subject to different cost shared requirements.

**Premium:** Dual eligibles in the community receive a full premium subsidy up to the average cost premium in their region. Therefore, as long as they select a standard coverage plan (or equivalent basic coverage plan) with a premium below the regional average, they do not need to pay a monthly premium. If they select a plan with a premium above the regional average, they are responsible for the premium cost above the regional average.

**Deductible:** Dual eligibles in the community have no deductible.

Coverage Gap: There is no coverage gap for dual eligibles in the community.

Cost-sharing: Until they qualify for catastrophic coverage, dual eligibles in the community are subject to two different levels of cost-sharing, depending on their income. If their income is below the poverty level (including SSI recipients), then they pay \$1 or \$3 per prescription, depending on whether their plan has determined that the specific drug they have been prescribed is a "preferred" drug which would have the lowest cost-sharing or "non-preferred" which would have the higher level of cost-sharing. For dual eligibles in the community with income above the poverty level, their cost-sharing is \$2 per preferred prescription and \$5 per non-preferred prescription.

Catastrophic cost-sharing: Once an individual's annual drug spending on Part D drugs reaches \$5,100, they qualify for catastrophic coverage. Dual eligibles in the community have no cost-sharing once they reach the catastrophic level of coverage.

# How much must assistance does *Extra Help* provide low-income people who are not dually eligible?

There are two levels of assistance for low-income Medicare beneficiaries who are not dually eligible.

**Non-dual eligibles below 135% of poverty:** Medicare beneficiaries who do not receive Medicaid with income below 135% of poverty (\$1,076.63 of monthly income for a single individual or \$1,443.38 for a couple) and limited assets (less than \$6,000 for single individuals or less than \$9,000 for couples) qualify for the same subsidy as dual eligibles above the poverty level.

Note: If an individual has income below 135% of poverty, but they are ineligible for this level of assistance because they have too many assets to qualify, they can qualify for the partial subsidy for individuals with income below 150% of poverty, as long as their assets are below

the higher asset level for this group (\$10,000 for single individuals or less than \$20,000 for couples). For individual in this situation, see below for information on the level of *Extra Help* that is available for non-dual eligibles below 150% of poverty.

**Premium:** Non-dual eligibles below 135% of poverty level receive a full premium subsidy up to the average cost premium in their region. Therefore, as long as they select a standard coverage plan (or equivalent basic coverage plan) with a premium below the regional average, they do not need to pay a monthly premium. If they select a plan with a premium above the regional average, they are responsible for the premium cost above the regional average.

Deductible: Non-dual eligibles below 135% of poverty have no deductible.

Coverage Gap: There is no coverage gap for non-dual eligibles below 135% of poverty.

Cost-sharing: Until they qualify for catastrophic coverage, non-dual eligibles below 135% of poverty pay \$2 or \$5 per prescription, depending on whether their plan has determined that the specific drug that are prescribed is a "preferred" drug which have the lowest cost-sharing or "non-preferred" which has the higher level of cost-sharing.

Catastrophic cost-sharing: Once an individual's annual drug spending on Part D drugs reaches \$5,100, they qualify for catastrophic coverage. Non-dual eligibles below 135% of poverty have no cost-sharing once they reach the catastrophic level of coverage.

Non-dual eligibles below 150% of poverty: Medicare beneficiaries who do not receive Medicaid who have income below 150% of poverty (\$1,196.25 of monthly income for a single individual or \$1,603.75 for a couple) and moderate assets (less than \$10,000 for single individuals or less than \$20,000 for couples) qualify for a "partial" subsidy.

**Premium:** Non-dual eligibles below 150% of poverty level receive a sliding scale premium subsidy. If their income is just above 135% of poverty, they will receive essentially a full premium subsidy, and if their income is at 150% of poverty, they will receive no premium subsidy.

**Deductible:** Non-dual eligibles below 150% of poverty have a deductible of \$50 per year in 2006.

Coverage Gap: There is no coverage gap for non-dual eligibles below 150% of poverty.

Cost-sharing: Until they qualify for catastrophic coverage, non-dual eligibles below 150% of poverty pay 15% of the cost of their drugs (based on the price their plan negotiates with the manufacturer).

Catastrophic cost-sharing: Once an individual's annual drug spending on Part D drugs reaches \$5,100, they qualify for catastrophic coverage. Non-dual eligibles below 150% of poverty pay \$2 or

\$5 per prescription, depending on whether their plan has determined that the specific drug that are prescribed is a "preferred" drug which have the lowest cost-sharing or "non-preferred" which has the higher level of cost-sharing.

# What level of *Extra Help* is available to a dual eligible if their income is above 150% of poverty?

Medicare beneficiaries who receive Medicaid qualify for the full *Extra Help* subsidy no matter how high their income. In some cases, Medicare beneficiaries qualify for Medicaid through Medicaid buyin programs, Home- and Community-Based Waiver programs, or programs that use the 300% of SSI eligibility rule. All of these individuals qualify for the same subsidy as other dual eligibles with income above the poverty level.

#### What level of Extra Help is available to Medicare Savings Program participants?

Medicare Savings Program participants—i.e. people who receive Medicaid assistance with Medicare cost-sharing without receiving other Medicaid benefits—are not considered dual eligibles for purposes of determining the level of Extra Help they can receive. Medicare Saving Program participants (also called QMBs, SLMBs, and QIs) are automatically eligible for Extra Help, but they will be placed in the assistance level for non-dual eligibles with income below 135% of the poverty level. Please note that eligibility rules for Medicare Savings Program participants may vary from state to state and some states do not consider assets when determining eligibility for the Medicare Savings programs. This has no impact on assistance under the Extra Help program—all Medicare Savings program participants are eligible for Extra Help.

#### What is the Extra Help premium subsidy for Part D coverage in my state?

The federal government has divided the country up into Part D regions. Some regions consist of a single state, and other regions consist of many states. The average premium in each region determines the level of premium subsidy available to *Extra Help* recipients.

Region	State(s)	Extra Help Premium Subsidy
1	NH, ME	\$36.09
2	CT, MA, RI, VT	\$30.27
3	NY	\$29.83
4	NJ	\$31.37
5	DE, DC, MD	\$33.46
6	PA, WV	\$32.59
7	VA	\$34.42
8	NC	\$36.30
9	SC	\$34.88
10	GA	\$33.15
11	FL	\$29.07
12	AL, TN	\$32.33
13	MI	\$33.22
14	ОН	\$30.69
15	IN, KY	\$35.69
16	WI	\$31.27
17	IL	\$31.60
18	MO	\$31.37
19	AR	\$35.45
20	MS	\$36.39
21	LA	\$34.14
22	TX	\$31.68
23	OK	\$35.13
24	KS	\$33.44
25	IA, MN, MT, ND, NE, SD, WY	\$33.11
26	NM	\$25.95
27	СО	\$28.92
28	AZ	\$24.62
29	NV	\$23.46
30	OR, WA	\$30.60
31	ID, UT	\$33.62
32	CA	\$23.25
33	HI	\$27.44
34	AK	\$34.66

### What happens if individuals cannot afford to pay the cost-sharing when they try to pick up a prescription they need?

Unlike in Medicaid, where pharmacists are required by law to dispense prescription drugs even in individuals cannot afford to pay their cost-sharing, pharmacists are permitted to deny drugs to customers when they fail to pay their cost-sharing.

However, the law permits pharmacies to dispense drugs when the cost-sharing is not paid as long as they do not advertise that they will not charge cost-sharing, and as long as the decision is based on a pharmacist's judgment that the individual is unable to pay the cost-sharing.

# What assistance may be available to assist with cost-sharing expenses for persons who do not qualify for *Extra Help*?

Several options exist that may be able to assist Medicare beneficiaries with the cost of their Part D prescription drug coverage. While these will not be viable options for all people or in all circumstances, they provide a place to start in seeking additional assistance:

#### • State Pharmacy Assistance Programs (SPAPs)

State pharmacy assistance programs (SPAPs) are state programs, other than Medicaid, that provide financial assistance to Medicare beneficiaries in purchasing prescription drugs. In the absence of Medicare prescription drug coverage, these programs have served as a low-cost way for participants to obtain prescription drugs. At least some SPAPs are planning to fill gaps in coverage that arise, such as assisting participants in meeting their Part D cost-sharing obligations.

As of 2004, 29 states operated SPAPs, and nine more states had passed legislation as a precursor to implementing such a program. To date, the majority of SPAPs serve only persons age 65 and over, although some states also cover non-elderly people with disabilities. SPAPs receive special treatment under the MMA compared to other government programs, and this may spur more states to cover non-elderly people with disabilities. The special treatment provided by the MMA refers to the treatment of SPAP assistance when calculating the level of Medicare drug coverage and eligibility for catastrophic coverage. For example, if an individual participates in an SPAP and receives cost-sharing assistance, or if the program provides prescription drugs during the coverage gap, the value of this assistance will count toward TrOOP.

#### Charitable Sources

Federal rules permit charities that are not connected to the Part D plan or the beneficiary's employer to play a role in helping beneficiaries with their out-of-pocket costs. These rules view charitable organizations broadly so that even if an organization is not a bona fide charity for purposes of Federal

fraud and abuse law, any drug payments it makes on behalf of Part D enrollees would count toward TrOOP.

#### Pharmaceutical Patient Assistance Programs (PAPs)

Pharmaceutical manufacturers operate patient assistance programs (PAPs) that assist individuals with access to drugs on a compassionate use basis for individuals without insurance or another payment source. Each PAP has different eligibility requirements, but it is unclear whether current law will allow PAPs to supplement Medicare drug coverage. Even if it is permitted, it is currently unclear whether the value of any assistance provided by the PAPs would count toward TrOOP.

One resource for finding out more about these programs is the Partnership for Prescription Assistance. It describes its mission as offering individuals, their families and health professionals "a single point of access to more than 475 public and private patient assistance programs, including more than 150 programs offered by pharmaceutical companies. The Partnership can be reached toll-free, 1-888-4PPA-NOW (1-888-477-2669) or online at http://www.pparx.org.

#### • Family Members

Although many families will not have the financial resources to assist their family members with supplementing Medicare drug coverage, the law permits their contributions to count as though they were made by the individual. Therefore, any spending by family members (such as by buying drugs for the individual during the coverage gap or paying the co-payment at the pharmacy) would count toward TrOOP.

#### **Action Steps for People with Disabilities**

Many people with disabilities rely heavily on prescription drugs, and any thought of changing how they get their drugs can produce a great deal of anxiety. While the new Medicare Part D program is complicated, it is expected that nearly everybody will have drug coverage that is as comprehensive as they had before. And, if problems arise, there are often solutions.

To help simplify what Medicare beneficiaries with disabilities need to do to protect their own access to prescription drug coverage, we have developed the following five steps for success. We encourage all Medicare beneficiaries with disabilities to:

- 1. Decide whether or not to participate in the Part D program;
- 2. Ensure that they get all of the financial assistance for which they are eligible;
- 3. Select a prescription drug plan that meets their needs;
- 4. Keep a Health Care Journal; and,
- 5. Advocate for themselves to get all of the drugs they need

#### 1. Decide whether or not to participate in the Part D program

Essentially all Medicare beneficiaries with disabilities should enroll in the Part D program. The one exception is in the case of people who receive retiree health coverage from their former employer. In this case, they will have the option of retaining this coverage without penalty, as long as their retiree coverage is at least as comprehensive as coverage under the Part D program. In the fall of 2005, individuals with retiree coverage should receive a letter from their retiree plan that will tell them whether or not their coverage is comparable to Part D coverage.

While participating in the Part D prescription drug program is voluntary, the program's structure is intended to lessen the cost for all beneficiaries by having all Medicare beneficiaries participate as soon as they become eligible for Medicare.

To prevent people from waiting to enroll in Part D until they need extensive prescription drugs, the program has substantial late enrollment penalties. As a general rule, the penalty is 1% of the premium per month that a person delays enrolling in these programs. Therefore, a one year delay results in premium surcharge of 12% and a five year delay results in a premium surcharge of 60%. Individuals are required to pay this late enrollment penalty for the rest of their lives—i.e. as long as they remain enrolled in the Medicare program.

#### 2. Ensure that they get all of the financial assistance for which they are eligible

Once a decision has been made to enroll in the Part D program, the next critical step is to ensure that individuals obtain all of the financial assistance for which they qualify. This includes *Extra Help*, as well as Medicaid and the Medicare Savings Programs.

*Extra Help:* To apply for *Extra Help* individuals should contact the Social Security Administration or the Medicaid office. While Social Security will be set up to handle the large volume of *Extra Help* applications, if individuals apply through their Medicaid office, they should also be screened for Medicaid eligibility and for the Medicare Savings Programs.

To help individuals find their local Social Security office, go online to: http://s3abaca.ssa.gov/pro/fol/fol-home.html. Individuals can also call toll-free 1-800-772-1213. For people who are deaf or hard of hearing, the toll-free TTY line is 1-800-325-0778.

Since each state operates its own program, there is not a central number that everyone can call nationwide to get information about Medicaid in each state. Therefore, to get information individuals should call their state Medicaid agency. The number can be found by looking in the phone book in the State Government pages (often blue pages). Some states refer to Medicaid as "Medical Assistance". In California, for example, Medicaid is called "Medi-Cal".

*Medicare Savings Programs (MSP)*: This program does not assist with prescription drug coverage, but pays Medicare Part B premiums, and depending on one's income, also pays Medicare cost-sharing for expenses other than drugs (such as cost-sharing for a hospital stay). These programs are operated by state Medicaid programs and participants are called *partial benefit dual eligibles*.

MSP includes the Qualified Medicare Beneficiary (QMB) program, the Select Low-income Medicare Beneficiary (SLMB) program, and the Qualifying Individual (QI) program. These programs offer differing levels of assistance as individuals move up the income scale. The QMBs, who have income below the poverty level (monthly income of \$797.50 for a single person in 2005) receive assistance with Medicare Parts A and B premiums and cost-sharing. SLMBs, persons with income from 100-120% of the poverty level (monthly income from \$797.50 – \$957 for a single individual in 2005) receive assistance with only the Part B premium (\$88.50 per month in 2006). The QI program is not guaranteed to individuals. States received fixed grants from the federal government, and if participation is full individuals are turned away. Individuals who qualify have income from 120-135% of poverty (monthly income between \$957 and \$1,076.63 for a single individual in 2005) and participants also receive assistance with the Part B premium. Participants in the Medicare Savings Programs automatically qualify for *Extra Help*. To be screened for eligibility for the Medicare Savings Programs, individuals should contact their state Medicaid office.

#### 3. Select a prescription drug plan that meets their needs

In order to ensure that dual eligibles will not experience interruptions in their drug coverage, they will be randomly assigned to a Part D plan even if they do not take any steps to enroll in the Part D program. They are receiving special treatment because they are the only group losing their current prescription drug coverage before the Part D program takes effect. Individuals who are assigned to a plan should clearly understand that this assignment was made on a random basis, and the specific plan in which they were enrolled may not meet their needs. These individuals may switch to another plan that may better meet their needs.

# All Medicare beneficiaries with disabilities must do the homework to educate themselves and select a plan that meets their needs.

Selecting a plan that meets their needs is often a very personal decision. Some people may care more about certain factors than others. For example, *Extra Help* recipients may want to eliminate all plans that cost more than the regional average, otherwise they would be responsible for some of the premium costs. Others, however, may be focused on ensuring that their local pharmacy is in their plan's network. Since the selection of a plan can be overwhelming for many people, a large number of people will need assistance with this decision.

Physicians can be an important source of information, although they will likely not be able to make an informed recommendation on what plan is best for an individual. However, physicians should be consulted to learn if an individual has flexibility in substituting other drugs for the ones they are currently taking, in case a certain drug is not on the formulary, or if the cost-sharing is prohibitively expensive.

Individuals will also have access to a wide range of information about plan options in their region. The first place that individuals should start in gathering information is Medicare. For persons with access to the Internet, this is perhaps the easiest way to get information. Go to http://www.medicare. gov. In addition to basic information, there is a plan comparison tool where individuals can input information about themselves, and it will provide information about some of the plans that will meet their needs.

Within the Medicare.gov website, there is a Landscape of Local Plans page, http://www.medicare.gov/medicarereform/map.asp where individuals can find Medicare prescription drug plans by state or Medicare Advantage plans with prescription drug coverage by county. Individuals can see the plans in their area that offer drug coverage, including basic information to help identify the plans that meet an individual's needs based on cost, coverage, and convenience.

Individuals who do not have internet access can call 1-800-MEDICARE (1-800-633-4227). For people who are deaf or hard of hearing, the toll-free TTY line is 1-877-486-2048.

The following is a list of some major questions that beneficiaries with disabilities and those that may assist them in selecting a plan might want to ask and answer in order to make an informed choice of plans:

#### **Questions To Ask Your Physician**

Before going to the doctor, individuals should make a list of all drugs they take, the dose of the drug they take (i.e. 20 mg.), and the frequency (2 times per day)

Questions for the doctor:

- What is the purpose for taking each drug?
- Are there alternative drugs that may be equally effective?
- If a Part D plan or my pharmacist wants to substitute another drug for the drug prescribed, is this safe? Are there certain drugs that raise special concerns?

#### **Questions To Answer Before Selecting A Plan**

Does the individual have a preferred pharmacy? Is it in the plan's network?

What prescription drugs does the person take?

For each drug, is the drug on the plan's formulary?

**If yes:** What is the cost-sharing for receiving the drug?

Is prior authorization required to receive the drug?

Are there quantity limits on the drugs that will be provided?

**If no:** What drugs in the same class are on the formulary?

Ask your physician, if it is acceptable to substitute the on-formulary Drug

In managing the cost of Part D coverage, is a low premium plan a priority? Is this still important if the low premium plans charge higher cost-sharing?

For assistance in answering these questions, use the worksheets at the back of this guide.

To enroll in a plan, individuals identify the plan they want, and they should contact the plan directly. If they do not know how to contact the plan, they can contact Medicare for this information.

#### 4. Keep a Health Care Journal

In most cases, access to prescription drugs under the Part D program will not be problematic. There will be cases, however, where the plan may initially deny coverage for a drug because they do not believe the drug is medically necessary, the drug is not on the formulary, or because the plan believes a lower cost drug may be more appropriate. Some of these plan decisions are in the best interest of the individual. In other cases, however, individuals may need to request an exception to the plan's normal coverage policy, or they may need to appeal a plan's denial of a drug. In such a case, the prescribing physician is likely an individual's best advocate in getting the plan to reconsider or getting the denial overturned. Individuals can also help bolster their case for needing a drug by supplementing their physician's professional judgments with their own detailed health history.

# **Empowered health care consumers should keep a Health Care Journal.**

In a notebook, folder, or journal, individuals should keep track of all medications they take; when they visit the doctor, the purpose, and the outcome of the visit; as well as a log of symptoms...individuals should be encouraged to write down the dates of every time they get sick, feel depressed, or encounter other health problems, as well as how long the problem lasts. If a drug is working effectively it is important that this be noted as well.

#### 5. Advocate for themselves to get all of the drugs they need

A new feature of the Medicare Part D program is the *exceptions process*. This is a process where an individual can request that a plan cover a drug at the lowest level of cost-sharing, even if the plan normally charges a higher level of cost-sharing for the drug. This process also creates an opportunity for an individual to obtain coverage for drugs that their plan has kept off the formulary. The exceptions process is intended to be an easier process than a formal appeal for requesting coverage for drugs. To request an exception, an individual needs the support of their treating physician, and the physician must state that the requested treatment is needed by the individual and less costly alternatives have not worked for the individual or are unsafe or inappropriate for the individual.

If an individual has gone through the exceptions process and has still been denied a prescribed drug that they need, they have a right to access the appeals process.

As a general rule, Part D plans must respond to a standard appeal within 7 days and they must respond to an expedited appeal within 24 hours; in all cases, however, plans must respond "as expeditiously as the enrollee's health requires".

If individuals are denied a drug and their health or safety is placed at risk by not having access to the drug, they should request an expedited appeal.

If an initial appeal is denied, there are several additional levels of review that can be pursued. This includes a right to have their request for a drug reviewed by an Administrative Law Judge, who is independent of the Part D plan. Once an individual has exhausted their appeals rights, they also can access the federal courts—although this process can take months or years and is not likely an option for resolving routine disputes over the coverage of drugs.

The first step in requesting an exception or an appeal is for the individual or their representative to contact their Part D plan and specifically state that they would like to request an exception (or appeal).

#### **Action Steps for Disability Organizations**

The Medicare Party D program is complicated...and it is probably not the main focus of your organization. Nonetheless, whatever the level of available resources, do what you can. The worst thing that disability organizations could do would be to decide the law is too complex—and thus, do nothing.

As with recommendations for individual Medicare beneficiaries with disabilities, we have sought to simplify the actions that disability organization could do—to spur you to action. We encourage all disability services providers and disability advocacy organizations to:

- 1. Train frontline staff who work directly with clients/members;
- 2. Conduct community forums and educational programs for clients/members;
- 3. Identify community resources for assisting with educational efforts and/or supplementing Part D coverage;
- 4. Provide one-on-one counseling, if practical; and,
- 5. Monitor the experience of Medicare beneficiaries with disabilities.

#### 1. Train frontline staff who work directly with clients/members

The federal Centers for Medicare and Medicaid Services (CMS) has devoted significant resources to help ensure that Medicare beneficiaries understand how to access prescription drugs through the Part D program. This includes several training opportunities for community-based organizations. Additionally, most of the national disability advocacy organizations have developed programs to train their members on the Part D program. Contact these organizations and request information and seek out training opportunities.

A number of organizations have also teamed up with federal officials to conduct outreach on the Part D program. The Access to Benefits Coalition has developed multiple resources that may be helpful to disability organizations. To learn more, go to http://www.accesstobenefits.org/.

#### 2. Conduct community forums and educational programs for clients/members

Do not become intimidated about being an expert on all of the details of the prescription drug program. In the absence of your organization preparing for the transition to Part D coverage, dual eligibles will have their Medicaid drug coverage end, and other Medicare beneficiaries will still have to select a plan. Your involvement can only help individuals to make more informed decisions. As with trainings for frontline staff, federal resources and national organizations may be available to assist with training and outreach.

# 3. Identify community resources for assisting with educational efforts and/or supplementing Part D coverage

As discussed earlier, states, Area Agencies on Aging, state pharmacy assistance programs, pharmaceutical patient assistance programs, churches and religious organizations and charities may be available to provide resources to assist organizations in conducting education and outreach—and to support individuals by providing supplementary financial assistance. An important role for community-based organizations is to assess which community resources exist and determine if such resources are planning to provide assistance to people with disabilities.

State Health Insurance Counseling and Assistance Programs (SHIPs) are federally funded programs operating in every state to assist Medicare beneficiaries. They are available to educate Medicare beneficiaries about Medigap supplemental insurance options, Medicare private plan options, procedures for appealing pre- or post-service denials, and low-income assistance programs. With the establishment of the Part D program, they also have an important role to play in assisting Medicare beneficiaries. To find the SHIP program in an individual state, go to http://www.medicare.gov/contacts/Static/SHIPs.asp?dest=NAV or call 1-800-MEDICARE (1-800-633-4227). For people who are deaf or hard of hearing, the toll-free TTY line is 1-877-486-2048.

#### 4. Provide one-on-one counseling, if practical

Despite the best efforts of many people and organizations to simplify the Part D program and to explain the range of options available to individuals, the system is too complicated for many individuals to navigate on their own. To the extent that it is feasible, disability organizations should seek to provide one-on-one counseling—or link individuals to such assistance if this support is available elsewhere.

As part of this effort or as a substitute for one-on-one assistance, organizations should develop sample plan comparisons. For example, an organization that works with people with a specific type of disability could develop a "typical" drug regimen, and use this to compare the plans available in the region. Or, it may be known that many people rely on one particular pharmacy. Therefore, a plan comparison could look at which plans provide access to a particular pharmacy. This could be especially important for residents of nursing home or other long-term care facilities.

#### 5. Monitor the experience of Medicare beneficiaries with disabilities

As of January 1, Medicare drug coverage will begin. But, this is the beginning, not the end of the story. Unforeseen issues will arise, and many problems will be resolved. To make future improvements to the Medicare Part D program possible, it will be important to gather evidence of *both* the successes and challenges experienced by Part D plans in meeting the needs of Medicare beneficiaries with

disabilities. Disability organizations have an important role to play in tracking the experience of people trying to access prescription drug coverage.

Do people with disabilities have a positive experience in a certain plan? Are there problems getting plans to approve coverage for a specific drug? Are there accessibility issues that arise?

In addition to individual stories (which are very helpful), organizations should consider developing a survey of their members/clients after some initial period (such as 6 months after the Part D program starts). Organizations should also be creative in thinking of other ways that they can collect information to shed light on how the Part D program is working from the perspective of people with disabilities.

#### **Key Contacts and Other Resources**

#### **Federal Government Resources**

Centers for Medicare and Medicaid Services (CMS) (FOR CONSUMERS): http://www.medicare.gov/medicarereform/default.asp

Centers for Medicare and Medicaid Services (CMS) (FOR ORGANIZATIONS): http://www.cms. hhs.gov/medicarereform/

Social Security Administration (SSA) (FOR CONSUMERS): http://www.ssa.gov/prescriptionhelp/

Social Security Administration (SSA) (FOR ORGANIZATIONS): http://www.ssa.gov/organizations/medicareoutreach2/

#### **National Organizations and Research Organizations**

Access to Benefits Coalition: http://www.accesstobenefits.org/

Center for Medicare Advocacy: http://www.medicareadvocacy.org/

Henry J. Kaiser Family Foundation: http://www.kff.org/medicare/rxdrugdebate.cfm

Medicare Rights Center: http://www.medicarerights.org/

# **Consumer Drug Information Worksheet**

(Make multiple copies, as needed)

# Questions for Your Physician

Before going to the doctor: Fill out this form for all drugs that you are taking. By looking at the prescription bottle, fill in the dosage and the frequency.

With your doctor, nurse or other provider: Ask for help in filling out the remaining cells.

	Physician Special Concerns										
	Treatment Substitutions Acceptable? (Circle One)	Yes No									
During the doctor visit	Purpose										
	<b>Frequency</b> (i.e. 2 times per day)										
ctor visit	<b>Dose</b> (i.e. 20 mg.)										
Before the doctor visit	Drug Name										

Name of Insurer:

Name of Plan:

# **Consumer Plan Selection Worksheet**

(Make multiple copies, as needed)

# Questions for Each Part D Plan

hard of hearing, the toll-free TTY line is 1-877-486-2048. To calculate plan premium level, determine if you qualify for Individuals who do not have internet access can call 1-800-MEDICARE (1-800-633-4227). For people who are deaf or Complete this form for each potential plan. For persons with access to the Internet, go to http://www.medicare.gov. Extra Help. If you qualify for the full subsidy, see table on page 15 for subsidy level.

Yes No	Using Physician Responses	Physician Special Concerns										
Is it in the plan's network? Yes	Using Physic	Treatment Substitutions Acceptable? (Circle One)	Yes No	Total:								
Is it in the p		Plan Has Quantity Limits? (Circle One)	Yes No	Total:								
	Drug Coverage Information	Prior Authorization Required? (Circle One)	Yes No	Total:								
		Cost- Sharing										Total \$:
pharmacy?		On Formulary? (Circle One)	Yes No	Total:								
our preferred		Drug Name										
Pharmacy Access: What is your preferred pharmacy?	Plan Premium Level	Individual Monthly Premium (C) $C = A - B$										
		Extra Help Premium Subsidy (B)										
Pha	Plan Pre	Monthly Plan Premium										