



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

IOM Essential Health Benefits Survey Responses

1. What is your interpretation of the word “essential” in the context of an essential benefit package?

The Consortium for Citizens with Disabilities (CCD) believes that “essential” benefits should be defined as follows:

“Health care benefits that the reasonable person would believe are covered under a standard policy of health insurance, not only to address primary and acute care needs, but also the ability to function physically and mentally after an illness, injury, disability, or chronic health condition.”

The Importance of Function: Essential benefits should clearly include emergency services and trauma care when life and limb are at risk. It should also include health services that sustain life and health status such as hospital and physician care, prescription drugs, kidney dialysis, organ transplantation, and mental health care, to name a few examples. But essential benefits should also include rehabilitation and habilitation services and devices that restore or maintain the ability of a person to ***function*** in their environment after an illness, injury or ongoing health condition or that allow a person (e.g., a child) to attain a level of functioning they would not be able to achieve without such services.

In 1998, the President’s Commission on Consumer Protection and Quality in the Health Care Industry issued its final report where it defined the purpose of the health care system. The report stated,

“the purpose of the health care system must be to continuously reduce the impact and burden of illness, injury, and ***disability***, and to improve the health ***and functioning*** of the people of the United States.”

For instance, a person with a missing limb can be perfectly healthy from a primary care standpoint, but without appropriate prosthetic limb care, that person would be largely non-functional and subject to secondary health conditions. After the initial period following amputation, this medical condition is not an acute health concern but rather a functional deficit that can be well addressed by prosthetic care that is consistent with contemporary standards of medical practice.

In addition to acute and primary care, the definition of essential health benefits must reflect this important component of health services, *i.e.*, coverage of services that improve, maintain, and lessen the deterioration of a person's functional status. If a person has a major health care event such as a traumatic brain injury, a stroke, or a spinal cord injury, essential benefits would obviously include emergency care, hospitalization, physician services and pharmaceuticals to address the immediate medical condition. But essential benefits must also include *rehabilitative and habilitative care*, both therapies and medical devices, as well as psychological and behavioral services to restore as much function as possible at the appropriate level of intensity and within a reasonable timeframe.

A Narrow Definition Will Subvert Health Reform: To more narrowly constrain essential health benefits would result in vast numbers of privately insured persons realizing too late that their essential health care needs are not met when a health care conditions strikes. This will prompt significant out-of-pocket costs on behalf of the affected person or result in the person going without needed care. Depending on the severity of not receiving needed services, in some instances, a person will ultimately be required to “spend down” and join Medicaid and other publicly supported programs in order to access needed care. In this manner, an essential benefits package that is too narrowly defined will subvert the intent of national health care reform.

Consideration of Publicly Supported Programs: In addition to examining the “typical employer plan” for guidance in defining the essential benefits package, the IOM and the Secretary of Health and Human Services should examine the benefit packages of the major publicly-supported programs as another point of reference. The Medicare program, the Veterans Health Benefits program, the Department of Defense health program and the standard option under the Federal Employee Health Benefits Program (FEHBP) all cover significant benefits relevant to people with disabilities and chronic conditions. The benefit packages of these plans should be considered in the development of the essential health benefits package.

In order to reflect a range of experience and accurately capture all essential benefits, we strongly recommend the development of a patient-centered, reasonable person definition of “essential health benefits” that focuses not only on acute and primary care, but also on a patient's functional capabilities and their needs over a lifetime and on a treatment continuum.

2. How is medical necessity defined and then applied by insurers in coverage determinations? What are the advantages/disadvantages of current definitions and approaches?

CCD believes the definition of medical necessity is critical if the essential benefits package is going to be meaningful. A generous benefit package can be easily rendered insufficient if a restrictive definition of medical necessity is employed. The definition of medical necessity must balance the need for consistency with the need to apply the

medical necessity definition to each individual, given the totality of that person's health condition. For instance, inpatient hospital rehabilitation may be medically necessary for a 60-year old stroke survivor who is in poor health and lives alone, but may not be medically necessary for a 60-year old with the same condition who is relatively healthy and has support in the home.

Importance of the Physician-Patient Relationship: Whatever definition of medical necessity that is used by health plans, it is critically important that the definition does not trump the physician-patient relationship. Deference to the determination of medical necessity should be given to the physician actually treating the patient and such deference should only be overridden if there is evidence that such deference is not appropriate in a given instance. Decisions that challenge this deference and limit health care services based on a lack of medical necessity must be clearly explained in writing to the patient and must be subject to a timely internal appeal as well as an external, independent review with decisions being binding upon the health plan.

Medical Necessity Considerations: Medical necessity has a variety of definitions, interpretations and applications in the private insurance market (See Singer, *et. al.*, Decreasing Variation in Medical Necessity Decision Making, Final Report to the California Health Care Foundation, 1999). Most plans and public health programs rely on some variation of medical necessity meaning “services required to preserve a patient’s health status, in accordance with the standards of medical practice.” Medical necessity should not be a global definition that is applied to individual patients without regard to their individual needs—health benefits covered should enable individuals to be healthy, functional, live as independently as possible, and participate in the community.

Other than being directed by physicians, all health care services should have a clear treatment or rehabilitative goal or other medically necessary goal, and services should not be denied if measureable progress towards that goal is being made. Medical necessity does not necessarily mean that the patient’s health or function will improve. Even if the intervention of services slows the deterioration of health status, services should be considered medically necessary. Medical necessity should not be a mechanism to intrude upon the patient and physician relationship or interfere with communications regarding the treatment options between the patient and provider.

The CCD also supports a definition and application of medical necessity that protects against restricted access to certain benefits or settings of care. Health care providers should be free to fully disclose all relevant treatment options and information to patients making health care decisions. Medical necessity reviews should be conducted by providers with parallel qualifications to the treating provider (*e.g.*, psychiatrists should review care furnished by treating psychiatrists and physiatrists should review care furnished by treating physiatrists).

Medical Necessity Applied to People with Disabilities: People with disabilities of all ages and their families must have access to health care that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic

conditions. It is critical for all patients to have access to services to address their functional status. While current outcome measures in our healthcare system tend to reflect the benefits of short-term acute and primary care, those measurements generally do not reflect the experience of patients seeking care for conditions that last for an extended period or for a lifetime and that manifest themselves in functional impairment.

CCD believes that it is just as medically necessary to provide antibiotics to a person with an infection as it is to provide rehabilitative and habilitative services and devices to a person with a functional limitation. The focus of these treatments is not to provide a cure or ultimately “fix” the condition—indeed such a “cure” is rarely an option—but rather to improve a patient’s quality of life by improving, maintaining or preventing deterioration of a patient’s capacity to function. Delivering appropriate care to such patients in the private insurance market to date has run the risk of violating this goal as health plans often limit risk and coverage to ensure profit.

It is most advantageous to patients when medical necessity is coupled with a directive to apply it to patient’s individual health needs in order to produce the best health outcomes. For instance, Medicaid’s Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) program includes medical necessity criteria that ties medical need directly to the individual. Whereas private market plans can limit medically necessary care to strict guidelines based on diagnosis codes to *restore* function only, EPSDT takes into account the treatment needs of people with disabilities so that benefits are provided to restore health, maintain function, and improve long-term health outcomes. (See Comparing EPSDT and Commercial Insurance Benefits, The Commonwealth Fund, September 2005).

Health care coverage denials in the private insurance market are often based on a “lack of medical necessity.” Through the years, patients and consumers began to demand help and oversight from the states, relying upon laws and regulations to ensure independent review of medical necessity. (External Review of Health Plan Decisions: An Overview of Key Program Features in the States and Medicare; K. Pollitz, et al, Kaiser Family Foundation). It is critical for plans to provide for independent review of denials or coverage limitations, including those that rely on medical necessity for the decision. Independent, prompt external reviews of medical necessity coverage determinations can benefit patients, prevent discrimination and fraud, and reduce administrative waste.

3. What criteria and methods, besides medical necessity, are currently used by insurers to determine which benefits will be covered? What are the advantages/disadvantages of these current criteria and methods?

Additional criteria and methods used to determine benefits include decisions based on evidence-based medicine or the use of comparative effectiveness research; coverage limitations such as “step” therapy, fail-first polices or other cost-effectiveness policies; and extra-contractual service provisions in contracts of insurance. Finally, a recent legal settlement is instructive as to the meaning of medical necessity and is cited below.

Evidence-Based Medicine: CCD believes that evidence based medicine or comparative effectiveness research is, and should continue to be, an important tool in helping patients and providers distinguish between the effectiveness of treatment options. Having better evidence to support the clinical effectiveness of a wide range of health care interventions has the potential to lead to improvements in the quality of care and could potentially maximize the impact of the healthcare dollars spent in this country. This research should be applied in a manner that does not lead to inappropriate restrictions in coverage of and access to assistive devices, therapies, treatments, medications, and long term services and supports for people with disabilities and chronic illnesses.

Many of the assistive devices, technologies, and therapies used by persons with disabilities to be functional and live independent and fulfilling lives have widespread application and are generally accepted by physicians and other health care professionals. Many of these services and devices do not have a robust evidence base in the traditional sense, especially with respect to treatments for children.

Disability Impact of Evidence-Based Practice: With respect to health coverage, it is important to recognize that disability conditions vary widely in severity and complexity. There are often multiple co-morbid conditions in play and many disabilities are low prevalence, making specific and meaningful clinical effectiveness studies challenging to pursue. Even well-grounded research on the general population can be easily misapplied to the disability and chronic illness populations, especially to persons with intellectual, behavioral and cognitive disabilities. It is critical that the outcomes of such research are not misapplied or used to broadly establish coverage rules that trump an individual's circumstances and specific needs.

Comparative effectiveness and evidence-based medicine should ultimately provide information to doctors and patients that will help guide real-world clinical treatment decisions for the individual patient at the point of care. Such research should be a tool for practitioners, patients and caregivers, not a bright-line decision applied across the board to the "average" patient as a final decision on coverage.

Cost-Effectiveness: CCD believes that coverage decisions, incentive programs, and benefit design must not discriminate against individuals because of their age, *disability*, or expected length of life. Coverage limitations that rely largely on cost effectiveness are of great concern, because they can ignore the patient's long-term health care needs and limit coverage by directing benefits to the short-term, least-costly options. For instance, the Medicare Part D program and many private insurers often use "fail first" or step therapy policies for prescription drug coverage that do not take into account the patient's health, history or physician choice of the most appropriate care. But this is not necessary. In private plans and public programs that do take these factors into account, the plans ultimately save money by reducing negative health outcomes while meeting the individual patient's unique healthcare needs.

Extra-Contractual Services: Insurance policies occasionally use contractual provisions known as "extra contractual services" to cover benefits that may not be explicitly listed in

the benefit package, but that are reasonable to treat a person's condition. The key element of this language is that such services are only covered if they would obviate the need for more expensive benefits that *are* explicitly included in the benefit package. An example might be where a health plan covers safety devices in the bathroom of a person with a history of falling. If coverage of these safety device benefits on an extra-contractual basis would eliminate the need to place that person in a nursing home, the plan may in fact cover that benefit. The CCD believes this is an important clause that should be included in the essential benefits package to ensure such flexibility in meeting patients' needs.

Legal Settlement: A recent, major legal settlement also helps define the term "medical necessity." Aetna, CIGNA, Health Net, Prudential, Anthem/WellPoint, and Humana agreed with the following general definition in a settlement agreement with 900,000 physicians during the time period of the suit, 2003 through 2006.

"Medically Necessary" or "Medical Necessity" shall mean health care services that a physician, exercising prudent clinical judgment, would provide to a patient for the purpose of preventing, evaluating, diagnosing or treating an illness, injury, disease or its symptoms, and that are: a) in accordance with generally accepted standards of medical practice; b) clinically appropriate, in terms of type, frequency, extent, site and duration, and considered effective for the patient's illness, injury or disease; and c) not primarily for the convenience of the patient, physician or other health care provider, and not more costly than an alternative service or sequence of services at least as likely to produce equivalent therapeutic or diagnostic results as to the diagnosis or treatment of that patient's illness, injury or disease. For these purposes, "generally accepted standards of medical practice" means standards that are based on credible scientific evidence published in peer-reviewed medical literature generally recognized by the relevant medical community or otherwise consistent with the standards set forth in policy issues involving clinical judgment. Further, the court stated that "unless the contrary is specified, the term "medical necessity" must refer to what is medically necessary for a particular patient, and hence entails an individual assessment rather than a general determination of what works in the ordinary case. But where, as here, the plan administrator presents sufficient evidence to show that a treatment is not medically necessary in the usual case, it is up to the patient and his or her physician to show that this individual patient is different from the usual in ways that make the treatment medically necessary for him or her." See, *Defining Medical Necessity*, Janet L. Kaminski, Attorney <http://www.cga.ct.gov/2007/rpt/2007-r-0055.htm>

4. What principles, criteria, and process(es) might the Secretary of HHS use to determine whether the details of each benefit package offered will meet the requirements specified in the Affordable Care Act?

The key principles and criteria the Secretary should use to ensure appropriate benefits packages are found in the ACA itself and include the following:

- The Secretary may not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of, among other things, disability. [See Section 1302(b)(4)(B) of the ACA]
- The Secretary must take into account the health care needs of persons with disabilities, among other segments of the population. [See Section 1302(b)(4)(C) of the ACA]
- The Secretary must ensure that health benefits established as essential are not subject to denial to individuals against their wishes on the basis of the individual's present or predicted disability, degree of medical dependency or quality of life. [See Section 1302(b)(4)(D) of the ACA]

CCD Principles: For many years, CCD has used the following principles to guide the assessment of healthcare reform proposals and recommend that the Secretary use these same principles to ensure that these statutory provisions are fully implemented:

- **Non-Discrimination:** People with disabilities and chronic conditions of all ages and their families must be able to fully participate in the nation's health care system.
- **Comprehensiveness:** People with disabilities and chronic conditions must have access to benefits that provide an array of health, rehabilitation, assistive device and support services across service categories and sites of service delivery.
- **Continuity:** People with disabilities and chronic conditions of all ages and their families must have access to healthcare that responds to their needs over their lifetimes, and provides continuity of care that helps treat and prevent chronic illness.
- **Appropriateness:** People with disabilities and chronic conditions and their families must be assured that comprehensive health, rehabilitation, and long term support services are provided on the basis of individual need and patient choice.
- **Equity:** People with disabilities and chronic conditions and their families must have equitable access to health coverage programs and not be burdened with disproportionate out-of-pocket costs.
- **Efficiency:** People with disabilities and chronic conditions and their families must have access to health care that is effective and high quality with a minimum of administrative waste.

When determining whether the details of the benefits packages meet the requirements specified in the Affordable Care Act, the Secretary of HHS should keep several issues in

mind. It is imperative that the essential benefits package provides the services necessary to cover all populations including people with mental illness, substance use disorders, physical disabilities, as well as the aging, low-income populations and children. The Secretary of HHS must remain cognizant of the challenges and difficulties that may be experienced by such persons in accessing benefits. We encourage the IOM and the Department of HHS to design an essential benefits package that is comprehensive enough to meet the needs of people with physical disabilities, chronic conditions, mental health and substance use disorders, as well as developmental, sensory, and intellectual disabilities.

Mental Health and Substance Use Disorders: As to mental health and substance use disorders, CCD asks that the Department make clear to health insurance plans that the ACA requires a robust benefits package for mental health and substance use disorders that includes the full range of Mental Health /Substance Use Disorders (MH/SUD) prevention, early intervention, treatment, and rehabilitative and recovery support services. Limits on benefits may be no more restrictive than those allowed under the *Wellstone/Domenici Mental Health Parity and Addiction Equity Act of 2008 (MHPAEA)* and that law’s corresponding regulations. The Parity Law requires virtually all financial requirements and treatment limitations for MH/SUD benefits to be no more restrictive than the “predominant” financial requirements and treatment limitations that apply to “substantially all” medical/surgical benefits. These requirements must be addressed in the essential benefits packages to ensure that the full range of individuals is able to receive benefit from them.

Processes to Ensure Appropriate Benefit Packages: There are many ways in which the Secretary of HHS can measure how the essential benefits packages are meeting the requirements of the Affordable Care Act as well as to continue to monitor them over time. The Secretary should create and utilize Advisory Groups as a regular and integral resource to provide input to design considerations, obtain feedback on benefit packages, and share information with people with disabilities. This group should include individuals with disabilities, family members and caregivers, and providers. It should also include representatives of all disability groups – sensory, physical, mental and cognitive. The Advisory Group should have real ability to influence the decisions of the HHS Secretary on an ongoing basis.

The Secretary should also meet with members of state organizations, non-profit associations, advocates, providers and other important stakeholders who are devoted to furthering the rights of those populations in order to inform the process. Advice should also be solicited from providers of services as to “best practices.”

Formal Process to Add, Modify or Delete Coverage: The most important mechanism the Secretary should establish is a formal process to appeal to HHS to add, modify, or delete coverage of a particular service or device to the essential benefits package. The benefits packages should be evaluated annually to identify patterns in order to encourage parity and compliance with the principles that are listed above. This evaluation can be facilitated by the development of a survey or checklist of requirements of the essential

benefits packages that can be used by the Department and by insurance companies in the future.

5. What types of limits on specific or total benefits, if any, could be allowable in packages given statutory restrictions on lifetime and annual benefit limits? What principles and criteria could/should be applied to assess the advantages and disadvantages of proposed limits?

Benefit-Specific Exclusions: CCD is concerned that benefit-specific limitations (*e.g.*, dollar or treatment frequency) could be imposed to subvert the intent of restrictions on lifetime and annual limitations. Different types of illnesses or injuries may require different levels of medical intervention, treatment, or care. Accordingly, it is important that health plans and health insurance issuers not sidestep restrictions on lifetime and annual limits by either imposing caps on costs related to a specific treatment, or by limiting treatment frequency. For instance, some private insurance plans limit artificial limb coverage to one prosthesis per lifetime or durable medical equipment to a \$500 annual maximum. Both of these types of restrictions are completely arbitrary, unrealistic, and should be prohibited by the Secretary.

The Secretary should require that health plans and health insurance issuers act in good faith and impose no restriction or limitation designed to subvert the intent of the annual and lifetime limit restrictions. Such a finding by the Department or state Insurance Commissioners should render these types of limitations null and void.

Condition-Based Exclusions: CCD is also concerned that health plans and health insurance issuers may impose additional condition-based exclusions of benefits in order to limit health expenditures in the future. The interim final rule of the lifetime and annual limit provisions explicitly permits “condition-based exclusions” of benefits. CCD recommends that any condition-based exclusion of benefits must be rigorously reviewed in order to determine whether the exclusion violates the requirements of the Americans with Disabilities Act of 1990, which prohibits disability-based distinctions in health insurance coverage. In fact, in issuing interim guidance on this issue in 1993, the Equal Opportunity Employment Commission (EEOC) stated the following:

“[H]ealth-related insurance distinctions that are based on disability may violate the ADA. A term or provision is disability-based if it singles out a particular disability (*e.g.*, deafness, AIDS, schizophrenia), a discrete group of disabilities (*e.g.*, cancer, 5 muscular dystrophies, kidney diseases), or disability in general (*e.g.*, noncoverage of all conditions that substantially limit a major life activity).”

The Secretary must not promulgate a regulation on the essential benefits package that violates existing federal civil rights laws. In addition, federal and state oversight must ensure that health plans are aware of the ADA requirements and do not create plans that violate existing law.

6. How could an “appropriate balance” among the ten categories of essential care be determined so that benefit packages are not unduly weighted to certain categories? The ten categories are: ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorders services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; pediatric services, including oral and vision care.

Look to the Statute Itself: An appropriate balance among the ten categories of benefits in the essential benefits package will be achieved, in part, if the Secretary takes into account the very specific parameters in which she must operate under the ACA statutory language. Provisions in the ACA specify that in defining essential health benefits, the Secretary must ensure that such essential benefits reflect an appropriate balance among the categories so that benefits are not unduly weighted toward any category. This provision also requires parity in the provision of all categories of benefits. [See Section 1302(b)(4)(A) of the ACA.] Thus, those people with disabilities and chronic conditions who need rehabilitative and habilitative services and devices should not be hampered by unreasonably restrictive coverage policies in their ability to access appropriate treatment, especially if these same arbitrary limitations do not apply to other types of services.

In addition, the Secretary may not make coverage decisions, determine reimbursement rates, establish incentive programs, or design benefits in ways that discriminate against individuals because of, among other things, disability. [See Section 1302(b)(4)(B) of the ACA.] The Secretary must take into account the health care needs of persons with disabilities, among other segments of the population. [See Section 1302(b)(4)(C) of the ACA.] The Secretary must ensure that health benefits established as essential are not subject to denial to individuals against their wishes on the basis of the individual’s present or predicted disability, degree of medical dependency or quality of life. [See Section 1302(b)(4)(D) of the ACA.] This is very powerful language that is designed to ensure that normative judgments about the quality of life of a person with a disability are not used against people with disabilities when decision makers determine the essential benefits package.

The Benefit Categories Themselves Help Achieve an Appropriate Balance: Under the ACA, the following benefits—in addition to others—are required by statute to be included under the essential benefits package:

- Rehabilitative and habilitative services and devices;
- Mental health and substance use disorders services, including behavioral health treatment;
- Chronic disease management;
- Prevention and wellness services, and;
- Pediatric services, including oral and vision care.

These categories are the very benefits that many private insurance plans typically either do not cover or place significant limitations on coverage. The very fact that these categories of benefits must be included in the essential benefits package will help ensure an appropriate balance of benefits under private plans. These categories have profound implications on the ability of the private insurance system to meet the needs of people with disabilities and chronic conditions. The Secretary should scrutinize coverage of these benefits and not permit plans to place arbitrary barriers and unrealistic limitations on benefits in these categories. If, in fact, limits are placed on these types of benefits in order to achieve cost savings, the Secretary should ensure that similar limits are placed on all categories of benefits, so an appropriate balance of benefits is achieved.

Rehabilitative and Habilitative Services and Devices: For many people with disabilities and chronic conditions, rehabilitative and habilitative services and devices are essential medical interventions—equivalent to the provision of antibiotics to a person with an infection. Rehabilitative and habilitative services and devices:

- Speed recovery (better outcomes and enhanced likelihood of discharge to one’s home, living longer and retaining a higher level of function post injury or illness);
- Improve long-term functional and health status and improve the likelihood of independent living and high quality of life;
- Reduce the likelihood of relapse and rehospitalization;
- Halt or slow the progression of primary and secondary disabilities (maintain functioning and prevent further deterioration); and
- Facilitate return to work in appropriate circumstances.

Therefore, an appropriately balanced “rehabilitative and habilitative services and devices” category would include, but not be limited to:

- Rehabilitation therapies and other treatments such as pain management that improve, maintain, and prevent deterioration of function;
- Habilitation therapies or other treatments that enable a person (*e.g.*, a child) with a disability to attain functional abilities or lessen the deterioration of function over time; and
- Durable medical equipment, prosthetics, orthotics, and other assistive technologies and related services that do not include arbitrary limits on access to these devices and related services.

In order to determine whether plans are appropriately balanced, the Secretary could require plans to annually undergo a certification process that requires releasing all relevant plan details and complaints/appeals lodged during the course of that year, particularly as it pertains to benefit design and patient populations served. HHS could compare the data and evaluate patient and consumer surveys and public health assessments regarding vulnerable patients and their access to needed benefits. If a plan fails to provide an appropriately balanced benefit package, the Secretary should require the plan to expand access to benefits.

7. How could it be determined that essential benefits are “not subject to denial to individuals against their wishes” on the basis of age, expected length of life, present or predicted disability, degree of medical dependency or quality of life? Are there other factors that should be determined?

Prohibiting denial of benefits based on these factors is critical to creating a health care system that meets the needs of people with disabilities and chronic health conditions. Implementing these provisions will help ensure that value judgments about disability and quality of life are not used against people with disabilities in terms of benefit design or access to covered benefits.

Lessons from Oregon Medicaid: This statutory language likely derives from the experience known in disability circles as the “Oregon Medicaid Rationing Plan.” This involved a Medicaid waiver application submitted to the HHS Secretary in the early 1990’s. The waiver sought to expand coverage to the Oregon population but to do so in a manner that ranked the value of health services and funded those services in priority ranking. The services below a certain line would not be covered. In establishing the rankings of health conditions, the state used measures that assessed normative judgments of nondisabled people on the quality of life of people with disabilities. The rankings were shown to disproportionately impact people with disabilities because nondisabled persons tended to view services for people with disabilities as less valuable than services for people without disabilities. This was determined to violate the Americans with Disabilities Act of 1990 and, because of this, the waiver application was denied until the priority listing of funded services was completely reformulated. The language of the ACA statute appears to reflect this concern and takes precautions against this happening again.

Expected Medical Improvement: Another factor that should be added to this list is the “degree of expected medical improvement.” People with disabilities and chronic health conditions are often denied crucial services or treatments because their conditions are not expected to “improve.” However, this standard ignores the medical benefit of a person with multiple sclerosis or another degenerative disease maintaining functional status through therapies or other services. It also ignores the value of lessening the pace of deterioration of function, as well as preventing the onset of secondary conditions.

Consumer Directed Health Care: The CCD interprets the phrase “against their wishes” to be a reference to the importance of the health care delivery system to be patient-centered and consumer directed to the maximum extent possible. A health care delivery system that is person-centered and consumer directed has informed consumer choice in relation to providers and services, an appropriate amount, duration and scope of services, devices and related benefits and access to trained, qualified and appropriately credentialed health care personnel among other features.

Oversight and Compliance: To ensure that health plans are complying with this and other requirements related to the essential benefits requirements, the Secretary must establish an oversight system for receiving consumer and provider feedback, collecting

and analyzing data, and evaluating plan performance. Collecting information about who is being denied services, what types of services are being denied, and other information will help determine if unacceptable patterns of service denials are developing. The state and federal government need to ensure that a meaningful and independent external appeals program is established. Information about internal appeals and external appeals must be part of the data collection efforts as well. This information will be crucial to evaluating plan performance and ensuring that the plans are meeting the high standards for access, nondiscrimination, comprehensiveness and quality that the ACA establishes.

8. How could it be determined that the essential health benefits take into account the health care needs of diverse segments of the population, including women, children, persons with disabilities and other groups?

The structure of the new health care marketplace created by the ACA (*i.e.*, the Exchanges) along with performance measures will help to expose whether essential health benefits have taken into account the needs of diverse segments of the population such as people with disabilities.

State Exchanges: The new marketplace, the insurance products that will be available in the exchanges, and providers who participate in health plans will need to demonstrate they are both physically and programmatically accessible to people with disabilities and chronic conditions if the benefit package is going to truly meet the needs of diverse segments of the population. The Exchanges and the plans offered through the Exchanges will need to:

- Be patient-centered and consumer-directed to the maximum extent so that informed choices can be made;
- Provide access to trained, qualified and appropriately credentialed health care personnel to allow for the best outcomes for special populations;
- Utilize providers that understand the unique health needs of different populations so that they can help plan and coordinate care to better address the needs of the individual; and
- Be trained and aware of disability culture and the unique needs of the disability population.

Performance measures will be integral to determining whether the health care needs of diverse populations are being met by the essential benefits package. Data collection and information from both providers and consumers about the use of services will provide insight into access and utilization. This data will help determine which complaints are being brought forward, where patterns of care provision are forming, what types of care or services are being denied, and how complaints are being resolved.

9. By what criteria and method(s) should the Secretary evaluate state mandates for inclusion in a national essential benefit package? What are the cost and coverage

implications of including current state mandates in requirements for a national essential benefit package?

State mandated benefit laws should be respected to the greatest degree possible as the Secretary develops the essential health benefits package. Exclusion of significant numbers of state mandated benefits will result in the preemption of a large number of state mandated benefit laws, thwarting the legislative intent of numerous states. These benefit laws were duly enacted by elected officials to protect the needs of consumers in their respective states. The goals of efficiency, consistency, and cost reduction that come with a national standardized benefit package should not summarily lead to the invalidation of years of state lawmaking in the benefits area.

Respect for State Mandated Benefit Laws: State mandated benefit laws arise for a reason. Residents of a particular state rely on the fact that their health plan covers a particular benefit and when they discover that their needs are not met, they petition the government for protection of themselves and similarly-situated health care consumers. State mandated benefit laws exist because the private insurance market has failed to cover health benefits that duly-elected legislators and Governors subsequently deem worthy of coverage. The HHS Secretary should be very careful and deliberate when determining how state mandated benefit laws can be incorporated into the essential health benefits package and err on the side of inclusion of as many mandated benefits as possible. To the extent that such laws are included as essential benefits, concern for the federal preemption issue is significantly decreased.

For individuals with disabilities, mandated benefit laws can remedy coverage determinations that reflect bad health policy. Arbitrary determinations of medical necessity, denials based on artificial distinctions between habilitation and rehabilitation, exclusions in benefits based on flimsy evidence, and faulty judgments that specific treatments are experimental or investigational in nature, can entirely shut out vulnerable populations from access to health care. One benchmark for evaluating mandates should be their efficacy in improving benefits and services to populations at risk of poor health outcomes.

Cost-Benefit of Mandated Benefit Laws: Another factor to consider is the benefit of a mandate law relative to its cost. Market decisions regarding coverage may place undue emphasis on short-term economic costs rather than longer-term gains. A broad-based calculus should be used when evaluating mandates; extended life, reduced disability, and community savings should be considered when evaluating mandates. The National Association of Insurance Commissioner's most recent draft American Health Benefit Exchange Model Act supports such an approach ("For States choosing to require additional benefits and defray the cost, it is recommended that the costs of the additional benefits be measured on a 'net cost' basis to the extent permitted by federal law or regulations or guidance, considering both the costs of the service and any associated savings, based on an evidence-based methodology to determine the net cost, if any, of each additional benefit, and the value of the benefit to the State's residents.").

In the case of existing state mandates, continuity of care should also factor into decisions about mandates. Millions of Americans with disabilities rely on existing state mandates to ensure access to quality health care. Failure to include state mandates in the national essential benefits package that protect these individuals could result in a net reduction of coverage and potentially jeopardize their health and functional status.

10.) What criteria and method(s) should HHS use in updating the essential package? How should these criteria be applied? How might these criteria and method(s) be tailored to assess whether: (1) enrollees are facing difficulty in accessing needed services for reasons of cost or coverage, (2) advances in medical evidence or scientific advancement are being covered, (3) changes in public priorities identified through public input and/or policy changes at the state or national level?

Updates to the essential benefit package must be inclusive of all new benefits that deliver improved health, wellness, rehabilitative and functional outcomes for beneficiaries. New preventive services that have demonstrated effectiveness should also be included in updates of the essential benefit package and should be provided with no cost sharing for beneficiaries in keeping with current law. Preventive services should be focused on primary conditions as well as conditions that are secondary to a disability.

Data Collection and Medical Evidence: In order to assess the challenges of beneficiaries in accessing services, it will be necessary to implement a system of data collection to document the nature of scope of difficulty faced by beneficiaries, including beneficiaries with disabilities and chronic conditions. Coverage criteria must keep pace with advances in treatments and technologies that deliver improved beneficiary outcomes. To demonstrate efficacy, all forms of medical evidence should be considered and weighted appropriately, so that services that are not necessarily backed by double-blinded, randomized controlled studies are not immediately denied consideration for inclusion in the essential health benefits package.

Transparent, Public Process for Updating Essential Benefits: In order to ensure that beneficiaries have access to the most effective and appropriate treatments, services, and devices, the Secretary of HHS should establish an open, public process for the regular review and update of the essential benefits package. The review and update should be performed on a schedule adequate to ensure timely beneficiary access to new interventions without unnecessary delay. The specific schedule for review should be established by the Secretary with provision for making immediate updates to the essential benefits package when important breakthroughs in interventions are developed that promise significantly improved preventive, health, rehabilitative, wellness or functional outcomes for beneficiaries.

This public process should be transparent, unbiased and should be established by formal regulation. It should allow for public comment and permit stakeholder input from consumer and provider organizations and individuals. Official comment periods should be offered for proposed changes to this process that allow for transparency and comment

before implementation of any changes that would potentially reduce or limit access to established benefits. The legislative process within states and Congress would continue to have the ability to amend the ACA statute and provide guidance to the Secretary with respect to implementation of health policy, including policies related to updating the essential benefits package. Finally, an appeals mechanism should be established to ensure due process.