



The Impact of the Affordable Care Act on People with Disabilities:

A 2015 Status Report



National Council on Disability

January 26, 2016



National Council on Disability

An independent federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families.

Letter of Transmittal

January 26, 2016

President Barack Obama
The White House
1600 Pennsylvania Avenue, NW
Washington, DC 20500

Dear Mr. President:

The National Council on Disability (NCD) is pleased to submit the enclosed second report in a series of three regarding implementation of the Patient Protection and Affordable Care Act (ACA) of 2008. The title of this report is *The Impact of the Affordable Care Act on People with Disabilities: A 2015 Status Report*.

NCD is an independent federal agency, composed of nine members appointed by the President and the U.S. Congress. The purpose of NCD is to promote policies, programs, practices, and procedures that guarantee equal opportunity for all individuals with disabilities and to empower individuals with disabilities to achieve economic self-sufficiency, independent living, and inclusion and integration into all aspects of society.

This second report seeks to explore how changes to the country's health care system are affecting people with disabilities by (1) examining and analyzing available literature, (2) conducting qualitative interviews of state-based disability rights leaders in ten states with diverse ACA implementation decisions, and (3) assembling summary tables of selected state policy choices. This report gathers and analyzes data that:

- Provides insight about the experiences of people living with a disability and/or closely associated with diverse functional categories of disability;
- Describes what we currently know about the impact of the ACA on people with disabilities based on available literature and qualitative interviews of disability leaders;
- Formulates recommendations for future research and tracking of effective results where appropriate; and
- Presents 50-state summary tables of information for stakeholders regarding:
 - Medicaid Alternative Benefits in states with expanded eligibility;
 - State eligible health benefits decisions about and coverage of habilitative services; and
 - Eligible health benefits benchmark coverage of rehabilitative services and durable medical equipment.

For people with disabilities and their families, the quality of health care, risks, and even some unintended consequences of ineffective planning, programs, processes, and practices reach

beyond meeting medical needs, such as being empowered to pursue one's training and/or employment goals. Appropriate health care for these individuals continues to be linked to access, discrimination, inclusion, disparities, employment impacts, and long-term services and supports. As we embark on a new calendar year, NCD is grateful for the opportunity to share this early snapshot on the implementation of the ACA.

Sincerely,

A handwritten signature in black ink, appearing to read "Clyde Terry". The signature is fluid and cursive, with a large, sweeping flourish at the end.

Clyde Terry
Chair

(The same letter of transmittal was sent to the President Pro Tempore of the U.S. Senate, the Speaker of the U.S. House of Representatives, and the Director of the Office of Management and Budget.)

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Acronym Glossary

ABA	Applied behavioral analysis
ABP	Medicaid alternative benefit plan
ACA	Patient Protection and Affordable Care Act
ACO	Accountable care organization
ACS	American Community Survey
CDC	Centers for Disease Control and Prevention
CFC	Community First Choice
CMS	Centers for Medicare and Medicaid Services
CPM	Continuous passive motion
CPS ASEC	Current Population Survey Annual Social and Economic Supplement
DME	Durable medical equipment
EHB	Essential health benefit
EHR	Electronic health record
FPL	Federal poverty level
HCBS	Home- and community-based services
HIE	Health information exchange
HIP	Healthy Indiana Plan
HIT	Health information technology
HRMS	Health Reform Monitoring Survey
IDD	Intellectual and developmental disabilities
IRB	Institutional Review Board
LTSS	Long-term services and supports
MEPS-HC	Medical Expenditure Panel Survey–Household Component
MCOs	Managed-care organizations
NHIS	National Health Interview Survey
NORC	National Opinion Research Center
PCO	Primary care option
POWER	Personal Wellness and Responsibility Account
QHP	Qualified health plan
SIPP	Survey of Income and Program Participation
SPA	State plan amendment
SSDI	Social Security Disability Insurance
SSI	Supplemental Security Income
STS	Sympathetic therapy stimulator
TENS	Transcutaneous electrical nerve stimulation
TMJ	Temporomandibular joint
T-MISIS	Transformed Medicaid Statistical Information System

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Executive Summary

The Patient Protection and Affordable Care Act (ACA) is one of the most significant health-related pieces of legislation enacted in decades. The act is especially important to people with disabilities, who rely on a broad range of health care services and supports, and for whom the details of health coverage can have an immediate effect on employment options. This report analyzes what we know about the ACA's impact on people with disabilities, using a formal literature review, interviews with key informants from disability organizations in ten diverse states, and a review of state policies involving key ACA provisions.

Literature review. Analyzing both peer-reviewed published studies and unpublished studies from the “grey literature”—that is, information and research output produced by various type of organizations outside of academic publishing¹—we find little research showing how people with disabilities have been affected by the early stages of ACA implementation.² This lack of empirical evidence is partially because the most important ACA provisions were only recently implemented. Thus, public surveys, which are often made available with a considerable time lag, do not yet reflect most of these provisions. Moreover, most studies do not appear to identify people with disabilities as a unique subgroup warranting specific analysis.

A number of studies have examined the ACA's dependent coverage provisions, which, starting in 2010, extended private coverage to dependents up to age 26. They found that young adults with disabilities and other young adults have experienced significant coverage gains because of this provision. Other studies showed that, starting in 2014, low- and moderate-income nonelderly adults, including both adults with chronic illnesses and other adults, experienced significant coverage gains. In some states and the District of Columbia, those gains resulted from Medicaid expansion to adults with incomes up to 138 percent of the federal poverty level. In all states and the District of Columbia, the gains resulted from subsidies for qualified health plans (QHPs) offered in health insurance Marketplaces combined with private insurance reforms, such as the prohibition of discrimination based on health status. Evaluations of the ACA's provisions involving long-term services and supports (LTSS) are just getting underway, and preliminary results vary; some early findings indicate initial implementation challenges.

Interviews. We selected key informants from ten states across geographic regions that differed in terms of their Marketplace enrollment success as well as key ACA implementation decisions, such as type of Marketplace exchange system, (non)expansion of Medicaid, and adoption of

an LTSS provision. Interviewees were chosen to represent a broad range of disabilities and to offer insight into the experiences of people with disabilities with ACA implementation in their states.

New insurance affordability programs.

Interviewees almost universally described Medicaid as the “first resource” for people with disabilities because it provides benefits that are more comprehensive than those offered by private plans. According to the interviewees, expanded eligibility tended to serve adults with comparatively moderate disabilities. Whether the alternative benefit plans (ABPs) provided to newly eligible adults aligned with Medicaid benefits for other adults varied among states. In states that modeled ABPs on employer-based plans rather than on pre-ACA Medicaid coverage, interviewees reported service limitations that disadvantaged people with disabilities. Despite broad knowledge of ACA implementation, no interviewee was aware that newly eligible adults could transfer from ABPs to standard Medicaid benefits by demonstrating “medical frailty,” which suggests a gap in the information some states provide on coverage options. A number of interviewees expressed concerns that expanded Medicaid enrollment without an accompanying increase in the number of providers appeared to be limiting previous beneficiaries’ access to certain specialty providers.

The ACA’s subsidies for QHPs were helpful in reducing premium costs, according to informants. Despite those subsidies, high deductibles and other out-of-pocket cost-sharing (for example, prescription drugs) were access barriers to many people with disabilities, as were some QHPs’ limited provider networks. Many states’ decisions about essential health benefits (EHBs),

apparently motivated by a desire to limit costs, excluded services that people with disabilities need. Some informants expressed concerns that the complexity of ACA implementation could let states and insurers avoid complying with federal legal requirements for EHBs.

Marketplace enrollment processes.

Interviewees described the enrollment process as complex and challenging for many people with disabilities, partially because some Marketplaces did not implement planned accessibility features as a result of budget constraints and other operational difficulties. Interviewees thought that Navigators, people trained to help consumers find health coverage options in the Marketplace, were helpful only when they had previous experience with health issues faced by people with disabilities. According to interviewees, many people with disabilities found it particularly hard to choose among available QHPs because the Marketplaces had limited information about important details of covered benefits and provider networks.

Long-term services and supports. With both demonstration projects that integrate Medicare and Medicaid coverage for dual eligibles and other uses of private managed-care plans to cover LTSS, key informants reported concerns about the plans’ incentives to limit services and lack of prior experience with LTSS. In states implementing the Community First Choice (CFC)³ option for Medicaid coverage of home- and community-based services (HCBS) for all eligible beneficiaries, informants expressed concerns about disruptions to previous arrangements that worked well for many people with disabilities. By contrast, informants in other states reported that disability organizations were advocating CFC implementation to address long

waiting lists for HCBS offered through pre-ACA Medicaid waivers.

Employment and financial impacts. Though most interviewees did not perceive direct impacts of the ACA on people with disabilities' employment prospects, some key informants asserted that access to coverage through the ACA decreased the pressure for people with disabilities to remain impoverished to qualify for Medicaid's comprehensive benefits or to pursue a job solely for its health benefits. As a result, more people with disabilities could search for jobs that aligned with their skills. Community First Choice options can also be used to provide services that support an individual's employment goals.⁴

State tables. Our summary of key state decisions involved (1) ABPs covered for newly eligible Medicaid adults and (2) state decisions about EHBs in the categories of habilitative services, rehabilitative services, and durable medical equipment. As of August 2015, 30 states plus the District of Columbia had adopted legislation expanding their Medicaid program. Of these, 18 states plus the District of Columbia offered ABPs that were aligned with standard Medicaid benefits for adults; 11 states offered ABPs that were based on employer-based plans and that typically provide fewer benefits than standard Medicaid benefits; one state (Alaska) was scheduled to start its expansion September 1, 2015; and one state (Montana) was awaiting approval by the Federal Government.⁵

In terms of EHBs, many features of coverage did not vary significantly among states and the District of Columbia. Exceptions included autism-related care and habilitative services. Habilitative services, which involve helping consumers keep, learn, or improve functions for daily living, is a newer benefit category for many private

plans and is undergoing a lot of change. Major interstate differences included provider visit limits and included services. Rehabilitative services have been part of most commercial plans and have only been marginally affected by the ACA. Recent regulations establish a January 2017 due date after which state EHBs are barred from applying a single-visit limit to both habilitative and rehabilitative services; 11 states had not yet met this requirement by August 2015.

Recommendations for future research. On the basis of the above analysis, we make several recommendations for future research into the ACA's effects on people with disabilities:

- The most important near-term research goal involves ensuring that forthcoming survey-based research analyzes the coverage, access, and other effects of the ACA on people with disabilities, along with other important groups. Major national survey data will soon become available that show health coverage in 2014, the first year during which the ACA's main provisions became effective. Both newly available data and 2014 data already available under other national surveys contain information about people with disabilities.
- Qualitative research involving focus groups and key-informant interviews could analyze the reasons that some people with disabilities have fared better than others in gaining improved coverage and access to health care. Such analysis could explore the relationship between state policy choices and health coverage and care of people with disabilities.
- Similar qualitative research, combined with evaluation data, could analyze the

effects of expanded Medicaid managed care coverage of LTSS, including analyzing demonstration projects that integrate Medicare and Medicaid coverage for dual eligibles.

- Researchers could analyze new sources of administrative data. Such administrative data include (1) information about a person's disability status requested on national applications for QHP subsidies and (2)

new, comprehensive Medicaid data that states and the District of Columbia are increasingly providing to the Centers for Medicare and Medicaid Services as part of the Transformed Medicaid Statistical Information System. Once all personally identifying information is removed, these administrative records could help researchers assess the coverage and care that QHPs and Medicaid furnish to people with disabilities.



“[It impacts] every kid with a disability whose parents have a job—it’s huge. It gives them an option of not having to impoverish themselves immediately to get SSI.”—Interview Participant from Colorado

Chapter 1. Introduction

Report Structure

We start this report by providing a topically organized overview of our findings; we then

- summarize available literature that describes the impact of the Patient Protection and Affordable Care Act (ACA) on people with disabilities;
- describe our qualitative interviews with key informants from the disability community in ten diverse states;
- inventory and analyze key ACA implementation choices that states made; and
- offer recommendations for future research to analyze the impact of the ACA on people with disabilities.

Overview

The ACA has the potential to deeply affect people with disabilities. Several provisions of the ACA stand out in their likely impact on the disability community:

- The expansion of Medicaid eligibility to adults with incomes at or below 138 percent of the federal poverty level (FPL), which went into effect in 2014 (States and

the District of Columbia had the option to expand Medicaid as early as 2010, and some did.)⁶

- Also starting in 2014: private insurance offerings through newly established health insurance Marketplaces (also called “exchanges”), supported by federal subsidies; marketwide prohibitions against insurance company discrimination; and essential benefit requirements that forbid certain overall limits on covered services
- Beginning in 2010, options to improve Medicaid coverage of long-term services and support (LTSS), which include demonstration projects that integrate Medicare and Medicaid coverage for dually eligible individuals and the Community First Choice (CFC) option, which provides home- and community-based services (HCBS) to all Medicaid beneficiaries who qualify
- Dependent coverage provisions, effective in 2010, that let young adults stay on their parents’ health insurance plans until age 26

The operation of these nationwide provisions is subject to implementation decisions by states (including the District of Columbia) and insurers. States can expand Medicaid and define

Medicaid services within federal parameters; as of August 2015, 30 states and DC have adopted such an expansion, 20 have not.⁷ Like most other forms of insurance, qualified health plans (QHPs) offered in Marketplaces need to cover essential health benefits (EHBs), but flexible federal guidelines have led to great variance between states and within some states, potentially leaving services important to people with disabilities uncovered.⁸ Thirteen states and DC run their own Marketplaces, ten states operate Marketplaces jointly with the Federal Government, and 27 states have the Federal Government administer Marketplaces.⁹

This report synthesizes emerging evidence of the ACA's impact on people with disabilities based on

- a review of the available literature, both peer-reviewed and “grey”;
- interviews with key informants from disability organizations in ten states with diverse ACA implementation approaches;¹⁰ and
- a state-specific summary of selected implementation decisions involving Medicaid expansion and selected EHBs of particular interest to people with disabilities.

There is little published research addressing the impact of the ACA on consumers with health problems, much less those with disabilities. One contributing factor involves lengthy standard delays in the release of national survey data. For example, information about coverage in 2014, the first year to which the ACA's central provisions applied, is not slated to become available until fall of 2015 for the two most widely used sources of health coverage data: the Current Population Survey Annual Social and Economic Supplement

and the American Community Survey. One exception involves the ACA's dependent coverage provisions, which became operative in 2010 and that research suggests have significantly increased coverage for young adults with and without disabilities. Because of these data limitations, most of the findings discussed in this report are based on the perception of informants.

Medicaid expansion. Both interview results and available literature suggest that Medicaid expansion has helped people with disabilities. Informants described Medicaid as a “first resource” for people with disabilities, on the basis of benefits that are broader than coverage by private plans and go farther toward meeting the needs of people with disabilities. Evidence based on surveys, though scant, points toward important gains in coverage for people with disabilities because of the Medicaid expansion. One study found a stronger decrease

Medicaid Expansion (as of August 2015)

- 18 states plus the District of Columbia offered alternative benefit plans (ABPs) that were aligned with standard Medicaid benefits for adults;
- 11 states offered ABPs that were based on employer-based plans and that typically provide fewer benefits than standard Medicaid benefits;
- One state (Alaska) was scheduled to start its expansion September 1, 2015; and
- One state (Montana) was awaiting approval by the Federal Government.

in the uninsured rate among chronically ill adults in Medicaid-expanding states versus nonexpanding-Medicaid states. According to another study, low-income people with health problems in Connecticut experienced the strongest uninsured rate decline of all demographic groups considered when the state expanded Medicaid early.

However, states expanding Medicaid provide newly eligible adults with an alternative benefit plan (ABP), which may not include all standard Medicaid benefits for adults. As of August 2015, 18 states plus the District of Columbia offered ABPs that were aligned with standard Medicaid benefits for adults; 11 states offered ABPs that were based on employer-based plans and that typically provide fewer benefits than standard Medicaid benefits; one state (Alaska) was scheduled to start its expansion September 1, 2015; and one state (Montana) was awaiting approval by the Federal Government.¹¹ Informants from states that did not align their ABPs to their standard Medicaid benefits reported that service limitations result in benefits that are less favorable to people with disabilities. The ACA lets newly eligible adults who are “medically frail” switch from the ABP to standard Medicaid benefits for adults. However, no key informants were aware of this safeguard, suggesting that states may not have educated beneficiaries about this potentially important

ACA lets newly eligible adults who are “medically frail” switch from the ABP to standard Medicaid benefits for adults. However, no key informants were aware of this safeguard, suggesting that states may not have educated beneficiaries about this potentially important route for people with disabilities to obtain broader services.

route for people with disabilities to obtain broader services. Some informants noted that increased demand for services resulting from expanded eligibility appeared to diminish access to some Medicaid specialty providers, such as those providing mental health care. According

to informants, among people with disabilities, expanded eligibility mainly benefited those with moderate disabilities—individuals whose conditions did not meet the severity requirements for pre-ACA disability-based Medicaid as well as those falling within the two-year waiting period before qualifying for disability-based

Medicare. Some informants also mentioned as another advantage of the new eligibility category that its assets are not considered in qualifying for Medicaid, a situation that allows people with disabilities to accumulate resources and increase self-sufficiency.

Insurance reforms and EHBs. Informants noted the significant gains that people with disabilities received from the ACA’s elimination of preexisting condition exclusions and lifetime coverage limits. However, informants reported serious limitations with state EHB definitions that prevented people with disabilities from receiving necessary care, which in some cases were written to accommodate policymakers’ desires to control costs. Limitations of particular concern involved durable medical equipment (DME), habilitative and rehabilitative services, mental

health care, and prescription drugs. Interviewees were also skeptical about state enforcement of applicable legal requirements, particularly as to coverage offered through federally facilitated Marketplaces.

Our analysis of EHBs in the 50 states and the District of Columbia suggests that, in terms of habilitative and rehabilitative care and DME, the broad parameters of covered benefits are similar across states, with some exceptions that involve habilitative services and autism care. Because rehabilitative services have been included in most commercial plans, they have been marginally affected by the ACA. However, habilitative care, which involves helping consumers keep, learn, or improve functions for daily living, is a newer benefit category for many private plans and is undergoing much change. Major interstate differences include which services are covered, such as maintenance therapy, and provider visit limits that vary among states from 20 to 90 visits a year. Recent regulations establish a January 2017 due date after which state EHBs are barred from applying a single-visit limit to both habilitative and rehabilitative services; 11 states have not yet met this requirement.

Marketplace QHP offerings. Federal subsidies to purchase QHPs led to significant coverage gains. Among chronically ill adults in the income range qualifying for subsidies, the number without coverage fell 53 percent, according to one study.¹² Key-informant interviews confirmed the importance of subsidies in making coverage more affordable. However, many informants reported that, despite subsidies, QHP costs were problematic for many people with disabilities. In particular, high deductibles and other out-of-pocket cost sharing have apparently reduced receipt of necessary services while imposing

cost burdens on consumers with significant health care problems. Some informants described QHP provider networks as similar to networks in other Markets, sharing underlying limits in provider capacity. Other interviewed informants were concerned about narrow QHP networks that prevented people with disabilities from accessing necessary providers.

Marketplaces as enrollment portals.

Informants reported shortcomings in Marketplace accessibility to people with disabilities, which may have resulted from budget constraints and other initial operational challenges facing Marketplaces. Informants also expressed concerns about the limited training that Navigators received in meeting the needs of people with disabilities. These gaps were often filled by disability organizations that furnished assistance to people with disabilities. Harder to overcome were limitations in Marketplace information about features of QHPs that were particularly important to people with disabilities, such as the details of covered benefits and drug formularies. The federally facilitated Marketplace provided little or no information about Medicaid eligibility categories that serve some people with disabilities with incomes above 138 percent of the FPL, in the range of financial eligibility for QHP subsidies. However, informants reported an example of a state-based Marketplace that effectively provided information about these Medicaid eligibility categories, which offer people with disabilities more comprehensive services at significantly reduced cost.

Employment and financial impacts. Some informants noted that extended coverage decreased the pressure for people with disabilities to impoverish themselves to fall under Medicaid coverage or to pursue a job solely for

its health benefits. As a result, more people with disabilities could search for jobs that aligned with their skills. Community First Choice options can also be used to provide services that support an individual's employment goals (for example, Kennedy-Lizotte 2011).

LTSS. As of August 2014, 13 states had implemented demonstration projects that integrate Medicare and Medicaid services for people who are dually eligible; 10 of these states are using private, managed care plans. Both with these demonstration projects and other uses of private, managed care plans to cover LTSS, informants reported widespread concerns about state contracts with plans that lacked significant experience managing LTSS and incentives for plans to increase profits by limiting services. States with dual-eligibility demonstrations have evaluations underway, though they are far from completion. Preliminary results indicate some initial implementation challenges.

Seven states have implemented the CFC option by August 2014.¹³ Formal evaluation results are not yet available, but informants from other states reported a significant interest in pursuing this option to address long waiting lists for HCBS provided through pre-ACA waivers. In states implementing CFC, informants expressed concerns about disruptions to previous arrangements that worked well for many people with disabilities.

Some informants noted that extended coverage decreased the pressure for people with disabilities to impoverish themselves to fall under Medicaid coverage or to pursue a job solely for its health benefits. As a result, more people with disabilities could search for jobs that aligned with their skills.

Recommendation for future research. As noted, ACA research to date has included little analysis of its effects on people with disabilities. Key informants likewise reported a disempowering absence of information about disability-based impacts. By fall 2015, health coverage and related data will be available from major federal surveys showing results from 2014, the first year during which the ACA's main provisions went into effect. Almost certainly, a wave of ACA-related research will ensue. If past trends hold true, this research will analyze

data in terms of race and ethnicity, income, age, gender, state of residence, and chronic health conditions, but not disabilities. *The most important near-term research goal for the disability community involves ensuring that forthcoming survey-based research analyzes the coverage, access,*

and other effects of the ACA on people with disabilities, along with other important groups. Other future research efforts could also prove important data:

- Qualitative research, including focus groups and key-informant interviews, could analyze the factors associated with differential coverage and access gains that different groups of people with disabilities experience, including differences that involve state of residence (and associated policy choices), disability category, income, age, race and ethnicity, education level, and gender.

- Similar qualitative research strategies could be combined with data gathered for evaluation purposes to analyze the impact of expanded Medicaid managed care coverage of LTSS, including through demonstration projects that combine Medicare and Medicaid coverage of dually eligible beneficiaries.
- Researchers could examine new sources of administrative data to investigate the coverage and services that people with disabilities receive through the ACA's insurance affordability programs. Such administrative data include information about disability status already provided on applications for QHP subsidies as well as comprehensive information state Medicaid programs are increasingly reporting to the Centers for Medicare and Medicaid Services as part of the Transformed Medicaid Statistical Information System, which is being phased in. This system includes data about enrollment, services, costs, demographic characteristics, and other factors. Once all personally identifying information is removed from these two sources of administrative data, they could help researchers assess the coverage and care that people with disabilities receive from QHPs and Medicaid.
- Health services and public health researchers could be encouraged to routinely analyze data by disability status, along with other key variables.

Chapter 2. Literature Review

In this chapter, we review studies examining the impact of the ACA on people with disabilities.

The first part of the review discusses the state of evaluation studies for ACA provisions that are likely to be most important for people with disabilities: state health insurance exchanges (Marketplaces), Medicaid expansion, and LTSS. Only a few peer-reviewed, published studies, or unpublished studies are available on these topics as of August 2014.¹⁴ In the second part of the review, we discuss publications studying the impact of the ACA provision that allows adult dependents 26 years or younger to remain on their parents' health insurance plans. Much more research describes the effects of this provision, dating back to its 2010 implementation. Although disability rates are much lower among younger adults, therefore affecting fewer people with disabilities than other ACA provisions,¹⁵ we include studies on this provision because some people with disabilities benefit from the dependent coverage requirement. Thus, analyzing this research yields important lessons that can shape future studies examining the impact on people with disabilities of other, more central ACA provisions.

Our review used tools such as Google Scholar to retrieve both published studies in peer-reviewed journals and other articles and reports, often called "grey literature."¹⁶ We also examined research described in these articles and reports

and reviewed Web sites of relevant organizations (for example, Urban Institute's Health Reform Monitoring Survey Web site and the Kaiser Family Foundation's Health Reform Web site). We visited Web sites to find experts conducting research on the ACA and people with disabilities.¹⁷

Primary ACA Provisions for People with Disabilities

Marketplaces and Medicaid Expansion

Only a few studies have examined the effect of the ACA on people with disabilities as of August 2014. A number of studies report outcomes by health status, but that is not the same as an explicit focus on people with disabilities. Studies that report outcomes separately by health status typically use one health measure (for example, overall self-reported health status). From a disability perspective, this approach is simultaneously too narrow, because it captures only some people with disabilities, and too broad, because it includes many people with health problems that do not involve disability.

An important reason for the lack of research is the short time that has elapsed since many major ACA provisions became effective, with the most important coverage expansions and insurance reforms beginning in 2014. This short time period constricts the availability of data sources for analysis even though population

surveys do include information about disability status (as required by ACA Section 4302) and coverage. For example, the two primary data sources for state-level coverage estimates—the American Community Survey (ACS) and the Current Population Survey Annual Social and Economic Supplement (CPS ASEC)—will not provide information about 2014 coverage until September 2015 or later. As time passes, it will be important for health care researchers, public policy analysts, and the disability community to monitor whether studies are conducted and published that use available data to assess the impact of the ACA specifically on people with disabilities. To illustrate, National Health Interview Survey (NHIS) data about health coverage in 2014 have become available.¹⁸ The NHIS questionnaire requests information about disability, but the authors are not aware of any published research that uses this data to assess the impact of the ACA on people with disabilities.¹⁹ Some published research uses NHIS data to examine issues involving people with disabilities, but even studies published as recently as June 2015, conference presentations scheduled for July 2015, and graduate-level theses slated for publication in August 2015 examine NHIS data only as late as 2013.²⁰ The Medical Expenditure Panel Survey—Household Component (MEPS-HC) has likewise released data showing health coverage and other characteristics of households interviewed during the early part of 2014, including information about limitations that signal likely disabilities and several options for tracking respondents’ changes longitudinally. As far as the authors are aware, no studies or reports have analyzed these data to show the 2014 effects of the ACA on consumers, much less those with disabilities.

That said, the few studies that do report outcomes by health status or activity limitations

that signal the possible presence of disability show initial positive impacts of the ACA on coverage for people both with and without health problems. A few studies also show that coverage obtained through the ACA increases access to care and, tentatively, health, but these studies do not report results by health status.²¹

Sommers, Kenney, and Epstein overcame the previously stated data limitations, finding that an early Medicaid expansion in Connecticut resulted in substantially greater coverage gains for adults whose health problems signaled potential disability than for other adults.²² Researchers examined coverage changes in Connecticut and the District of Columbia, where officials increased coverage in 2010 and implemented the ACA option to expand Medicaid eligibility before 2014. Using the 2008–2011 ACS, researchers compared coverage changes in Connecticut and the District of Columbia to changes in nearby states that did not implement early expansions.²³ Their sample included people targeted by the expansion: childless adults ages 19 to 64 with family income below 56 and 200 percent of the poverty level for Connecticut and Washington, DC, respectively. Researchers reported coverage changes within the target group both for adults as a whole and for multiple subpopulations, including people with health-related limitations that signaled possible disability.²⁴ Sommers and colleagues observed greater coverage gains in Washington, DC, than in the comparison state Virginia, but the ACS’s small sample size for the District of Columbia meant that this difference was not statistically significant under the authors’ metrics.²⁵ By contrast, the Connecticut sample was large enough for researchers to detect statistically significant differences between that state’s coverage changes and those in nearby states. Among all Connecticut adults targeted by expansion, the proportion of uninsured fell by

2.8 percentage points compared to changes in the uninsurance rate among similar adults in adjacent states. However, among adults within the target group who reported health-related limitations signaling possible disability, the expansion resulted in an 11.2 percentage point drop in the proportion of uninsured individuals, representing an almost 50 percent reduction compared with pre-ACA levels. No other subpopulation experienced a comparable coverage gain.

Other researchers addressed the delayed release of national survey data by developing new data sources. For example, Shartzter, Kenney, and Zuckerman analyzed the ACA's effects on coverage of adults with chronic illness by using data from the Urban Institute's Health Reform Monitoring Survey (HRMS).²⁶ HRMS is a quarterly survey that shows the ACA's effects on nonelderly adults. Shartzter and colleagues examined changes between September 2013 and March 2015 in the uninsurance rate of nonelderly adults with chronic physical or neurological health conditions.²⁷ That rate fell by 6.7 percentage points, which represented a 50 percent decline relative to the uninsurance rate of 13.2 percentage points in September 2013. This relative decline was somewhat larger than that of adults in general, for whom the uninsurance rate dropped by 42.5 percent relative to its September 2013 level.²⁸ However, the reported difference between relative coverage gains for chronically ill adults and for adults in general was not statistically significant. Both among adults with chronic illness and other adults, coverage gains were particularly pronounced in states expanding Medicaid and for adults with incomes at or below 138 percent of FPL. Reductions in the uninsurance rate were also pronounced in the income range typically qualifying for QHP subsidies—namely, between

138 and 400 percent FPL. Among adults with chronic conditions, the proportion of individuals without coverage fell by seven percentage points, representing a 53 percent relative decline. Similar results were observed for adults as a whole.

Long-Term Services and Supports: Selected Issues

It appears there are currently no findings of systematic, large-scale studies available that examine the impact of dual-eligibility demonstrations and the Community First Choice (CFC) option. The Centers for Medicare and Medicaid Services (CMS) have approved dual-eligibility memoranda of understanding for 13 states, including ten with private managed care plans by August 2014.²⁹ The earliest enrollment of eligible beneficiaries took place in Washington and Massachusetts in the second half of 2013.³⁰ California, which has by far the largest number of beneficiaries affected by such demonstrations, started enrollment in April 2014. RTI International is evaluating state demonstrations for CMS but has not yet released study results.³¹ State-based evaluations of dual-eligibility demonstrations in the form of enrollment analyses, focus group interviews, and key-informant interviews have begun. Some preliminary highlight general implementation challenges, such as managed care program staff with little or no prior LTSS experience ("steep learning curve"), concerns about the adequacy of provider networks, and other difficulties with transmission of accurate information,³² but evidence of people with disabilities' experience with these LTSS services are generally not available.³³ Both formal and informal reports suggest that in some states, efforts to educate consumers may be falling far short of goals. For example, beneficiaries have experienced significant confusion and sometimes

were unable to obtain care despite repeated attempts; managed care plans often could not reach enrollees to conduct assessments and develop care plans; and overall enrollment levels appeared to be falling short of projections.³⁴

As of August 2014, CMS has approved state plan amendments (SPA) to implement the CFC option from seven states: California, Connecticut, Maryland, Montana, Oregon, Texas, and Washington. California was the first state to submit a SPA in December 2011, and it was approved by CMS in August 2012.³⁵ We were able to find only one document related to an evaluation of the CFC option, the 2014 interim report by the Department of Health and Human Services to Congress.³⁶ This report states, “[I]t is too early to assess the effectiveness of services provided under CFC in allowing individuals to live independently, the impact of such services on recipients’ physical and emotional health, and the comparative costs of CFC services and those provided under institutional care.”³⁷ The National Opinion Research Center is currently conducting an extensive evaluation of this provision.³⁸

Dependent Coverage

In this section, we review studies evaluating the ACA’s expansion of private dependent coverage for young adults, implemented in October 2010. Population surveys covering the post-implementation period have been available since 2012, resulting in a much larger body of literature than applies to the ACA provisions discussed previously. Here, we first summarize

main findings for people with disabilities and then discuss what these studies can tell us about future research directions concerning the ACA’s impact on people with disabilities.

In terms of methodology, all studies reviewed here contrast outcomes before and after implementation for adults 19 to 25 years—the age group benefiting from this feature of the ACA. The studies then compare that change in outcomes with those experienced by certain adults over 26 years of age, who did not benefit from this policy change. Depending on the study, the precise definition of the latter comparison group varies between adults ages 27 to 29 and those ages 27 to 32.³⁹ The goal of this approach is to isolate the causal effect of implementing

the provision from other changes that occurred during that time that influenced outcomes for young adults targeted by the provision.

Studies show strong reported decreases in uninsurance rates. On

average, the uninsurance rate decreased by about six percentage points across the various studies (see Table 1). Because the uninsurance rate among young adults was 30 percent before implementation of the provisions,⁴⁰ this six percentage point decline amounts to a relative decrease in the uninsurance rate of about 20 percent.⁴¹ However, estimates vary widely across studies. Studies that did not go beyond the year 2010 found smaller effects because they do not capture the full effect of the provision.⁴² Sommers and colleagues included data from 2011 and reported a much higher overall decrease in the uninsurance rate during mid-2011 than during

Among young adults with possible mental health care needs, the receipt of treatment increased by 5.3 percentage points once the dependent coverage provision went into effect.

Illustrative Monitoring Questions

Table 1. Main Results of Studies of the Impact of the ACA Dependent Coverage Provision

Study	Decrease in Uninsurance Rate	Other Results
<i>Studies that report effects separately by health status or disability</i>		
Antwi, Moriya, and Simon (2013) ⁵⁰	3.2 percentage points for all young adults. Men, older young adults, and young adults with less than excellent self-related health status experienced a higher decrease.	Decrease in hours worked and in probability of working full time.
Porterfield and Huang (2014) ⁵¹	6.1 percentage points for young adults with dis-abilities and family income below 200 percent FPL. 9.0 percentage points for young adults with dis-abilities and family income above 200 percent FPL. 6.0 percentage points for young adults without dis-abilities and family income below 200 percent FPL. 9.3 percentage points for young adults without dis-abilities and family income above 200 percent FPL.	
Saloner and Lê Cook (2014) ⁵²	12.4 percentage points for patients with likely mental health issues. 6.5 percentage points for patients with likely substance abuse issues.	Increase in mental health treatment: 5.3 percentage points.
Sommers et al. (2013) ⁵³	4.7 percentage points for all young adults. Decrease is initially higher for those in fair or poor health.	
<i>Studies that focus on young adults admitted to hospitals</i>		
Antwi, Moriya, and Simon (2014) ⁵⁴	2.9 percentage points for young adults with all non-birth-related admissions to hospitals. 1.3 percentage points for young adults with mental illness admissions.	Increase in non-birth-related inpatient visits: 3.5 percentage points (overall), 9.0 percentage points (mental illness-related visits). No change in length of stay, number of procedures, and total charges.
Mulcahy et al. (2013) ⁵⁵	1.7 percentage points for young adults admitted to emergency departments.	
Scott et al. (2015) ⁵⁶	3.4 percentage points for trauma patients. The decrease is higher for men, non-Hispanic whites, those with relatively less severe injuries, and those admitted to nonteaching hospitals.	No significant change in mortality risk.

(Continued)

Illustrative Monitoring Questions (*continued*)

Table 1. (*continued*)

Study	Decrease in Uninsurance Rate	Other Results
<i>Other studies</i>		
Barbaresco, Courtemanche, and Qi (2014) ⁵⁷	6.2 percentage points for all young adults.	Increase in having a primary care doctor: 3.6 percentage points. Increase in excellent self-assessed health: 2.2 percentage points. Decrease in medical care forgone because of costs: 2.5 percentage points.
Busch, Golberstein, and Meara (2014) ⁵⁸		Decrease in annual out-of-pocket medical expenditures exceeding \$1,500: 2.4 percentage points (57 percent relative change).
Cantor et al. (2012) ⁵⁹	3.5 percentage points for all young adults.	
Carlson et al. (2014) ⁶⁰	Yes, but no percentage points reported.	Increase in self-rated health.
Kotagal et al. (2014) ⁶¹	7.7 percentage points for all young adults.	Increase in likelihood of having a normal source of care: 2.8 percentage points.
O'Hara and Brault (2013) ⁶²	4.2 percentage points for all young adults.	
Sommers and Kronick (2012) ⁶³	2.9 percentage points for all young adults.	

earlier periods.⁴³ Similarly, Antwi, Moriya, and Simon reported increased coverage gains as time since implementation passes.⁴⁴

Young adults with significant, foreseeable health care needs are at least as likely to

make coverage gains. Several studies reported results by disability or health status and generally found similar if not higher increases in coverage for young adults with health problems and foreseeable health care needs than increases

for other adults as reported in these or other studies. Saloner and Lê Cook found that the uninsurance rate among young adults who may have mental health care needs and seek treatment declined by 12.4 percentage points because of the provision.⁴⁵ No other study finds a similarly high decrease but this particular group might have an especially high incentive to obtain health insurance. One other study, by Porterfield and Huang, focused specifically on young adults with disabilities and is currently available only in the form of a conference presentation.⁴⁶ They found that health care coverage among young adults was similar for those with and without disabilities. Specifically, coverage for young adults with a family income less than 200 percent of the FPL increased by 6.1 and 6.0 percentage points for those with and without disability, respectively. For young adults with a family income above 200 percent of the FPL, coverage increased by 9.0 and 9.3 percentage points for those with and without disability, respectively.⁴⁷

Two other studies report results by health status. Antwi, Moriya, and Simon found that the uninsurance rate decreased slightly more for young adults with less than excellent self-reported health than for other young adults, but that the difference is not statistically significant.⁴⁸ Moreover, the former group includes those with self-reported “good” health status and is thus not limited to young adults with health problems, much less those with disabilities. Sommers and colleagues found that the uninsurance rate initially dropped more strongly for people in fair or poor health compared with people in good or excellent health but that those gains disappeared over time.⁴⁹ That result is consistent with the expectation that people with significant health care needs have especially good reason

to take advantage of new coverage options and so are likely to enroll more quickly than others are.

Three studies focus on young adults admitted to hospitals. Young adults tend not to have foreseeable health care needs and therefore no particularly strong incentives to obtain health insurance through their parents. Correspondingly, estimates of coverage change for this population group are relatively small. Specifically, the uninsurance rate for young adults with non-birth-related hospital admissions dropped by 2.9 percentage points.⁶⁴ Young adults admitted to hospitals because of a mental illness experienced an even smaller decrease (1.3 percentage points). Mulcahy and colleagues reported that the uninsurance rate decreased by 1.7 percentage points among young adults with nondiscretionary visits to emergency departments.⁶⁵ And Scott et al. found a 3.4 percentage point decrease in the uninsurance rate among trauma patients.⁶⁶

Access and affordability of health care increases due to the provision. Among young adults with possible mental health care needs, the receipt of treatment increased by 5.3 percentage points once the dependent coverage provision went into effect.⁶⁷ Other studies found effects among young adults as a whole, without separate tabulations for those with health problems.⁶⁸

The effect on health outcomes may be positive, but it is hard to detect. Only three studies examined health implications and none of them focused on people with disabilities. Barbaresco, Courtemanche, and Qi reported a small increase in excellent or good self-assessed health due to the provision.⁶⁹ Carlson et al. also found a positive effect on health in some but not all of their analyses.⁷⁰ Scott et al. could not

discern a decrease in mortality among young adults admitted to trauma centers.⁷¹ However, they did not include other health measures that might have changed because of implementation of the provision.

Only one study examines non–health-related outcomes. Antwi, Moriya, and Simon estimated that the provision decreased the number of hours worked and the probability of working full time.⁷² They argued that young adults may have gained more job flexibility because having a full-time job is no longer required to obtain health insurance.

Studies on dependent coverage not only provide some early evidence of the provision’s effect on young adults with disabilities or other health conditions, but also highlight trends in ACA research, including the type of outcomes researchers have focused on and the extent to which they have considered people with disabilities for their studies. These research design decisions may be informative for future research efforts on other ACA provisions central to people with disabilities, such as Marketplaces, Medicaid expansion and LTSS options. In the points that follow, we discuss such research design features of dependent coverage studies.

Most studies using population surveys do not report separate results for people with disabilities. Population studies include questions about disability, as required by ACA §4302. Despite availability of such information, studies on dependent coverage typically do not report separate results by disability status. It is conceivable that they do not include such estimates because few young adults have disabilities. However, as mentioned earlier, disability rates among adults in this age group are nonnegligible and Census surveys have sufficiently large sample sizes to analyze this

population group. Moreover, young adults with disabilities are an important population group to study because of their high health care needs and costs. It is therefore unclear why some studies focus on various population groups but not on people with disabilities. For instance, O’Hara and Brault report coverage changes by sex, race, ethnicity, English-speaking ability, and other demographic categories—but not by disability status.⁷³

No study has focused solely on people with disabilities. Even studies that report outcomes by health status do not provide detailed information about people with disabilities; instead, health status is just one of many demographic categories such as age or gender. It would be more useful to health care researchers, public policy analysts, and the disability community to provide results by various disability types, as outcomes may vary greatly among them. Shartzter, Kenney, and people with disabilities Zuckerman focused on adults with chronic physical or neurological illnesses, but they did not include other groups of people with disabilities, such as people with mental health problems.⁷⁴

Most studies focus on coverage changes without investigating access to care and health status effects. Health insurance coverage is an important prerequisite for accessing health care services that improve health, but coverage does not guarantee adequate access to all services that people with disabilities need. One reason dependent coverage studies may focus on coverage is that health status effects may not become evident until several years after implementation.

Studies using general population surveys are restricted to the outcomes measured in

these data sources. Census surveys such as CPS ASEC and ACS are attractive for studying the impact of ACA provisions on people with disabilities because they use large samples that enable analysis of both national and state-specific results. However, they have only a limited number of health-related questions because they cover a broad range of topics. For instance, we cannot learn from these surveys whether young adults with disabilities received help from their parents to obtain health care coverage. Unlike

NHIS, CPS ASEC and ACS do not ask about access to health care.

This literature review has shown that we currently have very limited and tentative evidence of the ACA's impact on people with disabilities. We next discuss results from our interviews with state-based community leaders of disability organizations who were familiar with ACA implementation in their state, shedding more light on how the various ACA provisions have affected people with disabilities.

Chapter 3. Qualitative Research: Interviews with Key Informants from the Disability Community

In this chapter, we report the results of interviews conducted with 16 key informants from ten states between March and April 2015. The interviews were designed to explore the early effects of state-level ACA implementation choices on people with disabilities and to provide preliminary data to aid in the development of research questions, policies, and tracking of the ongoing impacts of the ACA on people with disabilities. At this stage in implementation, five years since the ACA was signed into law, our findings reflect only early impressions of the ACA's impact on people with disabilities. Given the limited data on this topic, the key-informant interviews offer valuable insights on the experiences of people with disabilities with QHPs, expanded Medicaid for low-income adults, health care coverage enrollment processes, changes to long-term services and supports, and other health systems changes.⁷⁵

Selection of States and Participants

We selected participants from states with diverse ACA implementation approaches concerning Medicaid expansion, insurance Marketplaces, and state options specific to services for people with disabilities. First, we compiled information on state implementation approaches for all 50 states plus the District of Columbia and grouped them into broad categories (for example, states that

expanded Medicaid versus those that have not expanded eligibility). Second, we identified states where research team members had knowledge of or existing connections with disability leaders or organizations. We then used this information to compile a list of 13 states, prioritized on the basis of maximum variation in implementation choices, availability of existing contacts, and distribution across geographic regions of the United States. After obtaining feedback on state selection from National Council on Disability members, we conducted outreach to contacts in each target state.

We interviewed participants from ten states; the ACA implementation characteristics for each participating state are summarized in Table 2. Half of the states (N=5) opted to expand Medicaid to cover low-income adults up to 138 percent of the FPL. Two of the states pursued a nontraditional Medicaid expansion plan using Section 1115 waivers (for example, Medicaid funds used as premium assistance for newly eligible adults to purchase QHPs), and three of the states had not expanded Medicaid. We classified states' success with Marketplace enrollment using table 1 in Blumberg et al., which defines "high," "medium," and "low" success rates, respectively, on the basis of enrollment of more than 25 percent, from 15 percent to 25 percent, and under 15 percent of the state's target population

Illustrative Monitoring Questions

Table 2. State ACA Implementation Characteristics of States Included in the Interviews at the Time of Interviewee Selection (January 2015)

State	Medicaid Expansion	Enrollment Success*	States Options Relevant to People with Disabilities**	Exchange Type
Arkansas	Yes, nontraditional	Medium	CFC***	State partnership
California	Yes	High	CFC & DD	State-based
Colorado	Yes	High	DD	State-based
Florida	No	High	None	Federally facilitated
Kansas	No	Medium	None	Federally facilitated
Montana	No	Medium	CFC	Federally facilitated
North Dakota	Yes	Low	None	Federally facilitated
Oregon	Yes	Medium	CFC & DD***	Federally supported state-based
Pennsylvania	Yes, nontraditional****	Medium	None	Federally facilitated
New York	Yes	High	DD	State-based

Notes:

* Enrollment success is based on Blumberg et al., table 1.⁷⁷ The original table shows each state's current enrollment (as of April 2014) in the Marketplace as a percentage of the target population (defined as pre-reform non-group insurance enrollees and uninsured individuals who are ineligible for public insurance or affordable employer-based coverage). We have classified states into three broad categories of enrollment success using this percentage: low (below 15 percent), medium (15 percent to 25 percent), and high (above 25 percent).

** Community First Choice (CFC): States participating in the Section 1915(k) Community First Choice State Plan Option.⁷⁸ Dual Demonstrations (DD): State participating in the State Demonstrations to Integrate Care for Dual Eligible Individuals.⁷⁹

*** Participants provided different information on implementation status.

****The state's original proposal for Medicaid expansion involved a Section 1115 waiver. However, the state's new governor now plans to implement a standard Medicaid expansion.

(defined as pre-reform non-group insurance enrollees and uninsured individuals who are ineligible for public insurance or affordable employer-based coverage).⁷⁶

Most states had medium or high Marketplace enrollment success (N=5 and N=4, respectively); one state had low enrollment success. For LTSS options specific to services for people with disabilities, the CFC option was being implemented by four of the states shown in the table, and the State Demonstrations to Integrate Care for Dual Eligible Individuals, or “Duals Demonstration,” option was being implemented in four of the states shown in the table. The states also represented four Marketplace types: federally facilitated (N=5), state-based (N=3), state partnership (N=1), and federally supported, state-based Marketplaces (N=1).

Within each identified state, we purposely selected participants to provide broad perspectives on experiences with the ACA among people with disabilities. We targeted state-based community leaders (not employees of state agencies) who worked or volunteered for disability organizations and were familiar with ACA implementation in their state. In selecting our participant sample, we aimed to identify participants who have disabilities themselves and displayed diversity across functional categories of disability and demographic characteristics. We created an initial list of potential participants and organizational affiliations, then obtained feedback and additions from study partners and the National Council on Disability. In states where we did not have an individual identified who met the participant selection criteria, we identified and contacted individuals and organizations with knowledge of key disability stakeholders in the state to ask

for recommendations for potential interviewees. Potential participants were then contacted by the project team by e-mail and phone and invited to participate. In total, we contacted more than 60 individuals in the outreach process. Among state-based disability rights leaders who declined to participate and were themselves people with disabilities, limited knowledge of the ACA was a commonly cited reason.

Overall, we were able to identify 16 suitable interview participants for the ten state-based interviews. Four interviews had one interviewee each and the other six had two interviewees each. Table 3 displays characteristics of the 16 interview participants. Half (N=8) of them had personal disability experience, either directly (N=5) or through an immediate family member (N=2) or other individual (N=1) for whom the participant was caring. Participants’ personal disability experience included physical (N=5), vision (N=1), hearing (N=1), developmental (N=1), and other (N=1) disabilities; two participants indicated two disability categories, and one participant with personal disability experience did not disclose a disability category. In most of the interviews—in eight out of ten states—at least half of the interviewees had a personal disability experience.

All 16 participants had rich professional experience working on behalf of people with disabilities. Participants were engaged in both direct services and advocacy as well as policy and systems changes to improve health care access for this population. Most participants worked or volunteered for a cross-disability organization (that is, organizations working for the benefit of all people with disabilities), and one participant worked for a disability organization that served individuals with

Participant Characteristics

Characteristic	Number (Percent)
Gender	
Male	7 (44 percent)
Female	9 (56 percent)
Age	
Mean (Range)	53 years (32 years to 72 years)
Race/ethnicity	
Non-Hispanic White	12 (75 percent)
White	1 (6 percent)
Non-Hispanic Black	1 (6 percent)
Asian	2 (13 percent)
No response	
Personal disability experience*	
Physical	5 (31 percent)
Vision/Hearing	2 (13 percent)
Developmental	1 (6 percent)
Other	1 (6 percent)
Unspecified	1 (6 percent)
None	8 (50 percent)
Organizational affiliation	
Cross-disability organization	15 (94 percent)
Other disability organization	1 (6 percent)

Note: *Personal disability experience includes participants who have disabilities themselves or have an immediate family member or other individual for whom the participant was caring who has a disability.

physical, cognitive/intellectual, and mental health/psychiatric disabilities. Participants worked for or were affiliated with many organizational types, including disability

rights organizations, centers for independent living, legal aid, and disability and health programs. Most of these organizations (N=10) were accountable to people with disabilities through boards, advisory councils, and memberships in which people with disabilities and their caretakers constituted a majority. The majority of participants were involved in policy advocacy to improve health care for people with disabilities, both prior to the ACA and in recent years focusing on ACA implementation issues. Several participants had served on committees or provided input on state policy related to Medicaid reform and ACA implementation.

Five participants provided legal-based services related to access to health care for people with disabilities through their work for legal services organizations and state protection and advocacy organizations. Nearly half of participants (N=7) had a background in providing other direct services, including experience with centers for independent living, special education, habilitative and rehabilitative services, community mental health services, services for families of children with disabilities and special health care needs, peer support, and health coverage advocacy for people with disabilities. Four participants served as health care Navigators, assisting people with disabilities enrolling in coverage under the ACA; two of those who served as Navigators also held leadership roles in their respective Navigator programs.

Data Collection and Analysis

Between March and April 2015, we conducted ten state-based group interviews by phone following a semi-structured guide. Interviews included one to two key-informant participants and two to four research team members; during

each interview, one research team member facilitated the interview and other team members added follow-up and clarifying questions.

The interview guide used broad, open-ended questions followed by more specific probes and covered the following domains: experiences of people with disabilities with QHPs offered through the insurance Marketplace, experiences of people with disabilities with expanded Medicaid for low-income adults, barriers and facilitators to enrollment in health care coverage for people with disabilities, changes to LTSS, employment impacts for people with disabilities, and other effects of health system changes on people with disabilities. Interviews were audio recorded and lasted 50 to 100 minutes, with an average length of 80 minutes. Members of the research team listened to the phone interview or recording for each interview, took detailed notes, and conducted a brief post-interview discussion to reflect on key emerging themes and areas warranting additional exploration in subsequent interviews.

Members of the transdisciplinary team (with expertise in the health of people with disabilities, social insurance policy, family medicine, public health, and qualitative methods) reviewed interview notes concurrent with data collection and used a thematic analysis approach to identify emergent themes.⁸⁰ We developed a preliminary coding scheme using ACA implementation topics as a priori codes and early interview notes. After the first four interviews, an oversight group of investigators reviewed codes and discussed emergent results. For subsequent interviews, we used an iterative process to independently code interview notes, meeting in small groups to discuss codes and new findings. The emergent themes are reported here along with

recommendations for potential areas of focus for future research and policy.

Results

Themes emerged in nine core areas: coverage options, enrollment processes, benefits and features of newly available health plans, post-enrollment barriers, long-term services and supports, health system reforms, employment and financial impacts, engagement of people with disabilities in developing new programs, and data collection. These themes are described in this section with illustrative quotes.

Coverage Options

Medicaid. Across all interviews, participants identified Medicaid as the main coverage option accessed by people with disabilities. Participants described Medicaid as the “first resource” for people with disabilities because of more comprehensive benefit packages, long-term care coverage, and waiver programs providing access to additional services and supports. A participant from Colorado stated,

For people with significant disabilities, insurance just doesn't work. Medicaid is really what you need.... Insurance doesn't pay for what we need. It doesn't pay for outdoor, heavy-duty wheelchairs; it doesn't pay for personal assistance. I guess it pays for medications, doctor visits, that kind of stuff. But the big expenses are really what people consider long-term care. (Colorado)

Participants tended to work for organizations primarily serving people with disabilities with low incomes, thus a large share of their constituents were Medicaid beneficiaries. Although many

people with disabilities already qualified for Medicaid on the basis of their disability, participants discussed subpopulations of people with disabilities who may be experiencing more changes in coverage options as a result of the ACA. Specifically, Medicaid expansion was viewed as an important change for uninsured people with disabilities who had not previously qualified for Medicaid on the basis on their disability status or were in a waiting period before their disability benefits and Medicare coverage began. Participants

in California provided several examples of groups that were likely to benefit, including “people who are deaf, who often do have lower-income jobs, but the sheer fact of deafness wouldn’t inherently qualify

you for [Medicaid] ... people who are older immigrants [with functional limitations] who do not have Medicare.” In states that did not expand Medicaid, however, some uninsured people with disabilities with low incomes remain without coverage and access to appropriate care. People with family income below 100 percent of the FPL are not eligible for subsidies to help purchase insurance through the Marketplace, making QHPs unaffordable for them; therefore, in states that did not expand Medicaid, the individuals who do not qualify within pre-ACA Medicaid categories are de facto excluded from coverage.⁸¹

As one interviewee explained,

Florida didn’t expand Medicaid, so that leaves all individuals under 100 percent of the federal poverty level, who are our

poorest and often our sickest individuals, who cannot get coverage. They can’t afford it. Yes, they’re exempt from the fee [for not having coverage], but that doesn’t help them because they can’t get coverage ... [A person with disability under 100 percent FPL] who may not have Social Security approval at this point or maybe doesn’t qualify per se for Social Security because they’re able to work in some ways, they are being left without treatment still. In fact, I had

Families of children with disabilities who had previously accessed Medicaid as “back-up” or “wrap-around” coverage to private employer-based or individual insurance could not continue this practice if they changed to purchasing QHPs with subsidies.

someone not long ago say to me, “Well, I’ll just continue to go to the hospital, like I always did.” (Florida)

Differences across state Medicaid programs pre-ACA also influenced how options were evaluated under the ACA, as

robustness of benefits for both traditional and expansion Medicaid coverage varied between states. Participants often used their state’s pre-ACA Medicaid coverage as a point of reference for describing the merits of new coverage options. So variations in the generosity of covered benefits for adults’ pre-ACA affected interviewees’ analysis of benefits for newly eligible adults.

Qualified Health Plans. Participants saw the availability of QHPs through health insurance Marketplaces as having limited impact for people with disabilities, mainly helping those who had sufficient income to purchase private individual insurance but pre-ACA were prevented from doing so because of preexisting condition exclusions. The end of preexisting condition exclusions and lifetime

spending caps was viewed as a “step forward,” especially for people with disabilities with high enough incomes to purchase private insurance. Participants in New York, a state that had had guaranteed issue and community rating for private insurance but no individual mandate before the ACA,⁸² emphasized the affordability of QHPs purchased through the Marketplace compared with the cost of private individual insurance before the ACA:

[The ACA affected people with disabilities] at any higher income who were priced out of the individual insurance market—because it was very expensive in New York—the prices of direct pay insurance were cut by 53 percent they said at the beginning, and that’s unsubsidized. Then add in the subsidies and people have much more affordable access to comprehensive health insurance. (New York)

Coverage options for people with “mild” disability. Although traditional Medicaid remained important for self-identified people with disabilities, participants saw QHPs and the Medicaid expansion as critical to another group of people with “mild” disabilities that are not severe enough to establish eligibility for most public benefit programs such as Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI). Individuals with a “mild” disability were described as more likely to experience changes in coverage under the ACA, but participants noted a lack

of knowledge about this population’s health care experiences because of the group’s more limited engagement with disability programs and organizations.

The Medicaid expansion has, we think, admitted in a number of people with disabilities who are not going to be captured in terms of who they are and what their experience is but who inevitably are people with disabilities, who are within the

Participants from states that did not expand Medicaid shared that it was common for working people with disabilities with incomes below 100 percent of the federal poverty level to be surprised not to qualify for help purchasing coverage.

income level that would make them eligible for the expansion, who are not on any other programs or roles. I have a general sense that that’s a benefit, a pretty strong benefit. (California)

Participants indicated that this population may include individuals with chronic physical or mental health conditions that “rise to the level of impairment,” but these individuals may have fewer or less apparent limitations than those with “severe” disability. Participants noted that individuals in this population may not be recognized as people with disabilities because they do not self-identify as having a disability or because their disabilities are within the scope of the Americans with Disabilities Act definition of disability but not within more narrow definitions that would qualify them for receipt of certain disability services. As a participant from Colorado stated:

I think there are a whole lot of people out there with so-called mild disabilities, and

they have a disability and it affects their lives but it's not such a big part of their lives that they feel the need to join an organization. And those are probably the people that are using the exchange. Those are the people that have more traditional mainstream jobs that would be using the exchange. The kinds of people that join our organization tend to be the people with the most significant disabilities.

Benefits for families and young adult children.

Participants expressed positive views of the option for children to remain on their family's insurance plan up to age 26. A participant from Colorado explained the effect on the stability of families: "[It impacts] every kid with a disability whose parents have a job—it's huge. It gives them an option of not having to impoverish themselves immediately to get SSI."

Several interviewees emphasized the importance of this change to families with children who have autism or developmental disabilities. In New York, where coverage through parents' insurance was already available up to age 29, participants noted that the ACA regulations provided a more affordable coverage option than the separate premium required under the existing state law.

Consequences to existing coverage options. New coverage choices under the ACA have also affected some previously advantageous state and local programs and coverage options. A participant from Florida provided the example

of a local health care district that ended an affordable health coverage program in response to subsidized QHPs being made available through the insurance Marketplace. Because Florida did not expand Medicaid, the end of this program left many individuals below 100 percent of the FPL ineligible for QHP subsidies and without coverage.

One issue involved the ACA's denial of QHP subsidies when consumers receive other forms of comprehensive coverage, such as that typically furnished by Medicaid and the Veterans' Administration (VA). Participants from North

Dakota perceived this prohibition as a limitation that faced people with disabilities who change from private insurance plans to subsidized QHPs. Families of children with disabilities who had previously accessed Medicaid

as "back-up" or "wrap-around" coverage to private employer-based or individual insurance could not continue this practice if they changed to purchasing QHPs with subsidies. Similarly, veterans with disabilities could use employer-based insurance as their primary coverage and VA health benefits as secondary coverage—a valuable option in a rural state where a veteran may need to travel a long distance to access VA health care. But veterans could not purchase QHPs using subsidies while retaining their VA health benefits.

Enrollment Processes

People with disabilities who enrolled in QHP or Medicaid coverage through insurance

"Medicaid customer service is an hour on hold, and a lot of people with disabilities and low-income people have [prepaid cellphones with] 200 minutes a month, but they're expected to sit on hold for an hour. That doesn't work."

Marketplaces faced significant barriers, and Navigators and disability organizations played an important role in facilitating access to health plan information and enrollment. Interviewees reported that people with disabilities experienced Medicaid enrollment backlogs and delays in QHP application processing. Participants from states that did not expand Medicaid shared that it was common for working people with disabilities with incomes below 100 percent of the federal poverty level to be surprised not to qualify for help purchasing coverage. A participant from Florida who had provided enrollment assistance stated, “The reaction was quite often disbelief, frustration, because they thought that everyone was entitled to insurance now ... The message was not as clearly communicated as it needed to be.”

Although these enrollment problems were not unique to people with disabilities, some participants shared concerns that the barriers were amplified for people with disabilities, who may have more complex health coverage issues. As a participant in Colorado noted, “Medicaid customer service is an hour on hold, and a lot of people with disabilities and low-income people have [prepaid cellphones with] 200 minutes a month, but they’re expected to sit on hold for an hour. That doesn’t work.”

Accessibility features of insurance Marketplaces. Most participants were not aware of any accessibility features to assist people with disabilities in their state in enrolling through the insurance Marketplace. A participant from North Dakota indicated there was a 1-800 phone number available for hearing-impaired

consumers. Participants in California noted that accessibility features were a point of advocacy for the disability community and considered for the state Marketplace but were ultimately not included in the Marketplace because the state Medicaid program lacked the capacity to respond to individuals who identified a need for alternate formats. Participants from other states described Navigators and disability advocates helping to bridge the gaps in accessibility. One participant who had served as a Navigator in New York provided specific examples of how the Web site was inaccessible for blind consumers and lacked accessible communications features for people who are deaf or hard of hearing. In New York,

consumers who were deaf or hard of hearing faced an additional barrier if they lost their Marketplace login information, because a verbal statement via phone was required to

regain account access; the only alternative was a burdensome process involving additional calls and faxed documents.

Navigators and enrollment assistance.

Participants consistently highlighted Navigator programs and advocacy provided by disability organizations as the main facilitators of people with disabilities’ enrollment in coverage. Specifically, participants described the effectiveness of disability organizations that were funded to provide Navigator services. Participants reported that standard Navigator training included only basic disability awareness information and did not adequately prepare most Navigators to address enrollment issues for people with disabilities. However, Navigators based at

[Co]verage does not equate with access to care. Several barriers obstructed access to care even for people with coverage to pay for it.

disability organizations were able to draw on their existing knowledge to assist people with disabilities in the enrollment process:

[People with disabilities' experiences were] a matter of what entry point they chose into the system. If it was a person with a disability who chose to go into the IL [independent living] center, where they had trained Navigators who also were already working with different disability populations and understood accommodations, then probably those needs were met. If they walked into their county library, then probably not. There were a lot of different access points ... mostly county libraries and health departments, DHS offices ... [The Navigators] had basic information ... but it's not like you can run someone through a one-day, two-day course and have them come out on the other side understanding the complexity of disability accommodation needs. (Arkansas)

When ACA-funded Navigator programs were not adequate to meet the needs of people with disabilities, disability organizations and informal peer networks played an important role in assisting people with disabilities in the enrollment process. Participants in Pennsylvania and California provided examples of disability organizations that operated helplines, in one case using funding from a private foundation. Other participants noted the presence of application councilors in health centers as an important path for enrollment.

Availability of disability-relevant health plan information. Health plan information specific to the health care needs of people with disabilities was not easily accessible through state or federal insurance Marketplaces, necessitating considerable independent information gathering by people with disabilities and their advocates. Many participants noted that insurance plans and health care providers had to be contacted directly, generally with the assistance of Navigators or

“Now that you have coverage and you don't know how to use it, someone needs to help you learn how to use that coverage . . . like Insurance 101 . . . to think about the community at large, how many people have never had coverage. So they're getting the coverage through the Affordable Care Act, but they don't know what to do with it.”

advocates, to obtain pertinent information:

It was a question of whether you could get on the phone and try to extract enough information from a plan to be useful... [You try to] get

an evidence of coverage document [with detailed descriptions of covered services] before you sign up for a plan, which is really the only thing that reveals the answers to some of the questions that people had, and that depends on whether states ... allow for those to be provided without actually signing up—some do and some don't. It's kind of a tangled web of problems and solutions that require a lot of individual tenacity and innovation, particularly on the part of the Navigators or whoever is assisting people to try to get the answers that they need. (California)

People with disabilities sought detailed information on covered services, including the

number of visits for certain therapies, specific equipment types, and specific providers. Drug formularies were another area of concern; plans provided comprehensive listings of covered prescription medications, but they were difficult to understand and sometimes required consumers to look in the footnotes to see that their prescription would be covered only after other medications were found to be ineffective for the patient (that is, “fail first”).

Availability of information on disability-specific Medicaid options. The majority of participants familiar with Marketplace enrollment indicated that in their states, people with disabilities with incomes above 138 percent of the federal poverty level were not identified and provided with accurate information about their potential eligibility for unique Medicaid coverage options such as buy-in or medically needy spend-down. Several participants noted that Marketplace enrollment processes did not include adequate questions to identify people with disabilities. Not having questions about disability included in standard Navigator protocols made it difficult for Navigators in some states to match people they assisted with the best options to meet disability-related health care needs.

Unless the question gets asked through the Marketplace, we have no reason [to ask about disability]. Except sometimes when I'm working with a consumer I will ask them what their health needs are. Oftentimes that's when they'll disclose a health condition, but outside of that there really is no question to ask them outside of what kind of health care issue they have so we can help them choose a plan. (North Dakota)

Even if people with disabilities were identified, they were often not provided with information on their eligibility for disability-specific Medicaid options, and Navigators who received only standard training lacked knowledge of these options. Navigators from disability organizations, however, were able to draw on their existing knowledge of these Medicaid programs to address this gap:

[I]t's background information we have being in the field of people with disabilities, we know those options. If I came off the street and was hired as a Navigator without having a background with people with disabilities, I don't know where you'd get that information other than sending them to the state Medicaid office. (North Dakota)

In contrast to the experience in North Dakota, participants from New York described Marketplace enrollment questions about need for personal or long-term care and interest in the Medicaid buy-in program. In this case, the state insurance Marketplace “[made] the effort to identify people so that people don’t enroll in the wrong plan when they could get better coverage.” Participants in New York also noted that although their single eligibility system had not yet “achieved the ‘no wrong door,’” it was successfully identifying enrollees for other Medicaid programs. Differences across participant experiences also suggested that some state-based Marketplaces (New York, California) may be more successful than the federal Marketplace in linking Medicaid determination and enrollment with the insurance exchange. However, the success of state-based Marketplaces was not uniform, as Colorado’s state-based Marketplace was described as

lacking connectivity with Medicaid determination and enrollment.

Retention challenges. In addition to the initial enrollment process, several participants noted concerns about people with disabilities' experiences with redetermination and continued coverage in future enrollment periods. In North Dakota, the point-in-time income evaluation used in Medicaid determination tended to result in disenrollment for low-income beneficiaries with incomes that fluctuate through the year. This practice may increase enrollment challenges and decrease continuity of coverage compared with evaluation that accounts for an individual's income on an annual basis. Participants from Oregon anticipated challenges keeping newly covered people with disabilities engaged in future enrollment cycles, regardless of the state's initial success enrolling previously uninsured individuals in coverage. Participants shared that many new enrollees face confusion about the reenrollment process but that fewer resources would be available for reenrollment assistance than were available for the initial enrollment effort.

Benefits and Features of Newly Available Health Plans

Participants who had served as Navigators or worked directly with people with disabilities to help evaluate and select coverage had more extensive knowledge of QHP benefits and features than did participants who had not served in these Navigator or direct advocate roles. However, even the participants who had served as Navigators had unanswered questions about QHP benefits, suggesting a knowledge gap around how well QHPs met the needs of people with disabilities. Participants from Colorado

and Montana also mentioned the exemption of employer-sponsored self-funded health plans from many ACA requirements and the need for more information about the experience of people with disabilities with these benefits.

Alignment of benefits in Medicaid-expansion states. Participants from states that opted to expand Medicaid described mixed experiences in the alignment of existing Medicaid benefits and of benefits for the expansion population. Participants from California, Colorado, and Oregon noted that the Medicaid benefits for newly eligible low-income adults were the same package as existing Medicaid benefits. In North Dakota, participants indicated that the private managed care health plan selected as the alternative benefit plan (ABP) for the Medicaid expansion offered a less comprehensive benefit package and a more limited provider network for people with disabilities than had the state's previous Medicaid coverage. None of the participants were knowledgeable of the medical frailty exemption process for opting out of ABPs. The lack of such knowledge in states with ABPs that differ from Medicaid benefits for other adults suggests limited use of this provision to date as well as limited or ineffective efforts to educate beneficiaries about this process, a situation that could have major implications for people with disabilities.

Alternative Medicaid expansion plans. States also had the option to craft their own Medicaid expansion plan using a Section 1115 waiver (so-called nontraditional Medicaid expansion), and two of the states represented in our sample pursued this option. Pennsylvania's nontraditional Medicaid expansion plans were strongly opposed by the disability community. However, following the election of a new governor, the state was

changing course to pursue a Medicaid expansion model that would extend the existing state Medicaid benefits to the expansion population. In Arkansas, the nontraditional Medicaid expansion used funds to provide premium assistance for the purchase of QHPs for newly eligible adults. This plan was described as a positive measure compared with the likely alternative of no Medicaid expansion in the state.

Qualified Health Plan features. Participants familiar with QHPs described significant limitations in states' chosen packages for EHBs. Participants in North Dakota noted that habilitative, mental health, and equipment services became less accessible on private insurance plans because the state chose the "cheapest essential benefits, maybe not considering all the impacts for all consumers." Although lifetime and annual benefit payment limits for EHBs are prohibited, EHBs restricted important services for people with disabilities in other ways:

Physical, occupational, and speech therapy: 60 visits per condition, per lifetime. That's it. And that is whether it's rehabilitation, which is regaining function, or habilitation, which would be maintaining function. Home health care: 40 visits a year. Skilled nursing: 200 days per year. Medical equipment: standard equipment only. Hearing aid: one single purchase every three years. One external prosthetic device per limb, per lifetime. God forbid you ever need a different prosthesis.
(New York)

Additionally, participants noted that people with disabilities across all states were encountering challenges with prescription medication coverage

under QHPs' preferred drug lists, often facing "fail first" policies that can interfere with complex drug regimens:

For a lot of people with disabilities, they have a number of different drugs that they take together, and it's everything all together is what makes life work. If you pull away one, it may affect more than just that one thing that you're addressing. So it's really important to not mess with medications that work. (Colorado)

Impacts of cost sharing. Participants emphasized the financial burden on people with disabilities who enroll in QHPs, including both premiums and out-of-pocket costs. One participant described QHP cost-sharing as one of the "serious downsides" of the ACA:

There are people with disabilities in the pool who are purchasing private insurance through the Marketplace and then when they try to use it they're discovering—as many other people are too—that the copays are keeping them from receiving health care services. (California)

Another participant from Florida said some QHPs were a "smoke screen" because the deductibles and premiums were so unaffordable for people with disabilities. Some participants noted that those copays have greater impacts on people with disabilities, who are likely to use more health care services. Participants from North Dakota, however, described largely positive response to the cost of QHPs, with subsidies that were perceived as making private coverage more affordable for people with disabilities. Participants in New York—a state where insurers

had to sell an insurance policy to any applicant and could not vary insurance premiums except by geography pre-ACA—highlighted the steep drop in premiums for private insurance plans with the advent of the ACA's individual mandate, but they noted that people with disabilities can still face barriers with high deductibles and other forms of out-of-pocket cost-sharing.

Provider networks. Provider networks were often a determining factor in people with disabilities' QHP selections. New York participants highlighted narrow provider networks as a key concern for people with disabilities; before April 2015, New York QHPs did not include options for out-of-network coverage (unlike state Marketplaces in which preferred provider organizations (PPOs) or tiered provider networks covered non network care, albeit with elevated cost-sharing).⁸³ One New York participant stated, “[For] someone who sees a lot of doctors it’s going to be almost impossible to find a one-size-fits-all plan.” Participants in Pennsylvania described “sculpting and tiering” of networks that resulted in low QHP premiums but restricted access to health systems, for example, by covering primary care visits with relatively low copays only at federally qualified health centers. On the other hand, some participants from other states described QHPs' limited provider networks as normal in rural regions, where it is common to have fewer choices of health plans and providers. We discuss rural health care access further in the section “Postenrollment Access Barriers.”

Coverage limitations for durable medical equipment, habilitative services, and mental health care. For both Medicaid and QHP benefits, participants raised the most concerns about the adequacy of coverage for durable medical equipment (DME), habilitative services, and

mental health care. Two participants compared the limitations in DME coverage to Medicare guidelines, noting that current benefit problems are a continuation of covering only what is needed in the home instead of “*what’s needed for life.*” The inclusion of habilitative services in the EHB requirements was viewed as a positive step, but disability organizations now face the challenge of educating the broader health care community about habilitation. Several participants relayed that people outside the disability community don’t yet understand what habilitative services are and said that it is too early to assess people with disabilities' experiences with these benefits. Mental health benefits were a concern for several participants who had heard of QHPs that provide coverage that does not follow ACA and other state and federal parity laws; one participant likened mental health benefits in Montana QHPs to “catastrophic insurance,” falling far short of adequate coverage.

Health plan compliance with benefit requirements. The degree to which health plans would cover the disability-specific services defined in the EHBs and the mechanisms for monitoring health plan compliance also were points of concern. Participants relayed skepticism that health plans would actually adhere to the new benefit requirements and might have to “get caught” before they comply. Given the complexity of the new requirements, participants conveyed uncertainty and confusion about the implementation of these provisions and how health plans would be held accountable for delivering benefits that are important to people with disabilities.

Participants in Pennsylvania noted concerns about the level of coverage that would be provided for habilitation and rehabilitation services

and the lack of involvement of the state insurance department in the regulation of plans purchased through the federally facilitated Marketplace:

We think that the EHBs, specifically the category of habilitation and rehabilitation, really have a significant impact on persons with disabilities. [Some of the concerns might be expressed in questions about how] QHPs have put [their plans and guidance] together for their baseline in the first year. Also, what [is that] going to look like in future years, and what [is] the definition for medical necessity?... [What] is [used] for determining which plans are giving those [habilitation and rehabilitation] services in the way that they can or should be [beneficial] to people who need them]?.... We're concerned [about] our state insurance department, which has been relatively hands off because it's not their Marketplace—there's questions about enforcement. (Pennsylvania)

Postenrollment Access Barriers

Advocates frequently focus on coverage as the end goal for insurance reform. Participants in this study, however, reminded us that coverage does not equate with access to care. Several barriers obstructed access to care even for people with coverage to pay for it.

Knowledge of how to use coverage. Many receiving coverage through Medicaid expansions or exchange QHPs had never had health insurance before and were unsure how to navigate the system to obtain care. A participant from Colorado said, “You get a Medicaid card, but no one tells you what to do with it.” Funding for Navigators typically ended at enrollment, so the newly covered were left alone to wrestle with

Postenrollment Access Barriers

- Knowledge of how to use coverage
- System capacity and access problems
- Rural access disparities

learning where to seek care and how to navigate copays, deductibles, and other complexities. These barriers were compounded for those patients with language barriers. Participants spoke of the need for postenrollment navigation and educational resources such as “coverage to care” classes to remove these barriers. A participant in Florida described the need to provide training in the community:

What does a copayment mean? What does it mean when it says co-insurance? Try to bridge those barriers.... Now that you have coverage and you don't know how to use it, someone needs to help you learn how to use that coverage ... like Insurance 101 ... to think about the community at large, how many people have never had coverage. So they're getting the coverage through the Affordable Care Act, but they don't know what to do with it.

System capacity and access problems. In states expanding Medicaid, the flood of new enrollees overwhelmed already-taxed Medicaid provider networks. Participants in California and Colorado, two states experiencing vast Medicaid expansions, reported seeing long-time Medicaid members with disabilities crowded out by the flood of new enrollees. Shortages

of hearing interpreters exacerbated access for the deaf and hard of hearing in at least one state (North Dakota). Participants from Oregon, Colorado, and New York also noted the shortage of mental health providers as an access barrier for people with disabilities; in Colorado a patient may wait months before getting an appointment with a psychiatrist, especially with Medicaid.

Rural access disparities. The access barriers described were amplified for people with disabilities in rural states. Access to specialty providers such as psychiatrists and pediatricians was described as problematic to nonexistent in areas such as upstate New York and rural North Dakota. Getting Medicaid programs to cover care from specialists in adjacent states required “almost an act of Congress,” even in emergencies for people with disabilities in North Dakota. Participants noted that rural residents with disabilities were also more likely to face a “bootstraps mentality,” the attitude that they could manage conditions on their own, which made it hard for them to seek care even when coverage was available through the ACA.

Long-Term Services and Supports

Many states were undertaking multiple, significant changes in long-term services and supports, often making unclear what changes were the direct result of the ACA and what were the result of other initiatives. Participants noted a variety of changes in assessment processes, definitions for home and community-based versus institutional settings, and payment arrangements for employment of aides and family caregivers.

Dual demonstration option. In states that were testing models for integrating Medicaid

and Medicare benefits for dually eligible beneficiaries, interviewees were ambivalent about the program’s impact on services and uncertain about People with disabilities’ experiences to date. Although participants saw coordination and integration of services as good “in theory,” they shared concerns that the managed care organizations being selected lacked experience delivering long-term care for people with disabilities and that the groups would have an incentive to reduce services under a capitated rate. California and New York had low enrollment in the program; this led New York to switch from an opt-in to an opt-out enrollment, adding a layer of challenges and confusion. New York participants described additional challenges with training health care providers and assisting people with disabilities with network issues such as identifying a managed care plan that will allow someone to retain a particular home health aide. Colorado’s adoption of a managed fee-for-service model using primary care case management instead of managed care was viewed positively, but actual experiences of people with disabilities were unknown at this early stage. In Oregon that program was put on hold, and long-term care remained carved out of managed care, including in the new regional coordinated care organizations serving the Medicaid population.

Community First Choice option. Participants were also uncertain about the early impacts of the Community First Choice (CFC) option but described several implementation hurdles. As HCBS were added to California’s Medicaid plan, community-based providers experienced difficulties in contracting with managed care organizations and navigating a new business

environment. A participant in Oregon described a divide between care for aged people with disabilities, for whom CFC changes have been “fairly tranquil,” and for the intellectual and developmental disabilities (IDD) system, which must “totally transform;” these accounts may involve CMS’s changes to HCBS, which apply nationwide. However, the IDD community has raised concerns that changes made for CFC purposes will undermine choice and person-centered planning that Oregon has worked to develop over time. Changes in Montana have been “problematic” for people with disabilities with self-directed care and have led to significant billing confusion for home health care providers. In some states where the CFC option has not been implemented, the disability community is currently advocating for it, citing long waiting lists for home and community-based waivers. Advocates in Colorado have found that the six percent increase in federal match tied to CFC has provided strong motivation for action in their state.

Health System Reforms

Most states had concurrent non-ACA system or payment reforms underway in addition to ACA-led changes. Some reforms were viewed as beneficial to people with disabilities; others less so.

Health information technology. Participants saw promise in programs to enhance health information technology to improve care coordination and access. Telemedicine and e-mail-based communication could allow patients to access providers without requiring travel to clinic sites, particularly useful for rural patients and those with transportation barriers. Improved electronic health record systems and health

Health System Reforms

- Health information technology
- Patient-centered medical homes
- Managed care
- High-utilizer intervention programs

information exchange could improve information sharing and coordination between people with disabilities’ providers and care sites.

Patient-centered medical homes. Patient-centered medical home (PCMH) initiatives were underway in at least four states in our sample, and those programs also were regarded favorably for their case-management features, coordination between co-occurring physical and behavioral care needs, and patient-centered orientation. These changes in delivery of care were emphasized in several states where Medicaid expansion and other ACA provisions were not embraced; in the absence of expanded Medicaid programs, participants in Montana and Kansas described PCMH programs as a significant ACA outcome affecting people with disabilities in their states.

Managed care. In contrast, as discussed previously, participants were uniformly wary of systems reforms that aimed to move people with disabilities from traditional fee-for-service-based programs into capitated managed-care organizations (MCOs) or accountable care organizations (ACOs), regardless of whether the coverage was contracted via Medicaid alone or Medicaid/Medicare plans for dually eligible individuals. Participants doubted the capacity of most of these plans to provide continuity of care

or appropriate providers to meet the specialized needs of people with disabilities, diminishing quality of care even if services were technically covered.

[In ACOs] we had more emergency room visits, more unnecessary testing ... the numbers are actually showing that we're doing worse in the accountable care ... [the providers in ACOs] are not really geared toward people with disabilities. People with disabilities generally do best in small family practices where they have one doctor who really knows them, and maybe a receptionist and nurse who really know them, and going to a big clinic where they see different people all the time just does not work. (Colorado)

Advocates in several states noted a disappointing lack of transparency in contracting arrangements even for publicly funded plans. In New York, care reform had netted \$6 billion in Medicaid savings, but disability advocates had no way of knowing how the savings had been produced and whether care for people with disabilities had suffered.

High-Utilizer Intervention Programs. “Hotspotting” or high-utilizer intervention programs also were ongoing in a couple of states, and Arkansas was experimenting with “incident-based” payments to primary care providers. These programs targeted patients with complex health care needs who have frequent emergency department visits or inpatient hospital stays; the programs implemented care coordination and other interventions to reduce unnecessary hospital utilization, to improve care, and to reduce health care spending for this population. Participants noted that people with disabilities who use more health care services than do other consumers might be more likely

to be involved in these intervention programs. However, the impact of these measures on care for people with disabilities was yet to be seen.

Employment and Financial Impacts

The majority of participants did not perceive any direct impacts of the ACA on employment prospects for people with disabilities, but some noted that new coverage options might relieve insurance-related employment pressures. In several states, participants remarked that improving health care for people with disabilities is an important step, but many other employment barriers remain.

You have a population that has been told for decades, “You can’t work, you can’t work, you can’t work. The minute you work we’re taking away everything.” ... [F]or people who’ve been out of the workforce for all of this time, they aren’t going to be able to just jump right back in. (Colorado)

On the other hand, a participant from Montana described the positive impacts that the end of preexisting condition exclusions and newly available coverage options may have for working people with disabilities: “People are freer to choose employment that suits their skills and interest rather than shopping for employment based on insurance that can cover them.”

Medicaid buy-in coverage. Participants who were familiar with a Medicaid buy-in program for working people with disabilities in their state viewed the option positively but noted that it was generally underutilized. Participants in two states cited the availability and underutilization of Medicaid buy-in programs as evidence that employment barriers for people with disabilities extend beyond health care issues. Only one

participant was aware of any recent changes in their states' eligibility requirements for the Medicaid buy-in program; specifically, New York's resource limits increased to \$20,000 but do not include individual retirement accounts or other retirement savings.

Financial impact of asset limits. Medicaid expansion coverage for low-income adults and QHPs could have a positive financial impact for people with disabilities by allowing them to retain resources that are prohibited under the strict asset limits for people with disabilities receiving coverage based on SSI determination. These new coverage options were described as opening up opportunities for people with disabilities to improve their financial security. However, switching between the asset restrictions of one of these new coverage options and disability-related Medicaid eligibility can be challenging. "Some people get a taste of relief from expanded Medicaid, then find themselves under old rules again and have to make all of these adjustments," said a participant from New York. Participants gave examples of this change in asset restrictions that affect people with disabilities who obtained Medicaid expansion or QHP coverage during the waiting period before their disability benefits and coverage began and for many individuals who become dual eligible beneficiaries at age 65.

Engagement of People with Disabilities in Planning New Programs

Stakeholder engagement processes. The degree to which people with disabilities and disability advocacy organizations were engaged in designing and planning new programs under the ACA varied across states. In Colorado, a

participant described being actively involved in designing some of the changes in long-term services and supports programs. In other states, disability advocates were invited to participate in stakeholder meetings or to give input but did not see this as sufficient engagement of people with disabilities. A participant from California stated, "[There are] lots of opportunities to meet and talk; not as many opportunities to influence the outcome." Participants in Oregon described the inclusion of Medicaid consumer members on the boards of directors and community advisory councils overseeing each of the regional coordinated care organizations, but they noted that although people with disabilities and advocates were present at meetings, their participation was not always facilitated effectively; instead, the meetings were "dominated by health professionals."

Policy advocacy. In some states, implementation of the ACA has spurred advocacy within the disability community. In Arkansas, disability groups that have not historically worked closely with each other have come together to advocate for the adoption of the Community First Choice option. Participants in Montana, North Dakota, Kansas, and Pennsylvania described people with disabilities and their advocates' involvement in the state legislative process related to ACA implementation. Each state's disability community had to respond to a different political context, as a participant from Pennsylvania stated,

Because Pennsylvania not only didn't embrace the ACA but really fought it, was one of the states that filed the law suit ... over these last couple years folks with disabilities and their advocates, organizations like

ours and lots of others ... [had] to put so much time and energy into ... trying to get the basics that could have—and we would say should have—been afforded under the ACA.... [T]here was just so much time and resources and energy focused on to trying to preserve what we have and trying to at least get the minimum of the Medicaid expansion. So we'll never know what could have been had that not been the scenario, had we been a state where we were embracing the ACA.

Data Documenting the Experiences of People with Disabilities

Gaps in data collection showing the experiences of people with disabilities not only affect the current work but also future research. One indicator of the dearth of available information was how often participants asked the interview team for news from other states. Participants often noted that their interview responses were regrettably limited to anecdotal evidence. They described an informational landscape in which disability-related enrollment data were nonexistent or unobtainable.

Participants described the lack of disability-related data as harmful to efforts to improve coverage options for people with disabilities; it was difficult and in some cases impossible to track the enrollment choices people with disabilities were making and their short- and long-term impacts on health. Although the federal exchange included a question on disability that most participants found adequate, advocacy organizations had been unsuccessful in accessing these data. Participants from Pennsylvania described state-specific enrollment data on people with disabilities as unavailable. One

noted, “The state has not fully implemented the ACA the way that other states have.... Our [exchange] has always been federally operated ... so our state has been pretty hands-off in terms of that data.”

The development of state-based insurance Marketplaces was viewed as an opportunity for valuable data collection, but at least one state (California) with its own exchange had omitted disability-related questions from its enrollment process. A participant from California described the challenges in advocating for better data collection in the state-based exchange:

Because it's a time of flux and of building and developing, the reality is it has been really hard to get attention and priority on issues that are of long-standing importance to us: issues around data collection.... [T] here was a big coalition of language groups, consumer groups, health care groups, and we were in there all sort of making our pitches ... and wanting to gather demographic information. The whole IT team was under these intense pressures of having to be ready to go online for hundreds of thousands of people at a certain time.... [W] hen they're racing like that with set deadlines, getting sufficient attention to “Is the [Web site] accessible? Are you having questions about people with disabilities? Can you identify people with disabilities? Are you providing accessible formats?” It's not getting [attention].

One interviewee serving on a federal advisory panel described how six disability-related questions were cut from a list of 107 being considered for a consumer survey on quality of

OHPs, rendering disability-specific responses unidentifiable. Participants in Oregon also noted data gaps but pointed to recent state legislation that will create uniform data collection standards allowing for better identification of people with disabilities in the future.

Policy Recommendations Stemming from Key-Informant Interviews

Participants shared numerous challenges and successes for people with disabilities in the new ACA landscape. These early experiences across ten states with diverse ACA implementation choices suggest several future directions for policy:

Engage disability advocates as Navigators.

Many participants worked with disability advocacy groups that had received funds to train and serve as official ACA exchange Navigators. In their experiences, the combined value of disability-specific health systems knowledge and person-to-person contact (whether face to face or

via phone) was immeasurable for helping clients with disabilities gain access to the best coverage options. Participants shared that Navigators without prior experience working for people with disabilities, while well-intended, would not have had the tools to recognize or appropriately advise clients with disability. Providing support for disability organizations to offer Navigator services could strengthen the effort to enroll people with disabilities in the coverage options that best meet their needs.

Expand Navigator training. Participants recognized that many people with disabilities receive enrollment assistance from Navigators that are not based at a disability organization, and these Navigators likely lack the information and training needed to provide adequate assistance to people with disabilities. Content could be added to the Navigator training program to help familiarize Navigators with some of the key health care issues that people with disabilities face and with strategies to help people with disabilities with important enrollment issues. This training could include equipping Navigators with a list of disability advocates in their region or state to whom they can connect clients with disability who face unusually complex enrollment questions. More experienced Navigators from disability advocacy groups also could train other Navigators.

Make Marketplaces more accessible for people with disabilities. Improvements in the accessibility features of state and federal Marketplaces could enhance enrollment success for people with disabilities. Participant descriptions of current Marketplace features indicate ample room for improvement in this area. Providing information and forms in accessible formats, ensuring that Web sites are

Policy Recommendations Stemming from Key-Informant Interviews

- Engage disability advocates as Navigators.
- Expand Navigator training.
- Make marketplaces more accessible for people with disabilities.
- Standardize marketplace information available to enrollees.
- Provide health insurance education for new enrollees.
- Address data collection gaps.

accessible, and offering chat features are a few changes that could be implemented by state and federal Marketplaces for future enrollment cycles.

Standardize Marketplace information available to enrollees. Participants frequently identified that people with disabilities often lacked information to make informed coverage decisions. Although some of this information applied to the general population as well (for example, learning whether a familiar provider would be covered under a given plan), other issues were unique to the disability community (for example, number of visits for certain therapies or coverage for specific equipment types). Making this information easily accessible through the Marketplace as well as presenting the information in a standardized and consistent format would facilitate the enrollment of people with disabilities in coverage. As a starting point, advocates helping people with disabilities enroll in coverage could formulate standard questions to be asked of plans and providers that would assist clients in assessing options, and could advocate for the inclusion of these standard items in information submitted by QHPs.

Provide health insurance education for new enrollees. Participants described a knowledge

gap for new enrollees faced with understanding different plan features and the procedures for using insurance to obtain health care services. As suggested by one participant, “Insurance 101” education could increase people with disabilities’ knowledge about private insurance options and cost sharing, helping them to make informed decisions when selecting a plan or using insurance for the first time. Trainings could address how and where to seek care and how to navigate copays, deductibles, and other complexities.

Address data collection gaps. We consistently heard participants emphasize the importance of capturing data to assess the impact of the ACA on people with disabilities. Participants highlighted the need for Marketplace enrollment data that allow for the identification of people with disabilities and thus the ability to monitor ACA impacts on this population. In particular, data related to the subpopulation of people with disabilities who were previously uninsured and gained access to coverage through Medicaid expansion may provide valuable insight on the composition and experiences of this group of people with disabilities who may not be engaged with disability services or otherwise identified.

Chapter 4. Selected State Policy Choices Important for People with Disabilities

In this chapter, we describe state policy choices in two areas important to people with disabilities: Medicaid expansion, including decisions about ABPs, and the parameters of several EHBs that are particularly important to people with disabilities. We begin by explaining our methodology for developing this analysis of 50 states and the District of Columbia and then discuss notable differences in policy choices between states. Tables showing policy choices by state are in the appendix.

Methodology

Appendix Table 1 shows the status of state Medicaid expansion decisions as of December 2014. Information was drawn from an analysis by the National Academy for State Health Policy's StateRefor(u)m project.⁸⁴ The StateRefor(u)m table was missing some detailed information on certain states' ABPs, and in those cases we referenced the CMS SPA approval letters, which provide detailed information on the base plan and the coverage of each EHB.⁸⁵

Appendix Tables 2 through 4 show by state the amount, duration, and scope of EHBs that involve habilitative services, rehabilitative services, and DME. To analyze these benefits, we began with CMS's online compilation of state-specific information about EHBs, including coverage offered by benchmark benefit plans.

CMS developed tables for each state showing specific details about each EHB benefit category, including limits, exclusions, and explanations. Additionally, a CMS cover page for each state summarized plan information, including whether habilitative services were included in the benchmark plan's coverage, whether the state defined habilitative services, and, if so, the state's coverage definition. The cover page also provided the benchmark plan's name, type, and issuer.

However, some states' CMS tables provided no coverage details, or the information provided was insubstantial and missed many of the key points included in other state tables. In these cases, we referenced certificates of coverage, which set out the details of benchmark plans' coverage.⁸⁶ Carriers often do not provide certificates of coverage until after a customer subscribes to the plan, making these certificates difficult to obtain. We were able to access such certificates through StateRefor(u)m's online compilation of certificates of coverage for benchmark plans, updated as of February 5, 2014. Though this access to coverage documents is a valuable resource, StateRefor(u)m has collected certificates of coverage for only 23 states and the District of Columbia. Our principal use of this collection involved information about rehabilitation services. When a state had little

or no information concerning rehabilitative services in its CMS table, we drew from the applicable certificate of coverage to provide the same level of basic information for each state. Using this two-fold method, we were able to gather complete information for all states except Minnesota, New Mexico, and South Dakota.

This approach had several limitations. Because regulations regarding EHB habilitative services changed in February 2015, some states have been shifting or will soon change their coverage to meet new criteria. However, the CMS summaries were originally prepared on the basis of 2012 plan designs. Some states have already changed their regulations, but the CMS summaries are undated so it is difficult to tell which of them reflect current state law. Additionally, there are some inconsistencies between the CMS cover sheets and tables; in some cases, the certificates of coverage contradicted information in the CMS documents. These discrepancies and our resolution of them are indicated in each table's notes.

Medicaid Expansion: Benefits for Low-Income Adults

As originally enacted, the ACA required each state to expand Medicaid eligibility to all adults under age 65 with incomes at or below 138 percent of the FPL. However, in June 2012 the U.S. Supreme Court ruled that states can opt out of Medicaid expansion, giving them the authority to accept or reject this aspect of the ACA. If a state expands eligibility, it can craft the terms of coverage within federally defined parameters.

Appendix Table 1 details the various approaches that states took to the expansion and ABP coverage. Although 20 states chose not to expand coverage as of the date of

the StateRefor(u)m summary, 22 states and the District of Columbia opted for traditional expansion through SPAs. Six others have received demonstration waivers under Section 1115 of the Social Security Act and are expanding via experimental, nontraditional systems. One state (Alaska) was scheduled to start its expansion September 1, 2015, and one state (Montana), has adopted the expansion and was awaiting federal waiver approval. Note that Alaska, Montana and the 20 states that did not expand are not listed in the table.

In states that chose to expand, newly eligible adults receive a package of benefits called the Alternative Benefit Plan (ABP). ABPs must meet EHB requirements, which include covering each of ten statutorily specified categories and providing parity in physical and mental health care coverage. The state can choose from several benchmark plans as the basis for ABPs. Some benchmark plans—for example, the most highly subscribed plan offered by small employers—are commercial, but a state can also opt for “secretarially approved” benchmark benefits, which can provide newly eligible adults with standard Medicaid benefits offered to other adults. If a state decides to align benefits for newly eligible adults with benefits for other Medicaid-eligible adults, it may need to adjust the latter benefits to meet EHB requirements.

The StateRefor(u)m analysis found that 20 state plans drew their ABPs from the state's Medicaid plan and 13 plans drew upon one of the qualifying commercial plans. Most of these plans had to be expanded to meet the new requirements introduced by ACA. To align Medicaid benefits for all adults, the ACA's EHB standards required broadening benefits for

Medicaid adults who had previously qualified. For ABPs, the most common method of meeting the law's requirements was to supplement Medicaid with the services provided by the benchmark plan. However, in four state plans, Medicaid benefits were slightly cut back, as permitted by federal EHB guidelines. Many states explicitly mentioned that the adoption of Medicaid or the benchmark plan as the ABP was an intentional choice seeking to streamline the transition process when consumers moved between programs.

Essential Health Benefits

Another important ACA policy requires most individual and small-group plans⁸⁷ to cover ten broad categories of benefits as EHBs. These ten categories are ambulatory patient services; emergency services; hospitalization; maternity and newborn care; mental health and substance use disorder services, including behavioral health treatment; prescription drugs; rehabilitative and habilitative services and devices; laboratory services; preventive and wellness services and chronic disease management; and pediatric services, including oral and vision care. In defining the details of coverage within each category, states can choose from among certain benefits packages offered by employers to workers and dependents. States have selected varying employer-based plans as their benchmarks, so states differ in the amount, duration, and scope of benefits that are required within broad EHB service categories.

Because many employer-based plans did not previously cover habilitative care, a unique process determines the benefits within this service category. In CMS's original EHB regulations, if habilitative services were not

Federal definition of habilitative services

"health care services that help you keep, learn, or improve skills and functioning for daily living. . . . [T]hese services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings"

included in the selected benchmark plan, the state was allowed to define the benefits provided in that category. If the state chose not to define the benefits, insurers could define the habilitative services they chose to cover. In February 2015, new regulations eliminated insurers' ability to define habilitative services, instead creating a federal definition that applies unless the state issues its own definition. The federal standard defines *habilitative services* as "health care services that help you keep, learn, or improve skills and functioning for daily living.... [T]hese services may include physical and occupational therapy, speech-language pathology, and other services for people with disabilities in a variety of inpatient and/or outpatient settings."⁸⁸ New federal rules forbid operating habilitative services and rehabilitative services with a shared visit limit; instead, any such limits must apply separately to these two service categories. The requirement goes into effect in January 2017. The federal standard also requires habilitative services to be in parity with coverage of rehabilitative services. According to the information posted by CMS and supplemented by certificates of coverage as described in our earlier methodology

section, habilitative services are included in the benchmark plans of 34 states, are defined by the state in 11 states, and are defined exclusively by federal law in seven states.

Though the details of services within EHB categories are determined on a state-by-state basis, state and benchmark plans alike follow some general trends in habilitative, rehabilitative, and DME coverage. For habilitative services, limits range from 20 to 60 visits per year, though there is a wide variance as to whether the limit includes all types of

therapy or is divided between specific categories. Most plans include, at minimum, physical, occupational, and speech therapies; however, Michigan and Oklahoma exclude speech therapy and South Carolina covers only physical therapy. The majority of states explicitly exclude vocational training, and

nine states directly exclude maintenance therapy as well. The latter exclusion raises questions about compliance with the federal definition of habilitative services as including services that “help you *keep ... skills and functioning*” (emphasis added).

As noted earlier, 11 states do not yet comply with the prohibition on limits that combine habilitative and rehabilitative services, a prohibition that becomes effective on January 1, 2017. The federally required separation of services is important for people with disabilities. Some states have apparently applied the same limits

that previously applied to rehabilitative services to the new category of habilitative services, effectively doubling the total amount of coverage available within these two service categories.⁸⁹ Even if the total volume of covered services does not increase, the new federal limit means that using services in one category will not diminish the total volume of services available in the other category.

Though states cover a relatively similar package of services, some benefit areas, including

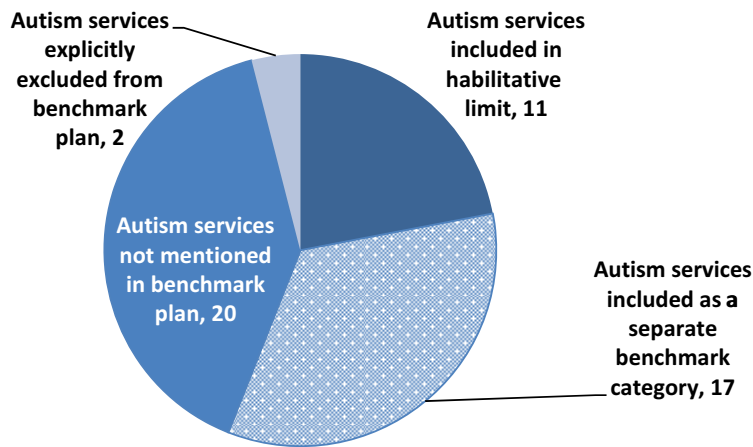
treatment of autism, have a wide variety of coverage structures. In Mississippi and North Dakota, autism therapies are explicitly excluded from benchmark coverage of habilitation, as is speech therapy related to autism in Rhode Island. Twenty other benchmark plans do not address autism at all. Twenty-eight states cover autism services in their benchmark plan,

with 17 of those states listing it as a benefit category independent from habilitative care. Massachusetts and Nevada include autism services under habilitative services but apply a separate limit to the treatment of autism⁹⁰ (Figure 1).

Unlike habilitative care, rehabilitation services have long been part of coverage plans, so the implementation of ACA has made less of a change in this service area. The US Department of Health and Human Services defines rehabilitation as “health care services that help a person keep, get back or improve skills and

The majority of states explicitly exclude vocational training, and nine states directly exclude maintenance therapy as well. The latter exclusion raises questions about compliance with the federal definition of habilitative services as including services that “help you keep . . . skills and functioning” (emphasis added).

Figure 1. Number of States (including the District of Columbia) with EHBs That Cover Autism Services in Various Ways



Source: Center for Consumer Information and Insurance Oversight.⁹¹

Note: Figure 1 depicts the number of states (including the District of Columbia) adopting each of four strategies regarding coverage of services related to autism: autism services explicitly excluded from benchmark plan (two states, four percent of all states), autism services included in habitative limit (11 states, 22 percent), autism services included as a separate benchmark category (17 states, 34 percent), and autism not mentioned in benchmark plan (20 states, 40 percent).

functioning for daily living that have been lost or impaired because a person was sick, hurt or disabled. These services may include physical and occupational therapy, speech-language pathology and psychiatric rehabilitation services in a variety of inpatient and/or outpatient settings.”⁹²

Rehabilitative coverage is similar among states and generally includes physical, occupational, and speech therapies and employs limits ranging from 20 to 60 visits per year. Many states also include pulmonary and cardiac rehabilitation in their benefits. To qualify for rehabilitative services coverage, patients in most states must have reasonable potential for improvement in their applicable conditions. Most states also end coverage of rehabilitative services when the patient regains a pre-injury or pre-illness level of functionality.

Other aspects of rehabilitative services coverage vary among states:

- Some states require a hospital stay or surgery before consumers receive coverage of physical, pulmonary, and cardiac services.
- Coverage may exclude certain kinds of rehabilitation work deemed nonessential, such as rehabilitation to enhance athletic or job-specific skills
- In some states, new and less expansive limits apply to rehabilitative services when treatment moves from short- to long-term rehabilitation. Similarly, the rehabilitation performed postsurgery in the hospital may be subject to different limits than apply to outpatient rehabilitation, as they are listed in different benefit categories.

- Depending on the state, rehabilitative services coverage may exclude part of the three generally accepted phases of cardiac and pulmonary rehabilitation.⁹³ Altogether, 18 states completely exclude one or both of these therapies.

DME across states follows a pattern similar to that of rehabilitation, including the same general services with variations in the specific pieces of equipment covered and the frequency at which they will be replaced. Most states limit coverage to devices and supplies that are primarily for medical use, not useful in the absence of illness

or injury, and able to withstand repeated use. DME coverage typically excludes anything above standard grade and does not cover replacements or upgrades due to technological advances. If an item can either be rented or purchased, insurers typically decide on a case-by-case basis which option is covered. While prosthetics are usually included, most orthotics are not. Glasses, dental braces, and anything that must be surgically implanted are covered by other benefit categories in most plans, but the coverage varies among states.

Chapter 5. Recommendations for Future Research

The analysis in this report brings together early evidence of the ACA's impact on people with disabilities by summarizing existing studies and reports, describing findings from interviews with key informants, and itemizing selected state policy choices. Perhaps equally important, this report also shows the tremendous need for research focused on people with disabilities' experience with the ACA. In this chapter, we outline our recommendations for future research that follow from our analysis. Some questions can be readily addressed using national surveys that contain measures to identify people with disabilities; other future research questions require the collection of new data, for example, in the form of focus group interviews or small-scale, targeted surveys such as the HRMS.

We begin by noting that several major surveys that provide information about health coverage and include measures to identify people with disabilities already have or will make available data showing coverage in 2014, the first year that the major coverage expansion and insurance reform provisions of the ACA became effective. *All of these surveys contain questions about disability, as required by ACA Section 4302 and summarized by Livermore et al, and about health insurance coverage.*⁹⁴ As mentioned, MEPS-HC 2014 and early release NHIS data for 2014 are already available. The 2014 ACS is scheduled to

be released on September 17, 2015 and the CPS ASEC for 2014 is likely to be realized in January 2016, assuming the release date is similar to that of the 2013 CPS AHEC. Another national survey not mentioned thus far with measures of health coverage and disability is the Survey of Income and Program Participation.⁹⁵ This survey's data for 2014 will be released by the end of 2015.⁹⁶

The availability of surveys makes it feasible for researchers to prioritize two areas of work recently identified in a groundbreaking paper recognized by the CDC:⁹⁷

- Using “existing data sets to compare health outcomes and health differences across multiple data systems, and to disaggregate disability into different functional categories (for example, vision, hearing, mobility, problem solving or concentration)”; and
- Having health service and public health researchers “routinely analyze their data by disability status to determine when disability is important as a demographic characteristic variable for the focus of their study.”⁹⁸

The key point to emphasize is that health services researchers, who are accustomed to analyzing data with tabulations that involve income, gender, and race or ethnicity, need to incorporate into those analyses tabulations that address people with disabilities. *A major*

new wave of ACA-related research is almost certain to begin in the coming months. A key unresolved question is the extent to which that research will address the needs of people with disabilities. Health care researchers, public policy analysts, and the broader disability community need to ensure that research that focuses on people with disabilities is adequately represented in the emerging ACA research.

In what follows, we present major research topic for such a people with disabilities-centric research agenda.

Documentation of coverage changes for people with disabilities. Little academic research describes health insurance coverage gains for people with disabilities resulting from the ACA's major provisions, including Medicaid expansion and Marketplaces. Future research should track the progress in people with disabilities' coverage due to these provisions and examine differences in coverage gains for people with different types of disability. Possible research questions include

- How has health insurance coverage increased for people with disabilities since the implementation of the Medicaid expansion and Marketplaces? How have different subgroups (for example, people with physical disabilities, vision limitations, hearing limitations, developmental or intellectual disabilities, and mental health disabilities) fared?
- How have health insurance coverage increases for people with disabilities varied by
 - Income relative to the FPL (for example, 0 percent to 99 percent, 100 percent to 138 percent, 139 to 400 percent, and 401 percent plus) and

- Other demographic factors, including age, race or ethnicity, education level, and gender?
- How have state decisions about ACA implementation (for example, whether to expand Medicaid) affected health insurance coverage increases for people with disabilities?

This type of research could be undertaken with data from Census surveys such as the ACS, NHIS, CPS ASEC, and MEPS-HC (and, if resources permit, targeted surveys such as HRMS).

Factors contributing to differential coverage gains. Other important research would address possible reasons that differential coverage gains have been realized by people with disabilities (compared with other consumers) and key subgroups of people with disabilities. Possible research questions involve the impact on enrollment of

- Limited accessibility of Marketplace Web sites and other features of Marketplace administration, including
 - Call centers and
 - The provision of information particularly relevant to people with disabilities;
- Different features of subsidized QHP coverage, including
 - Benefit limitations,
 - Premium costs,
 - Deductibles and other out-of-pocket cost-sharing, and
 - Limited provider networks;
- Medicaid enrollment backlogs and other enrollment system “glitches”; and

- The availability of Navigators and other application assisters, including
 - The total supply of application assistance resources, include those focused at Medicaid as well as QHPs;
 - The participation of disability groups in offering Navigators and other application assistance services; and
 - Training for Navigators and other application assisters not affiliated with disability groups.

Focus groups with people with disabilities could help to address these questions, along with key-informant interviews like those conducted for this report.⁹⁹ Such additional qualitative research would not only broaden the experiential base of analysis, but it could also highlight developments later in the evolution of ACA implementation, compared with interviews for this project. Some of these issues could also be the focus of more targeted surveys.

Documentation of other changes for people with disabilities involving access to care.

National survey data sets include substantial information beyond coverage. Topics covered include financial barriers to care; whether survey respondents have delayed seeking or failed to receive necessary care and, if so, the financial and other factors underlying such choices; whether respondents have a regular source of care; utilization of various services, and so forth. All of these topics could become the subject of analysis, with researchers examining changes in 2014, including those affecting people with disabilities as a whole as well as the subsets of people with disabilities we have described.

Factors contributing to differential access gains among people with disabilities. Building

on national survey results, qualitative research strategies could also be important in exploring people with disabilities' experiences obtaining health care, addressing issues raised by the interviews conducted for this paper. Potential research questions involve the impact of the following on access to care:

- Limitations on EHBs, including the impact on QHP coverage within benefit categories that include
 - Habilitation and rehabilitation services,
 - DME,
 - Prescription drugs, and
 - Treatment of mental health and substance use disorders;
- Out-of-pocket cost-sharing amounts charged by QHPs and nontraditional Medicaid expansions;
- State decisions about Medicaid ABPs, including the scope of covered services and consumer information about medical frailty exemptions;
- Public education strategies involving health insurance literacy and "coverage to care" initiatives; and
- The previously noted subgroups of people with disabilities, including variations by disability type, income, education level, and state policy choices.

In addition to focus groups and key-informant interviews, future researchers could explore these questions with targeted surveys.

Evaluation of LTSS options. Many people with disabilities are affected by LTSS changes, including those involving dual demonstrations,

CFC, and, above all, increased use of private, managed-care plans to furnish LTSS. Important questions for these options include:

- How did health care services provided to people with disabilities change after implementation of these options? What services were furnished? How robust were provider networks, taking into account expertise in people with disabilities as well as all dimensions of accessibility? Did performance on quality of care metrics change? Were there important differences in services provided across states?
- Were changes observed in beneficiaries' use of "checks and balances," such as appeals, grievances, and complaints?
- How did spending on LTSS change?
- How many people with disabilities were affected by these changes? What were their characteristics? How did people with disabilities experience these changes? What were the gains and losses? Were people with disabilities with certain types of disabilities particularly affected?

Focus group interviews with people with disabilities and key-informant interviews might be useful data sources to address these questions. In addition, researchers could analyze data gathered by states and health plans, including information about services furnished and quality of care.

Analysis of administrative data involving people with disabilities. Consumers who apply for QHP subsidies must answer, on national application forms (but not forms in all state Marketplaces) questions about limitations they experience that may signal the presence of disabilities. Researchers could use those answers to analyze people with disabilities' enrollment into QHPs and insurance affordability programs. Moreover, CMS is now phasing in a new Transformed Medicaid Statistical Information System, which includes comprehensive data about Medicaid enrollees, their eligibility, services, costs, and characteristics, including an identification of people with disabilities within all eligibility categories. This system could prove a rich source of data that researchers could use to explore Medicaid coverage of people with disabilities in the future.

Appendix

Appendix Table 1. Medicaid Alternative Benefit Plans (ABPs)

State	Type of Expansion	Type of plan on which ABP is based		Commercial Plan Name
		Medicaid	Commercial	
Arizona	Traditional	Yes	No	N/A
Arkansas	Waiver	Yes	No	N/A
California	Traditional	No	Yes	Standard Blue Cross/Blue Shield Preferred Provider Option-FEHBP
Colorado (two options offered)	Traditional	Yes	Yes	Kaiser Foundation Health Plan of Colorado Deductible HMO 1200D
Connecticut	Traditional	Yes	No	N/A
District of Columbia	Traditional	Yes	No	N/A
Delaware	Traditional	Yes	No	N/A
Hawaii	Traditional	Yes	No	N/A
Illinois*	Traditional	No	Yes	Blue Cross Blue Shield BlueAdvantage Entrepreneur
Indiana (1)**	Proposed Waiver	No	Yes	Advantage 1001
Indiana (2)***	Proposed waiver	No	Yes	Advantage 1001
Iowa (1)	Waiver	No	Yes	Iowa Wellness Plan
Iowa (2)	Waiver	No	Yes	Iowa Marketplace Choice Plan
Kentucky	Traditional	Yes	No	N/A
Maryland	Traditional	Yes	No	N/A
Massachusetts (1)****	Traditional	Yes	No	N/A
Massachusetts (2)*****	Traditional	Yes	No	N/A
Michigan	Waiver	No	Yes	Priority Health HMO
Minnesota	Traditional	Yes	No	N/A
Nevada	Traditional	Yes	No	N/A

(continued)

Appendix Table 1. (continued)

State	Type of Expansion	Type of plan on which ABP is based	Commercial Plan Name
New Hampshire	Waiver	No	Matthew Thornton Blue Health Plan
New Jersey	Traditional	Yes	N/A
New Mexico	Traditional	No	Expansion Alternative Benefit Plan
New York	Traditional	No	Standard Blue Cross Blue Shield Federal Employee
North Dakota	Traditional	No	Sanford Health Plan
Ohio	Traditional	Yes	N/A
Oregon	Traditional	Yes	N/A
Pennsylvania	Waiver	No	Plans vary by region*****
Rhode Island	Traditional	Yes	N/A
Vermont	Traditional	Yes	N/A
Washington	Traditional	Yes	N/A
West Virginia	Traditional	Yes	N/A

Notes: In Illinois, the state benchmark plan is used as the ABP. However, any services provided by the benchmark plan that are not covered by Medicaid are excluded from coverage. **Health Indiana Plan (HIP) Basic Plan; ***HIP Plus Plan. Enrollment in HIP Plus is dependent on enrollees' monthly contributions to their Personal Wellness and Responsibility (POWER) account. If they contribute, they remain eligible for HIP Plus, which offers extended services and fewer copays. If not, coverage is reduced to HIP Basic; ****MassHealth Standard Plan; *****MassHealth Care Plus, which is a limited version of Medicaid, available only to people over age 21; *****Under the waiver, Pennsylvania has been divided into nine regions, each of which has at least two Primary Care Options (PCOs), which newly eligible adults can choose between. However, Pennsylvania's current governor has announced plans to transition to a traditional Medicaid expansion.

Appendix Table 2. Essential Health Benefit (EHB) Coverage of Habilitative Services and Devices

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
Alabama	Benchmark	30 visits per year for habilitative and rehabilitative services combined. Includes physical therapy, speech therapy, and occupational therapy.	Yes
Alaska	Benchmark	45 visits per year for habilitative and rehabilitative services combined. Excludes recreational, vocational, or educational therapy, exercise, or maintenance-level programs; social or cultural therapy; treatment that is not actively engaged in by the ill, injured, or impaired member; gym or swim therapy; custodial care. Applicable deductible and coinsurance apply.	Yes
Arizona	Federal	Federally defined coverage	No
Arkansas	State	Defined by the state as services provided for a person to attain and maintain a skill or function that was never learned or acquired and is necessary due to a disabling condition. Coverage includes physical, occupational, and speech therapies, developmental services and durable medical equipment for developmental delay, developmental disability, developmental speech or language disorder, developmental coordination disorder and mixed developmental disorder. Autism spectrum disorders are included under this coverage.	No
California	Benchmark and State	Defined by the state as medically necessary health care services and health care devices that assist an individual in partially or fully acquiring or improving the skills and functioning that are necessary to address a health condition, to the maximum extent practical. These services address the skills and abilities needed for functioning in interaction with an individual's environment. Excludes respite care, day care, recreational care, residential treatment, social services, custodial care, or education services of any kind, including, but not limited to, vocational training. Certain limitations on types of caregivers for behavioral health treatment as described in H&S Code section 1374.73. Coverage includes treatment for behavioral health treatment for autism and related disorders. Habilitative services shall be covered under the same terms and conditions applied to rehabilitative services under the policy.	No
Colorado	State	20 visits per year for each physical, occupational, and speech therapies. Defined by the state as services that help a person retain, learn, or improve skills and functioning for daily living that are offered in parity with, and in addition to, any rehabilitative services offered in Colorado's EHB benchmark plan. Parity in this context means of like type and substantially equivalent in scope, amount, and duration.	No

(continued)

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
Connecticut*	Benchmark	Services addressing habilitation needs caused by autism are covered under "Autism Services" and not "Habilitation Services."	No
Delaware***	State	30 visits per year for physical and occupational therapy combined. A separate 30 visits per year for speech therapy. Delaware requires that coverage for habilitative services be on parity with those for rehabilitative services.	No
DC	Benchmark	Defined in DC Code Section 31-3272, health insurers must provide children 21 and under with habilitative services not more restrictive than coverage provided for any other illness, condition, or disorder for purposes of determining deductibles, benefit year or lifetime durational limits, benefit year or lifetime dollar limits, lifetime episodes or treatment limits, copayment and coinsurance factors, and benefit year maximum for deductibles and copayments and coinsurance factors. Includes occupational therapy, physical therapy, and speech therapy for the treatment of a child with a congenital or genetic birth defect to enhance the child's ability to function.	No
Florida	Federal	Federally defined coverage	No
Georgia	Benchmark	20 visits per year for physical and occupational therapies combined. A separate 20 visits per year for speech therapy. Benefit limits are shared between rehabilitation and habilitation services. Excludes hypnotherapy, vestibular rehabilitation, primal therapy, chelation therapy, rolfing, psychodrama, megavitamin therapy, purging, bioenergetic therapy, cognitive therapy, electromagnetic therapy, orthoptics, salabrasion; chemosurgery and other such skin abrasion procedures associated with the removal of scars, tattoos, actinic changes for acne treatment; smoking cessation programs, services, and supplies, treatment of nicotine addiction; self-help, biofeedback, recreational, educational or sleep therapy or other forms of self-care or self-help training and any related diagnostic testing. Includes treatment for autism spectrum disorders.	Yes
Hawaii*	Benchmark	Coverage not detailed.	No

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
Idaho	Benchmark	20 visits per year for habilitative and rehabilitative services combined. Habilitation services payment is limited to physical, speech, and occupational therapy services related to developmental and rehabilitative care, with reasonable expectation that the services will produce measurable improvement in the Insured's condition in a reasonable period of time. Services are for the purpose of restoring certain functional losses due to disease, illness or injury only and do not include maintenance services.	Yes
Illinois	Benchmark	Habilitative services apply only to treatments for congenital, genetic, or early acquired disorders. Applicable only if a physician has diagnosed the congenital, genetic, or early acquired disorder; the treatment is administered by a licensed speech-language pathologist, audiologist, occupational therapist, physical therapist, physician, licensed nurse, optometrist, licensed nutritionist, clinical social worker, or psychologist with a physician referral; and the treatment is medically necessary and therapeutic and benefits are the same as those for any other condition. Excludes services that are solely educational in nature.	No
Indiana	Benchmark	20 visits per year for habilitative and rehabilitative services combined. Separate 20-visit limits for each physical therapy, occupational therapy, and speech therapy. Excludes maintenance therapy to delay or minimize muscular deterioration in patients suffering from a chronic disease or illness; repetitive exercise to improve movement, maintain strength, and increase endurance (including assistance with walking for weak or unstable patients); range of motion and passive exercises that are not related to restoration of a specific loss of function but are for maintaining a range of motion in paralyzed extremities; general exercise programs; diathermy, ultrasound, and heat treatments for pulmonary conditions; diapulse; work hardening; diversional, recreational, vocational therapies (e.g., hobbies and crafts); therapy to improve or restore functions that could be expected to improve as the patient resumes normal activities again; general exercises to promote overall fitness and flexibility; therapy to improve motivation; suction therapy for newborns (feeding machines); soft tissue mobilization (visceral manipulation or visceral soft tissue manipulation), augmented soft tissue mobilization, myofascial; adaptations to the home such as ramps, door widening, automobile adaptors, kitchen adaptation, and other types of similar equipment; home programs and ongoing conditioning and maintenance for cardiac rehab; pulmonary rehabilitation in the acute inpatient rehabilitation setting; admission to a hospital mainly for physical therapy; long-term rehabilitation in an inpatient setting.	Yes

(continued)

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
Iowa	Benchmark	Includes services for congenital disorders and developmental delays. Excludes therapies rendered primarily for job training and therapy services related to general conditioning of the patient. Any habilitation not related to developmental delay is not covered.	No
Kansas	State	90 visits per year, including speech, occupational, and physical therapy. Parity with rehabilitative services.	No
Kentucky	Benchmark	20 visits per year for each physical, occupational, and speech therapy. Limits are shared between habilitation and rehabilitation services.	Yes
Louisiana**	Benchmark	Rehabilitative care benefits will be available for services provided on an inpatient or outpatient basis, including services for occupational therapy, physical therapy, speech-language pathology therapy, and chiropractic services. The member must be able to tolerate a minimum of three hours of active therapy per day. An inpatient rehabilitation admission must be authorized before the admission and must begin within 72 hours following the discharge from an inpatient hospital for the same or similar condition. Day rehabilitation programs for rehabilitative care may be authorized in place of inpatient stays for rehabilitation. Day rehabilitation programs must be authorized before beginning the program and must begin within 72 hours following discharge from an inpatient admission for the same or similar condition. Excludes visual therapy, lifestyle or habit changing clinics or programs, recreational therapy, therapy primarily to enhance athletic abilities, inpatient pain rehabilitation and pain control programs.	No
Maine	Benchmark	60 visits per year for speech, occupational, and physical therapies combined. Limits are shared between habilitation and rehabilitation. Includes respiratory therapy and cardiac rehabilitation. Excludes health club and health spa memberships, exercise equipment, physical fitness instructor or personal trainer, charges for activities, equipment, or facilities used for developing or maintaining physical fitness, even if ordered by a physician; treatments such as massage therapy, paraffin baths, hot packs, whirlpools, or moist or dry heat applications unless in conjunction with an active course of treatment; maintenance services, treatments or therapy; speech therapy benefits for deficiencies resulting from mental retardation and/or dysfunctions that are self-correcting, such as language treatment for young children with natural dysfluency or developmental articulation errors; vision therapy, including treatment such as vision training, orthoptics, eye training, or eye exercises.	Yes

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Rehabilitative and Rehabilitative Services?
Maryland	Benchmark	<p>30 visits per year for each physical, speech, and occupational therapies for age 19 and above. Covers members age 19 and above in parity with benefits covered for rehabilitative services.</p> <p>For members from birth to age 19, rehabilitative services means services, including occupational, physical, and speech therapies, orthodontics, oral surgery, otologic and audiological therapy for the treatment of children with congenital and genetic birth defects to enhance the child's ability to function.</p>	No
Massachusetts	Benchmark	<p>60 visits per year. Includes outpatient physical and occupational therapy. No limit applies to autism, home health care, and speech/hearing disorders</p>	No
Michigan	State	<p>Defined by the state as health care services that help a person keep, learn, or improve skills and functioning for daily living. Examples include therapy for a child who isn't walking or talking at the expected age. Includes physical and occupational therapy, speech-language pathology, and other services for people with disabilities. Rehabilitative services encompass many types of services, including but not limited to applied behavioral analysis (ABA) for the treatment of autism spectrum disorder. ABA includes the design, implementation, and evaluation of environmental modifications, using behavioral stimuli and consequences, to produce significant improvement in human behavior, including the use of direct observation, measurement, and functional analysis of the relationship between environment and behavior.</p>	No
Minnesota	Benchmark	<p>Coverage not detailed.</p>	No
Mississippi	Benchmark	<p>20 visits per year for physical and occupational therapy combined, a separate 20 visits for speech therapy. Covered as defined by Rehabilitation Services, which includes the coordinated use of medical, social, educational, or vocational services beyond the acute care stage of disease or injury for the purpose of upgrading the physical functional ability of a patient so that the patient may independently carry out ordinary daily activities. Excludes job training therapies; pulmonary rehabilitation; speech therapy for learning disabilities and developmental problems.</p>	No

(continued)

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
Missouri	Benchmark	<p>20 visits per year for each physical, occupational, and speech therapy. Limits are shared between habilitation and rehabilitation services. Excludes maintenance therapy to delay or minimize muscular deterioration in patients suffering from a chronic disease or illness; repetitive exercise to improve movement, maintain strength, and increase endurance (including assistance with walking for weak or unstable patients); range of motion and passive exercises that are not related to restoration of a specific loss of function but are for maintaining a range of motion in paralyzed extremities; general exercise programs; diathermy, ultrasound and heat treatments for pulmonary conditions; diapulse; work hardening; activity supplies (looms, ceramic tiles, leather, utensils); therapy to improve or restore functions that could be expected to improve as the patient resumes normal activities again; general exercises to promote overall fitness and flexibility; therapy to improve motivation; suction therapy for newborns (feeding machines); soft tissue mobilization (visceral manipulation or visceral soft tissue manipulation), augmented soft tissue mobilization, myofascial; adaptations to the home such as rampways, door widening, automobile adaptors, kitchen adaptation, and other types of similar equipment; admission to a hospital mainly for physical therapy; long-term rehabilitation in an inpatient setting; services, supplies, and equipment for gastric electrical stimulation, hippotherapy, intestinal rehabilitation therapy, prolotherapy, recreational therapy, and sensory integration therapy.</p>	Yes
Montana**	Benchmark	<p>\$50,000 for ABA services for members 0 through eight years of age and \$20,000 for ABA services for members nine through 18 years of age. Includes specialized, intense, and comprehensive therapy programs and treatment services including but not limited to physical, occupational, and speech therapy provided by a multidisciplinary team for treatment of an injury or physical deficit. A Rehabilitation Therapy program is provided by a rehabilitation facility in an inpatient care or outpatient setting; provided under the direction of a qualified physician and according to a formal written treatment plan with specific goals; designed to restore the patient's maximum function and independence; and medically necessary to improve or restore bodily function, and the member must continue to show measurable progress. For Autism Spectrum Disorders,</p>	

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
		covered services include professional counseling and guidance services and treatment programs; ABA (discrete trial training, pivotal response training, intensive intervention programs, and early intensive behavioral intervention); medications; psychiatric or psychological care; and therapeutic care provided by a speech-language pathologist, audiologist, occupational therapist, or physical therapist. Excludes custodial care, diagnostic admissions, maintenance, nonmedical self-help, or vocational educational therapy, social or cultural rehabilitation, learning and developmental disabilities, and visual, speech, or auditory disorders because of learning and developmental disabilities.	No
Nebraska	Benchmark	Excludes therapies rendered primarily for job training.	No
Nevada	State	\$36,000 per year for coverage of autism spectrum disorders, 60 visits per year for outpatient habilitation services.	No
New Hampshire	Benchmark	20 visits per year. Limit is shared between habilitation and rehabilitation services. A separate 20 visits per year applies to physical, occupational, and speech therapy. Excludes ongoing or lifelong exercise and education programs intended to maintain fitness, including voice fitness, or to reinforce lifestyle changes, including lifestyle changes affecting the voice; voice therapy and vocal retraining; preventive therapy; therapy provided in a group setting; educational reasons; therapy for developmental disabilities, except for “early intervention services”; sport, recreational, or occupational reasons and for health club or spa memberships, exercise equipment, physical fitness instructor or personal trainer, or any other charges for activities, equipment, or facilities used for developing or maintaining physical fitness, even if ordered by a physician; physical therapy for TMJ disorders; rehabilitation services primarily intended to improve the level of physical functioning for enhancement of job, athletic, or recreational performance; work hardening programs and programs for general physical conditioning.	Yes
New Jersey	Benchmark	30 visits per year for physical and occupational therapy combined. A separate 30 visits per year for speech, physical, and occupational therapy due to autism or developmental disabilities. Habilitation services are subject to the limits applicable to rehabilitation services, other therapies, services, and supplies. Habilitations as provided through rehabilitation services are covered. Includes hearing aids as prescribed by a physician for patients 15 years of age and younger; speech, physical, and occupational therapy treatment of diagnosis of autism or developmental disability including ABA (need not be restorative) Therapy received through early intervention services does not count toward annual limit.	No

(continued)

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
New Mexico	Benchmark	Coverage not detailed.	No
New York	State	60 visits per condition per lifetime combined. Includes physical, speech, and occupational therapies. Habilitative services are at parity with the rehabilitative benefit in the outpatient setting only. New York does not consider the post hospitalization and postsurgical requirements for rehabilitative services to be requirements for habilitative services.	No
North Carolina	Federal	Federally defined coverage	No
North Dakota*	Benchmark	30 treatments per year.	No
Ohio****	State	20 visits per year of each speech and occupational therapy, 30 visits per year of mental or behavioral health services for patients diagnosed on the Autism Spectrum who are under the age of 21. Habilitative services benefits are determined by individual plans and must include, but are not limited to, habilitative services to children from birth to age 21 diagnosed on the Autism Spectrum, which at a minimum includes speech and language therapy; clinical therapeutic intervention defined as therapies supported by empirical evidence such as ABA, provided by or under the supervision of a professional who is licensed, certified, or registered by an appropriate agency of this state to perform the services in accordance with a treatment plan, 20 hours per week; and mental or behavioral health outpatient services performed by a licensed psychologist, psychiatrist, or physician to provide consultation, assessment, development, and oversight of treatment plans.	No
Oklahoma	Benchmark	25 visits per year combined with rehabilitative physical, occupational, and manipulative therapy.	No
Oregon****	State	Defined by the state to require eligibility, medical necessity, preauthorization, provider credentialing and accreditation standards, subject to carrier-specific requirements. When medically necessary for maintaining, learning, or improving skills and function for daily living, benefits include services provided by a licensed physical or occupational therapist, speech-language pathologist, physician, or other practitioner licensed to provide physical, occupational, or speech therapy. Services must be prescribed in writing by a licensed	

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
		physician, dentist, podiatrist, nurse practitioner, or physician assistant and include site, modality, duration, and frequency of treatment. Only treatment of neurologic conditions (e.g., stroke, spinal cord injury, head injury, pediatric neurodevelopmental problems, and other problems associated with pervasive developmental disorders for which rehabilitative services would be appropriate for children under 18 years of age) may be considered for additional benefits, not to exceed 30 visits per condition, when criteria for supplemental services are met. Speech therapy only allowed to correct stuttering, hearing loss, peripheral speech mechanism problems, and deficits due to neurological disease or injury. 30 visits per year for speech therapy. Excludes functional capacity evaluations, work hardening programs, vocational habilitation, community reintegration services, driving evaluations and training programs, motion analysis including videotaping and 3-D kinematics, dynamic surface and fine wire electromyography, including physician review.	No
Pennsylvania	Federal	Federally defined coverage	No
Rhode Island	State	Required by the state to be comprehensive and measured as per member per month cost of rehabilitation services covered under the plan. Issuer is required to attach an exhibit that identifies the habilitative services covered by the plan, an actuarial memorandum estimating the per member per month cost of the habilitative and rehabilitative services covered, and includes in the actuarial memo the calculation and analysis used to develop the identified cost. Excludes maintenance therapy.	No
South Carolina	Federal	30 visits per year for physical therapy. Includes only physical therapy.	No
South Dakota	Benchmark	Coverage not detailed.	No

(continued)

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Habilitative and Rehabilitative Services?
Tennessee**	Benchmark	<p>20 visits per year. Includes outpatient, home health, or office therapeutic and rehabilitative services that are expected to result in significant and measurable improvement in your condition resulting from an acute disease, injury, autism in children under age 12, or cleft palate. Services must be performed by or under the direct supervision of a licensed therapist, upon written authorization of the treating practitioner. Therapeutic/rehabilitative services include physical therapy, speech therapy for restoration of speech, occupational therapy, manipulative therapy, and cardiac and pulmonary rehabilitative services. Speech therapy is covered only for disorders of articulation and swallowing resulting from acute illness, injury, stroke, autism in children under age 12, or cleft palate. The limit on the number of visits for therapy applies to all visits for that therapy, whether received in a practitioner's office, outpatient facility, or home health setting; services received during an inpatient hospital, skilled nursing, or rehabilitative facility stay are not subject to the therapy visit limits. Excludes treatment beyond what can reasonably be expected to significantly improve health, including therapeutic treatments for ongoing maintenance or palliative care; enhancement therapy that is designed to improve your physical status beyond pre-injury or -illness state; complementary and alternative therapeutic services; modalities that do not require the attendance or supervision of a licensed therapist; duplicate therapy; behavioral therapy, play therapy, communication therapy, and therapy for self-correcting language dysfunctions as part of speech, physical, or occupational therapy programs. Behavioral therapy and play therapy for behavioral health diagnoses may be covered under the Behavioral Health Rider (if applicable).</p>	No
Texas	Benchmark	35 visits per year, in parity with rehabilitation services.	No
Utah	Benchmark	20 visits per year. Limit is shared between habilitation and rehabilitation services. Includes physical, speech, occupational therapy, and habilitative services.	Yes
Vermont*	Benchmark	Includes autism coverage from birth to age 6 years per Vermont state mandate.	No

Appendix Table 2. (continued)

State	Source of definition	Details of Coverage	Limit Combines Rehabilitative and Rehabilitative Services?
Virginia	Benchmark	30 visits per year for physical and occupational therapy combined. Limit shared between rehabilitative and rehabilitative services. Includes physical, occupational, and speech therapy, respiratory therapy and cardiac rehabilitation. Excludes physical or occupational therapy to maintain or preserve current function if there is no chance of improvement or reversal; group or individual exercise classes or personal training sessions; recreational therapy including but not limited to sleep, dance, arts, crafts, aquatic, gambling, and nature therapy.	Yes
Washington	Benchmark	25 visits per year for physical, occupational, and speech therapies combined. In parity with rehabilitative services.	No
West Virginia	Federal	Federally defined coverage	No
Wisconsin*	Benchmark	Coverage not detailed	No
Wyoming	Federal	Federally defined coverage	No

Notes

*These states' benefit summaries indicate that rehabilitative care is covered by their benchmark plans. However, the cover sheet provided by CMS states that rehabilitative services are neither included in the benchmark nor defined by the state.

**The rehabilitative benefits descriptions for these states contain language that seems to address rehabilitation, not habilitation. It appears that they simply copied language from the rehabilitative services category. Such copying may have been intended to provide parity with rehabilitation coverage.

***This state's benefit summary indicates that rehabilitative care is not covered. However, the CMS cover sheet states that rehabilitative services are covered by either the Benchmark plan or state definition.

****The benefit summaries reference pre-February 2015 statutes allowing insurance companies to define rehabilitative services if not defined by the benchmark plan or the state.

Appendix Table 3. Essential Health Benefit (EHB) Coverage of Rehabilitative Services and Devices

State	Details of Coverage
Alabama*	30 visits per year for physical, speech, and occupational therapies combined. Limit shared between habilitative and rehabilitative services.
Alaska	45 visits per year. Limit is shared between habilitative and rehabilitative services. Excludes recreational, vocational, or educational therapy, exercise, or maintenance-level programs; social or cultural therapy; treatment that isn't actively engaged in by the ill, injured, or impaired member; gym or swim therapy; and custodial care. Applicable deductible & coinsurance apply.
Arizona	60 visits per year of physical, occupational, speech, chiropractic, pulmonary, and cardiac therapies combined.
Arkansas	60 visits per year of physical, occupational, speech, and chiropractic therapies combined. Cardiac rehabilitation sessions are limited to 36 visits per year. Pulmonary rehabilitation therapy is also covered.
California	Includes physical, occupational, and speech therapies; pulmonary and cardiac therapies are also covered.
Colorado	20 visits per year of each physical, occupational, and speech therapies. Pulmonary therapy is also covered.
Connecticut	40 visits per year for physical, speech, and occupational therapies combined. Pulmonary and cardiac therapies are covered under separate benefit categories. Includes short-term physical, occupational, and speech therapy necessary to restore a function lost through or to eliminate an abnormal function that has developed due to injury or illness; postoperative physical therapy for temporomandibular joint (TMJ) dysfunction surgery is covered when the TMJ surgery is covered under this plan, is obtained during the 90-day period beginning on the date of the covered TMJ surgery, and preauthorized as part of the surgical procedure. Excludes speech therapy for developmental speech delays, stuttering, lisps, and other non-injury- or non-illness-related speech impediments. These are not covered, except as provided in the "Autism Services" or "Birth To Three Program (early intervention services)" provisions of "Other Outpatient Services" subsection (c); medically necessary short-term outpatient rehabilitative therapy, including those services rendered at a day program facility and in an office.
Delaware	30 visits per year for physical and occupational therapies combined, 30 visits per year for speech therapy, 30 consecutive days per year for cognitive therapy, and three sessions per week for three months for cardiac therapy.
DC	Includes occupational, physical, speech, pulmonary, and cardiac therapies.
Florida	35 visits per year. Includes speech therapy for child cleft lip and cleft palate; outpatient cardiac, occupational, physical, speech, and massage therapies in the home health care, hospital, and skilled nursing facility setting.
Georgia	20 visits per year for physical and occupational therapies combined. Separate 20 visits for speech therapy. Separate 20 visits for respiratory therapy. Limits are shared between habilitation and rehabilitation services. Includes physical, occupational, speech, and respiratory therapy, and cardiac rehabilitation. Excludes hypnotherapy, vestibular rehabilitation, primal therapy, chelation therapy, rolfing, psychodrama, megavitamin therapy, purging, bioenergetics therapy, cognitive

Appendix Table 3. (continued)

State	Details of Coverage
	therapy, electromagnetic therapy, orthoptics, salabrasion, chemosurgery and other such skin abrasion procedures associated with the removal of scars, tattoos, actinic changes or which are performed as a treatment for acne; services and supplies for smoking cessation programs and treatment of nicotine addiction, and carbon dioxide, self-help, biofeedback, recreational, educational, or sleep therapy or other forms of self-care or self-help training and any related diagnostic testing.
Hawaii	Includes physical, occupational, speech, and pulmonary therapies. Excludes maintenance therapy, which is defined as activities that preserve present functional level and prevent regression; cardiac rehabilitation.
Idaho	20 visits per year for physical, occupational, and speech therapies combined. Respiratory therapy is covered under a separate benefit category.
Illinois	Includes physical, occupational, speech, pulmonary, and cardiac therapies. 36 outpatient treatments every six months are allowed for cardiac therapy. Cardiac rehabilitation services are only provided in Blue Cross and Blue Shield approved programs, if you have a history of any of the following: acute myocardial infarction, coronary artery bypass graft surgery, percutaneous transluminal coronary angioplasty, heart valve surgery, heart transplantation, stable angina pectoris, compensated heart failure, or transmyocardial revascularization.
Indiana	20 visits per year for each physical, occupational, pulmonary, and speech therapies. 36 visits per year for cardiac rehab. Limits are shared between rehabilitation and habilitation services. Excludes maintenance therapy to delay or minimize muscular deterioration in patients suffering from a chronic disease or illness; repetitive exercise to improve movement, maintain strength, and increase endurance (including assistance with walking for weak or unstable patients); range of motion and passive exercises that are not related to restoration of a specific loss of function but are for maintaining a range of motion in paralyzed extremities; general exercise programs; diathermy, ultrasound, and heat treatments for pulmonary conditions; diapulse; work hardening; diversions, recreational, vocational therapies and supplies (e.g., hobbies and crafts); therapy to improve or restore functions that could be expected to improve as the patient resumes normal activities again; general exercises to promote overall fitness and flexibility; therapy to improve motivation; suction therapy for newborns (feeding machines); soft tissue mobilization (visceral manipulation or visceral soft tissue manipulation), augmented soft tissue mobilization, myofascial; adaptations to the home such as ramps, door widening, automobile adaptors, kitchen adaptation, and other types of similar equipment; home programs and ongoing conditioning and maintenance for cardiac rehab; pulmonary rehabilitation in the acute inpatient rehabilitation setting; admission to a hospital mainly for physical therapy; long-term rehabilitation in an inpatient setting.
Iowa	Includes cardiac rehabilitation, services to treat the upper extremities (arms from the shoulders to the fingers), and rehabilitative speech therapy when related to a specific illness, injury, or impairment, and occupational and pulmonary therapies. Excludes occupational therapy supplies and occupational therapy provided as an inpatient in the absence of a separate medical condition that requires hospitalization; speech therapy services not provided by a licensed or certified speech pathologist; speech therapy to treat certain developmental, learning, or communication disorders such as stuttering and stammering; physical therapy as provided as an inpatient in the absence of a separate medical condition that requires hospitalization.

(continued)

Appendix Table 3. (continued)

State	Details of Coverage
Kansas	Includes physical, occupational, speech, respiratory, neuropsychological, cardiac, and pulmonary therapies. Excludes vocational rehabilitation and cognitive therapies.
Kentucky	20 visits per year for each physical, occupational, pulmonary, and speech therapies. 36 visits per year for cardiac rehab. Limits are shared between rehabilitation and habilitation services. Excludes maintenance therapy to delay or minimize muscular deterioration in patients suffering from a chronic disease or illness; repetitive exercise to improve movement, maintain strength, and increase endurance (including assistance with walking for weak or unstable patients); range of motion and passive exercises that are not related to restoration of a specific loss of function but are for maintaining a range of motion in paralyzed extremities; general exercise programs; diathermy, ultrasound, and heat treatments for pulmonary conditions; diapulse; work hardening; supplies (looms, ceramic tiles, leather, utensils); therapy to improve or restore functions that could be expected to improve as the patient resumes normal activities again; general exercises to promote overall fitness and flexibility; therapy to improve motivation; suction therapy for newborns (feeding machines); soft tissue mobilization (visceral manipulation or visceral soft tissue manipulation), augmented soft tissue mobilization, myofascial; adaptations to the home such as ramps, door widening, automobile adaptors, kitchen adaptation, and other types of similar equipment; home programs, ongoing conditioning and maintenance for cardiac rehab; pulmonary rehabilitation in acute inpatient rehabilitation; admission to a hospital mainly for physical therapy; long-term rehabilitation in an inpatient setting.
Louisiana	Occupational, physical, speech-language, and chiropractic therapies. Rehabilitative care benefits are available for services provided on an inpatient or outpatient basis. The member must be able to tolerate a minimum of three hours of active therapy per day. An inpatient rehabilitation admission must be authorized prior to the admission and must begin within 72 hours following the discharge from an inpatient hospital for the same or similar condition. Day rehabilitation programs may be authorized in place of inpatient stays for rehabilitation but must be authorized prior to beginning the program and must begin within 72 hours following discharge from an inpatient admission for the same or similar condition. Excludes visual therapy, lifestyle or habit changing clinics or programs; recreational therapy; therapy primarily to enhance athletic abilities; and inpatient pain rehabilitation and pain control programs.
Maine	60 visits per year physical, occupational, and speech therapies combined. Respiratory therapy and cardiac rehabilitation are not included in the above limit but are covered. Limits are shared between rehabilitation and habilitation services. Excludes health club and spa memberships, exercise equipment, charges from a physical fitness instructor or personal trainer, or any other charges for activities, equipment, or facilities used for developing or maintaining physical fitness, even if ordered by a physician; massage therapy, paraffin baths, hot packs, whirlpools, or moist or dry heat applications unless in conjunction with an active course of treatment; maintenance services, treatments or therapy; speech therapy benefits for deficiencies resulting from mental retardation or dysfunctions that are self-correcting, such as language treatment for young children with natural dysfluency or developmental articulation errors; vision therapy, including treatment such as vision training, orthoptics, eye training, or eye exercises.

Appendix Table 3. (continued)

State	Details of Coverage
Maryland	30 visits per year for each physical, speech, and occupational therapies. Pulmonary therapy is covered under a separate category and is limited to one program per lifetime for those who have been diagnosed with significant pulmonary disease or surgery, and visit limit for each type of therapy is increased to 90 per year when in parity with cardiac rehabilitation.
Massachusetts	Includes physical, occupational, cardiac, and speech therapies.
Michigan	30 visits apply to all rehabilitation services, including physical, occupational, chiropractic, speech, pulmonary, cardiac, and biofeedback therapies.
Minnesota	Coverage not detailed.
Mississippi	20 visits per year for physical and occupational therapies combined. Separate 20-visit limit for speech therapy. 36-visit limit for cardiac rehabilitation. Benefits are for the coordinated use of medical, social, educational, or vocational services, beyond the acute care stage of disease or injury, for the purpose of upgrading the physical functional ability of a patient disabled by disease or injury so that the patient may independently carry out ordinary daily activities. Excludes therapy services related to general conditioning of the patient; therapies rendered primarily for job training; pulmonary rehabilitation; speech therapy for learning disabilities and developmental problems.
Missouri	20 visits per year for physical, occupational, and pulmonary therapies combined. 36 visits per year for cardiac rehab. Also covers speech therapy. Limits are shared between rehabilitation and habilitation services. Excludes maintenance therapy to delay or minimize muscular deterioration in patients suffering from a chronic disease or illness; repetitive exercise to improve movement, maintain strength and increase endurance (including assistance with walking for weak or unstable patients); range of motion and passive exercises that are not related to restoration of a specific loss of function but are for maintaining a range of motion in paralyzed extremities; general exercise programs; diathermy, ultrasound, and heat treatments for pulmonary conditions; diapulse; work hardening; supplies (looms, ceramic tiles, leather, utensils); therapy to improve or restore functions that could be expected to improve as the patient resumes normal activities again; general exercises to promote overall fitness and flexibility; therapy to improve motivation; suction therapy for newborns (feeding machines); soft tissue mobilization (visceral manipulation or visceral soft tissue manipulation), augmented soft tissue mobilization, myofascial; adaptations to the home such as ramps, door widening, automobile adaptors, kitchen adaptation, and other types of similar equipment; home programs and ongoing conditioning and maintenance for cardiac rehab; pulmonary rehabilitation in the acute inpatient rehabilitation setting; admission to a hospital mainly for physical therapy; long-term rehabilitation in an inpatient setting; services, supplies, and equipment for gastric electrical stimulation, hippotherapy, intestinal rehabilitation therapy, prolotherapy, recreational therapy, and sensory integration therapy.
Montana	Includes physical, occupational, cardiac, and speech therapies.
Nebraska	Quantitative limit units apply. Includes physical, occupational, cardiac, pulmonary, and speech therapies. Excludes therapies rendered primarily for job training.
Nevada	60 visits per year combined with inpatient rehab, includes physical, occupational, and speech therapies.

(continued)

Appendix Table 3. (continued)

State	Details of Coverage
New Hampshire	20 visits per year respiratory therapy and cardiac rehabilitation combined. Separate 20 visits per year for physical, occupational, and speech therapy. Limits are shared between rehabilitation and habilitation services. Excludes ongoing or lifelong exercise and education programs intended to maintain fitness, including voice fitness, or to reinforce lifestyle changes, including lifestyle changes affecting the voice; voice therapy, vocal retraining, preventive therapy, or therapy provided in a group setting; educational reasons or for developmental disabilities, except for "early intervention services"; sport, recreational or occupational reasons; physical therapy for TMJ; health club and spa memberships, exercise equipment, charges from a physical fitness instructor or personal trainer, or any other charges for activities, equipment, or facilities used for developing or maintaining physical fitness, even if ordered by a physician; rehabilitation services primarily intended to improve the level of physical functioning for enhancement of job, athletic, or recreational performance; work hardening programs and programs for general physical conditioning.
New Jersey	30 visits per year. Preapproval required. Separate from services provided through home health care benefits. Includes physical, occupational, speech, and respiratory therapies.
New Mexico	Coverage not detailed.
New York	60 visits per condition per lifetime combined. Covers physical, speech, and occupational therapies. Speech and physical therapy are covered only following a hospital stay or surgery.
North Carolina	30 visits per year for physical, occupational, and chiropractic therapies combined. Separate 30 visits for speech therapy, not including treatments for stuttering. Separate 30 visits per year for cardiac therapy with the option to expand the initial allotment if medically necessary. One course of treatment per year for pulmonary rehab, excluding group classes. Excludes cognitive therapy.
North Dakota	30 treatments per year. Includes physical, occupational, speech, cardiac, and water therapies. Excludes services provided in the members' home for convenience; that are not expected to make measurable or sustainable improvement within a reasonable period of time including therapy for chronic or recurring symptoms including but not limited to arthritis, back pain, and fibromyalgia; hot or cold pack therapy, including polar ice therapy and water circulating devices; speech therapy for the purpose of correcting speech impediments (stuttering or lisps) or assisting the initial development of verbal facility or clarity; voice training and voice therapy.
Ohio	20 visits per year. Separate 20 visits per year for each physical, occupational, pulmonary, and speech therapies. Separate 36-visit limit for cardiac rehab. Excludes maintenance therapy to delay or minimize muscular deterioration in patients suffering from a chronic disease or illness; repetitive exercise to improve movement, maintain strength, and increase endurance (including assistance with walking for weak or unstable patients); range of motion and passive exercises that are not related to restoration of a specific loss of function but are for maintaining a range of motion in paralyzed extremities; general exercise programs; diathermy, ultrasound, and heat treatments for pulmonary conditions; diapulse;

Appendix Table 3. (continued)

State	Details of Coverage
	work hardening; diversional, recreational, and vocational therapies (e.g., hobbies, arts and crafts) and their supplies; therapy to improve or restore functions that could be expected to improve as the patient resumes normal activities again; general exercises to promote overall fitness and flexibility; therapy to improve motivation; suction therapy for newborns (feeding machines); soft tissue mobilization (visceral manipulation or visceral soft tissue manipulation), augmented soft tissue mobilization, myofascial; adaptations to the home such as ramps, door widening, automobile adaptors, kitchen adaptation, and other types of similar equipment; home programs, ongoing conditioning and maintenance in cardiac rehab; pulmonary rehabilitation in the acute inpatient rehabilitation setting; admission to a hospital mainly for physical therapy; long-term rehabilitation in an inpatient setting.
Oklahoma	25 visits per year of physical, occupational, and manipulative therapies combined.
Oregon	30 visits per year. Covers services provided by a licensed physical therapist, occupational therapist, speech-language pathologist, physician, or other practitioner licensed to provide physical, occupational, or speech therapy. Services must be prescribed in writing by a licensed physician, dentist, podiatrist, nurse practitioner, or physician assistant. The prescription must include site, modality, duration, and frequency of treatment. Only treatment of neurologic conditions (e.g., stroke, spinal cord injury, head injury, pediatric neurodevelopmental problems, and other problems associated with pervasive developmental disorders for which rehabilitative services would be appropriate for children under 18 years of age) may be considered for additional benefits, not to exceed 30 visits per condition, when criteria for supplemental services are met. Includes pulmonary therapy and speech therapy only when needed to correct stuttering, hearing loss, peripheral speech mechanism problems, and deficits due to neurological disease or injury. Cardiac therapy is covered by a separate benefit category.
Pennsylvania	30 visits per year for physical and occupational therapies combined. Separate 30 visits per year of speech therapy.
Rhode Island	Includes physical, occupational, and speech therapies. 18 weeks (or 36 visits, whichever occurs first) per covered episode of cardiac rehab. Respiratory therapy is covered under a separate benefit category. Excludes maintenance therapy.
South Carolina	Includes physical therapy and pulmonary therapy when in conjunction with a lung transplant.
South Dakota	Coverage not detailed.

(continued)

Appendix Table 3. (continued)

State	Details of Coverage
Tennessee	20 visits per year. Outpatient, home health, or office therapeutic and rehabilitative services that are expected to result in significant and measurable improvement in a condition resulting from an acute disease, injury, autism in children under age 12, or cleft palate. The services must be performed by or under the direct supervision of a licensed therapist, upon written authorization of the treating practitioner. Includes physical, occupational, manipulative, pulmonary, and cardiac therapies and speech therapy for restoration of speech. Speech therapy is covered only for disorders of articulation and swallowing resulting from acute illness, injury, stroke, autism in children under age 12, or cleft palate. The limit on the number of visits for therapy applies to all visits for that therapy, whether received in a practitioner's office, outpatient facility, or home health setting. Excludes treatment beyond what can reasonably be expected to significantly improve health, including therapeutic treatments for ongoing maintenance or palliative care; enhancement therapy that is designed to improve physical status beyond preinjury or pre-illness state; complementary and alternative therapeutic services; modalities that do not require the attendance or supervision of a licensed therapist; duplicate therapy; behavioral therapy, play therapy, communication therapy, and therapy for self-correcting language dysfunctions as part of speech therapy, physical therapy, or occupational therapy programs. Behavioral therapy and play therapy for behavioral health diagnoses may be covered under the Behavioral Health Rider (if applicable).
Texas	35 visits per year of physical, occupational, and speech therapies combined. Limit shared with habilitation and chiropractic services.
Utah	20 visits per year of physical, occupational, and speech therapies combined. Limit shared with habilitative services. Separate five visits per year combined of phase 2 cardiac rehabilitation following heart attack, cardiac surgery, severe angina, and phase 2 pulmonary rehabilitation resulting from chronic pulmonary disease or surgery.
Vermont*	30 outpatient sessions per year of physical, occupational, and speech therapy but may also include radiation therapy, chemotherapy, dialysis, and infusion therapy. Cardiac rehabilitation is covered up to 36 visits per cardiac event. Three supervised exercise sessions per week up to total of 36 sessions for cardiac and pulmonary rehab programs.
Virginia	30 visits per year for physical and occupational therapies combined. Separate 30 visits per year for each speech, respiratory, and cardiac therapies. Limit shared between rehabilitation and habilitation services. Excludes physical or occupational therapy to maintain or preserve current function if there is no chance of improvement or reversal; group or individual exercise classes or personal training sessions; recreational therapy including but not limited to sleep, dance, arts, crafts, aquatic, gambling, and nature therapy.
Washington	25 visits per year. Benefits cover physical, occupational, and speech therapies.

Appendix Table 3. (continued)

State	Details of Coverage
West Virginia	Includes treatment for stroke, spinal cord injury, congenital deformity, amputation, major multiple traumas, fracture of femur, brain injury, polyarthritis, including rheumatoid arthritis, neurological disorders, cardiac disorders, and burns when there is a reasonable likelihood services will restore optimal physical, medical, psychological, social, emotional, vocational, and economic status. Excludes services associated with mental conditions, chemical dependency, vocational rehabilitation, long-term maintenance, and custodial services. All covered services must be medically necessary unless otherwise specified.
Wisconsin	25 visits per year for each physical, occupational, speech, and pulmonary therapies. 36 visits per year for cardiac rehab. 30 visits per year for post-cochlear implant therapy. Includes speech therapy only for the treatment of disorders of speech, language, voice, communication, and auditory processing resulting from injury, stroke, cancer, congenital anomaly, or autism spectrum disorders.
Wyoming	60 visits per year of physical and occupational therapies combined. A separate 20-visit limit for speech therapy. Rehabilitative care provides coverage for an accidental or medical injury. The intent is to return patients to their physical status (as much as possible) prior to the injury. Excludes hypnosis, cardiac, and pulmonary rehabilitation, biofeedback, or pain treatment.

* These states' benchmark plan summary tables include, as outpatient rehabilitation services, physical, occupational, and speech therapies. However, in more detailed tables that separately list individual categories of rehabilitative speech therapy, rehabilitative occupational therapy, and rehabilitative physical therapy, they are described as not covered.

Appendix Table 4. Essential Health Benefit (EHB) Coverage of Durable Medical Equipment

State	Details of Coverage
Alabama	<p>Covers services, supplies, equipment, accessories, or other items that can be purchased at retail establishments or otherwise over the counter without a doctor's prescription. Excludes hot and cold packs, including circulating devices and pumps; standard batteries used to power medical or durable medical equipment; solutions used to clean or prepare skin or minor wounds, including alcohol solution or wipes, povidone-iodine solution or wipes, hydrogen peroxide, and adhesive remover; standard dressing supplies and bandages used to protect minor wounds such as Band-Aids, 4 x 4 gauze pads, tape, compression bandages, eye patches; elimination and incontinence supplies such as urinals, diapers, and bed pans, and blood pressure cuffs, sphygmometers, stethoscopes, and thermometers; sleep studies performed outside of a health care facility, such as home sleep studies, whether or not supervised or attended; transcutaneous electrical nerve stimulation (TENS) equipment and all related supplies, including TENS units, conductive garments, application of electrodes, leads, electrodes, batteries, and skin preparation solutions; services for personal hygiene, comfort or convenience items such as air-conditioners, humidifiers, whirlpool baths, and physical fitness or exercise apparel; exercise equipment including shoes, weights, exercise bicycles or tracks, weights or variable resistance machinery, and equipment producing isolated muscle evaluations and strengthening; treatment programs, the use of equipment to strengthen muscles according to preset rules, and related services performed during the same therapy session.</p>
Alaska	<p>Excludes supplies or equipment not primarily intended for medical use; special or extra-cost convenience features; exercise equipment and weights; orthopedic appliances prescribed primarily for use during participation in sports, recreation, or similar activities; penile prostheses; whirlpools, whirlpool baths, portable whirlpool pumps, sauna baths, and massage devices; overbed tables, elevators, vision aids, and telephone alert systems; structural modifications to your home or personal vehicle; eyeglasses, contact lenses, and other vision hardware for conditions not listed as a covered medical condition, including routine eye care; prosthetics, intraocular lenses, appliances, or devices requiring surgical implantation; hypodermic needles, syringes, lancets, test strips, testing agents, and alcohol swabs used for self-administered medications. Applicable deductible and coinsurance apply.</p>
Arizona	<p>Excludes DME due to misuse, damage, or replacement when lost.</p>
Arkansas	<p>Durable Medical Equipment is equipment that can withstand repeated use, is primarily and customarily used to serve a medical purpose, generally is not useful to a person in the absence of an illness or injury, and is appropriate for use in the home. DME delivery or set up charges are included in the allowance. A single acquisition of eyeglasses or contact lenses within the first six months following cataract surgery is covered. With respect to such eyeglasses or contact lenses, tinting or anti-reflective coating and progressive lenses are not covered. Frames are subject to a \$50 maximum allowance. Replacement of DME is covered only when necessitated by normal growth or when it exceeds its useful life; maintenance and repairs resulting from misuse or abuse of DME are the responsibility of the member. When it is more cost-effective, Health Advantage in its discretion will purchase rather than lease equipment. In making such purchase, Health Advantage may deduct previous rental payments from its purchase allowance. Coverage for supplies used in connection with DME is limited to a 90-day supply per purchase.</p>

Appendix Table 4. (continued)

State	Details of Coverage
California	Prior authorization required.
Colorado	Coverage not detailed.
Connecticut	<p>DME, including prosthetics, consists of nondisposable equipment that is primarily used to serve a medical purpose that is generally not useful to a person in the absence of illness or injury and is appropriate for use in the home, including breast prosthetics following a mastectomy. DME benefits also include DME for the treatment of insulin-dependent diabetes, insulin-using diabetes, gestational diabetes, and noninsulin-using diabetes, and craniofacial disorders, hearing aids for a member age 12 and under, and wigs for a member suffering hair loss as a result of chemotherapy or radiation therapy when the wig is prescribed by an oncologist. Includes DME that does not duplicate the function of any previously obtained equipment; DME for the treatment of craniofacial disorders; hearing aids for a member age 12 and under up to a maximum of \$1,000 every 24 months. Excludes hearing aids, except as noted; medical supplies or equipment that are not considered to be durable medical equipment or disposable medical supplies or that are not on our covered list of such equipment or supplies; nondurable equipment such as orthopedic or prosthetic shoes, foot orthotics, and prophylactic antiembolism stockings (jobst stockings) without a history of deep vein thrombosis and varicose veins. To be covered, DME must be prescribed by a physician, preauthorized (as required), and provided by a DME supplier that is a participating provider. However, if the participating provider does not carry the covered DME, it may be purchased at a store that is a nonparticipating provider as long as the DME is both prescribed and preauthorized. Having a prescription for DME from a physician is not a guarantee the DME is covered. Preauthorization only will be required for insulin pumps, wound vacs, real-time continuous blood glucose monitors, customized wheelchairs and scooters, and osteogenic stimulators (including spinal, non-spinal, and ultrasound). DME may be authorized for rental or purchase on the basis of the expected length of medical need and the cost-benefit of a purchase or rental. We will decide whether DME is to be rented or purchased. If a rental item is converted to a purchase, the coinsurance the member pays for the purchase will be based on only the balance remaining to be paid to purchase the equipment.</p>
Delaware	Coverage not detailed.
DC	Coverage not detailed.
Florida	<p>Excludes DME which is primarily for convenience or comfort; modifications to motor vehicles or homes, including but not limited to wheelchair lifts or ramps; water therapy devices such as jacuzzis, hot tubs, swimming pools, or whirlpools; exercise and massage equipment; electric scooters; hearing aids; air conditioners and purifiers, humidifiers, water softeners and purifiers, heat appliances, dehumidifiers; pillows, mattresses, or waterbeds; escalators, elevators, stair glides; emergency alert equipment, handrails, and grab bars. The replacement of DME solely because it is old or used are excluded.</p>

(continued)

Appendix Table 4. (continued)

State	Details of Coverage
Georgia	Includes DME, medical devices and supplies, prosthetics, and appliances. Excludes air conditioners, humidifiers, dehumidifiers, or purifiers; arch supports and orthopedic or corrective shoes, shoe inserts, orthotics (except for care of the diabetic foot), and orthopedic shoes (except when an orthopedic shoe is joined to a brace); heating pads, hot water bottles, home enema equipment, or rubber gloves; sterile water; deluxe equipment or premium services, such as motor-driven chairs or beds, when standard equipment is adequate; rental or purchase of equipment in a facility which provides such equipment; electric stair chairs or elevator chairs; physical fitness, exercise, or ultraviolet and tanning equipment; residential structural modification to facilitate the use of equipment; other items of equipment that the Blue Cross Blue Shield Healthcare Plan decides do not meet the listed criteria; Band-Aids, tape, nonsterile gloves, thermometers, bed boards; rental of exercise cycles, hypoallergenic pillows, mattresses, or waterbeds, whirlpool, spa or swimming pools, exercise and massage equipment, air purifiers, escalators, elevators, ramps, emergency alert equipment, handrails, heat appliances, improvements made to a participant's house or place of business, and adjustments made to vehicles.
Hawaii	DME can be rented or purchased, however certain items are covered only as rentals. Supplies and accessories necessary for the effective functioning of the equipment are covered subject to certain limitations and exclusions.
Idaho	Includes orthotics; prosthetics and equipment; medical equipment and supplies. Excludes common household items such as hot tubs, convenience items, air conditioners, humidifiers, etc.
Illinois	Includes internal cardiac valves, internal pacemakers, mandibular reconstruction devices (not used primarily to support dental prosthesis), bone screws, bolts, nails, plates, and any other internal and permanent devices; insulin pumps; CPAPs; the rental (but not to exceed the total cost of equipment) or purchase of DME required for temporary therapeutic use provided that this equipment is primarily and customarily used to serve a medical purpose; supportive devices for the body or a part of the body, head, neck, or extremities, including but not limited to leg, back, arm, and neck braces and their necessary adjustments, repairs, and replacements. Excludes implants (covered separately); foot orthotics defined as any in-shoe device designed to support the structural components of the foot during weight-bearing activities; special braces, splints, specialized equipment, appliances, ambulatory apparatus, battery implants, and wigs (also referred to as cranial prostheses). Benefits will cover prosthetic devices, special appliances, and surgical implants only when they are required to replace all or part of an organ or tissue of the human body or they are required to replace all or part of the function of a nonfunctioning or malfunctioning organ or tissue. Benefits will also include adjustments, repair, and replacements of covered prosthetic devices, special appliances, and surgical implants when required because of wear or change in a patient's condition (excluding dental appliances other than intraoral devices used in connection with the treatment of temporomandibular joint (TMJ) dysfunction and related disorders, subject to specific limitations applicable to TMJ dysfunction and related disorders, and replacement of cataract lenses when a prescription change is not required).

Appendix Table 4. (continued)

State	Details of Coverage
Indiana	Includes DME, medical devices and supplies, and prosthetics and appliances, including cochlear implants. Excludes items for personal hygiene, environmental control or convenience; exercise equipment; repair and replacement due to misuse, malicious breakage or gross neglect, lost or stolen items; adhesive tape, Band-Aids, cotton-tipped applicators; arch supports; doughnut cushions; hot packs, ice bags; vitamins; medijectors; air conditioners; cold pack pump; raised toilet seats; rental of equipment if the member is in a facility that is expected to provide such equipment; translift chairs; treadmill; tub chair used in shower; dentures replacing teeth or structures directly supporting teeth; dental appliances; nonrigid appliances as elastic stockings, garter belts, arch supports, and corsets; artificial heart implants; wigs (except following cancer treatment); penile prosthesis in men suffering impotency as a result of disease or injury; orthopedic shoes (except therapeutic shoes for diabetics); foot support devices, such as arch supports and corrective shoes unless they are an integral part of a leg brace.
Iowa	Includes diabetic supplies and prosthetic limbs. Excludes orthotics, wigs or hair pieces, pools, whirlpools, spas, common first aid supplies, and health club memberships.
Kansas	Includes orthopedic and prosthetic devices, orthopedic braces, artificial limbs, artificial eyes, auditory osseointegrated devices. Benefits are limited to the amount normally available for a standard item; charges for deluxe items are not covered. Excludes eyeglasses and contact lenses (except the initial eyeglasses or contacts following surgery for cataracts, aphakia, or pseudophakia); hearing aids; hair prosthesis; dental plates, bridges or any dental prostheses, dental braces; apparel (coverage available for two postmastectomy bras per year); individualized, custom-fabricated shoe insert orthotic devices, appliances, and those available commercial over-the-counter foot devices.
Kentucky	Includes DME, medical devices and supplies, prosthetics and appliances, and cochlear implants. Excludes personal hygiene items, items for environmental control or convenience; exercise equipment; repair and replacement due to misuse, malicious breakage, or gross neglect, lost or stolen items; adhesive tape, Band-Aids, cotton-tipped applicators; arch supports; doughnut cushions; hot packs, ice bags; vitamins; medijectors; air conditioners; cold pack pump; raised toilet seats; rental of equipment if the member is in a facility that is expected to provide such equipment; translift chairs; treadmill; tub chair used in shower; dentures replacing teeth or structures directly supporting teeth; dental appliances; elastic stockings, garter belts, arch supports, and corsets; artificial heart implants; wigs (except following cancer treatment); penile prosthesis in men suffering impotency that results from disease or injury; orthopedic shoes (except therapeutic shoes for diabetics); foot support devices, such as arch supports and corrective shoes unless they are an integral part of a leg brace; standard elastic stockings, garter belts, and other supplies not specially made and fitted (except as specified under Medical Supplies).

(continued)

Appendix Table 4. (continued)

State	Details of Coverage
Louisiana	Includes DME, orthotics devices, and prosthetic appliances and devices (limb and nonlimb); repair or adjustment of purchased DME or for replacement of components; medical equipment and supplies. There are reasonable quantity limits on DME as determined by the insurer. Excludes coverage during rental of DME for repair, adjustment, or replacement of components and accessories necessary for the effective functioning and maintenance of covered equipment as this is the responsibility of the supplier; coverage for equipment for which a commonly available supply or appliance can substitute; coverage for the repair or replacement of equipment lost or damaged due to neglect or misuse; coverage for fitting or adjustments as this is included in the allowable charge; repair or replacement is covered only within a reasonable time period from the date of purchase as determined by insurer and is subject to the expected lifetime of the device; supportive devices for the foot, except when used in the treatment of diabetic foot disease; hairpieces, wigs, hair growth, or hair implants; personal comfort, hygiene, and convenience items including air conditioners, humidifiers, personal fitness equipment, or alterations to a member's home or vehicle. Benefits based on the allowable charge for standard devices will be provided toward any deluxe device when the member selects a deluxe device solely for comfort or convenience when documented to be medically necessary.
Maine	Includes DME, medical supplies, and prosthetic devices. Excludes personal comfort items; orthotic devices; prosthesis designed exclusively for athletic purposes; bandages and other disposable items that may be purchased without a prescription; food or dietary supplements; shoe inserts; fixtures installed in your home or installed on your real estate; exercise equipment.
Maryland	Coverage not detailed.
Massachusetts	Excludes foot orthotics; medical supplies; equipment not designed to serve medical purpose.
Michigan	Coverage not detailed.
Minnesota	Excludes equipment and supplies not obtained from or repaired by approved vendors; diabetic supplies and equipment besides indicated models and brands; PKU and oral amino acid-based formulas outside medical coverage criteria; costs exceeding the cost of an alternative piece of equipment or service that is effective and medically necessary; replacement or repair of any items if they are damaged or destroyed by member misuse, abuse, or carelessness, lost or stolen items; duplicate or similar items; labor and related charges for repair that are more than the cost of replacement by an approved vendor; sales tax, mailing, delivery charges, services call charges; items for education, hygiene, vocation, comfort, convenience, or recreation; communication aids or devices; household equipment that primary has customary uses other than medical; household fixtures, modification to the structure of the home, vehicle, car, or van modifications; rental equipment while member's owned equipment is being repaired by noncontracted vendors beyond one month rental; other equipment and supplies that we determine are not eligible for coverage. Insurer determines if an item will be approved for rental versus purchase.

Appendix Table 4. (continued)

State	Details of Coverage
Mississippi	Includes items that are used to serve a medical purpose, can withstand repeated use, are generally not useful to a person in the absence of illness, injury, or disease, and are appropriate for use in the patient's home. This includes orthotic devices and prosthetic appliances. Excludes hot tubs, swimming pools, whirlpools, lift chairs, air purifiers; alterations or structural changes to the member's home, auto, or personal property to accommodate any DME. Benefits provided only when equipment is prescribed by a physician and is not a comfort or convenience item.
Missouri	Includes DME, medical devices and supplies, prosthetics and appliances, including cochlear implants. Excludes items for personal hygiene, environmental control or convenience; exercise equipment; repair and replacement due to misuse, malicious breakage, or gross neglect, lost or stolen items; adhesive tape, Band-Aids, cotton-tipped applicators; arch supports; doughnut cushions; hot packs, ice bags; vitamins; medinjectors; elastic stockings or supports; gauze and dressing; air conditioners; cold pack pump; raised toilet seats; rental of equipment if the member is in a facility that is expected to provide such equipment; translift chairs; treadmill; tub chair used in shower; dentures replacing teeth or structures directly supporting teeth; dental appliances; elastic stockings, garter belts, arch supports, and corsets; artificial heart implants; wigs (except following cancer treatment); penile prosthesis in men suffering impotency that results from disease or injury; orthopedic shoes (except therapeutic shoes for diabetics); foot support devices, such as arch supports and corrective shoes unless they are an integral part of a leg brace; standard elastic stockings, garter belts, and other supplies not specially made and fitted.
Montana	Includes appropriate equipment used for therapeutic purposes where the member resides. The equipment must be able to withstand repeated use, primarily used to serve a medical purpose rather than for comfort or convenience, generally not useful to a personal who is not ill or injured, and prescribed by a physician. One insulin pump each warranty period. Excludes exercise equipment; car or stair lifts; whirlpool baths, hot tubs, saunas, waterbeds; computerized or deluxe equipment; computer-assisted communication devices; DME primarily for use in athletics; replacement of lost or stolen durable medical equipment; repair or rental equipment; duplicate equipment purchased primarily as a convenience.
Nebraska	Includes orthotics only for diabetics, medical equipment and supplies. Excludes replacement of rental equipment due to misuse, abuse, or loss; wigs; items for personal comfort; home exercise; pools, whirlpools, spas, hydrotherapy equipment; surgical supports, corsets, clothing unless for the purpose of recovery from surgery or injury; common first aid supplies; and health club membership.
Nevada	\$4,000 per lifetime.

(continued)

Appendix Table 4. (continued)

State	Details of Coverage
New Hampshire	Includes DME, medical supplies, and prosthetic devices. Excludes arch supports, corrective shoes, foot orthotics and fittings, castings or any services related to footwear or orthopedic devices or any shoe modification; special furniture such as seat lift chairs, elevators (including stairway elevators or lifts), back chairs, special tables, and posture chairs, adjustable chairs, bed boards, bed tables, and bed support devices of any type, including adjustable beds; glasses; sports bras, nursing bras, and maternity girdles or any other special clothing except as stated; nonprescription supplies, first aid supplies, ACE bandages, cervical pillows, alcohol, peroxide, betadine, iodine, or phisoHex solution, alcohol wipes, betadine or iodine swabs, items for personal hygiene; bath seats or benches (including transfer seats or benches), whirlpools or any other bath tub, rails or grab bars for the bath, toilet rails or grab bars, commodes, raised toilet seats, bed pans; heat lamps, heating pads, hydrocollator heating units, hot water bottles, batteries, and cryo cuffs; biomechanical limbs; computers, physical therapy equipment, physical or sports conditioning equipment, exercise equipment, or any other item used for leisure, sports, recreational, or vocational purposes; any equipment or supplies intended for educational or vocational rehabilitation; vehicles, scooters, or any similar mobility device; safety equipment including but not limited to hats, belts, harnesses, glasses, or restraints; costs related to residential or vocational remodeling or indoor climate or air quality control, air conditioners, air purifiers, humidifiers, dehumidifiers, vaporizers, and any other room heating or cooling device or system; self-monitoring devices except as stated; TENS units for incontinence; biofeedback devices, self-teaching aids, books, pamphlets, video tapes, video disks, fees for Internet sites or software, or any other media instruction or for any other educational or instructional material, technology, or equipment; and dentures, orthodontics, dental prosthesis and appliances; appliances used to treat temporomandibular joint (TMJ) disorders.
New Jersey	Preapproval required, must be ordered by a network practitioner and arranged through the carrier.
New Mexico	Coverage not detailed.
New York	DME defined as equipment that is designed and intended for repeated use, primarily and customarily used to serve a medical purpose, generally not useful to a person in the absence of disease or injury and is appropriate for use in the home. \$1,500 per year for nonessential DME and medical supplies. Coverage for standard equipment only. Excludes orthotics, arch supports, corrective shoes, false teeth, maintenance, and repairs due to member's misuse.
North Carolina	Includes orthotics, prosthetics, medical devices, and medical equipment and supplies. Excludes wigs; items of personal comfort; home exercise; pools, whirlpools, spas, hydrotherapy equipment; surgical supports, corsets, clothing unless for the purpose of recovery from surgery or injury; common first aid supplies; health club membership.

Appendix Table 4. (continued)

State	Details of Coverage
North Dakota	Unit limits unique to type of DME defined per medical coverage policy. Excludes home traction units; DME replacements due to physical growth; DME to aid in the correction of congenital anomalies over the age of five years; orthopedic shoes; custom-made orthotics; over-the-counter orthotics and appliances; disposable supplies (including diapers) or nondurable supplies and appliances, including those associated with equipment determined not to be eligible for coverage; revision of durable medical equipment, except when made necessary by normal wear or use, replacement or repair of equipment if items are damaged or destroyed by member misuse, abuse, or carelessness, or are lost or stolen; duplicate or similar items; sales tax, mailing, delivery charges, service call charges, or charges for repair estimates; items that are primarily educational in nature or for vocation, comfort, convenience, or recreation; communication aids or devices to create, replace, or augment communication abilities including, but not limited to, hearing aids, speech processors, receivers, communication boards, or computer- or electronic-assisted communication; household equipment that primarily has customary uses other than medical, such as air purifiers, central or unit air conditioners, water purifiers, nonallergic pillows, mattresses, or waterbeds, physical fitness equipment, hot tubs, or whirlpools; household fixtures including escalators or elevators, ramps, swimming pools, and saunas; home modifications including wiring, plumbing, or changes for installation of equipment; vehicle modifications including hand brakes, hydraulic lifts, and car carrier; remote control devices as optional accessories; any other equipment and supplies that the plan determines is not eligible for coverage.
Ohio	DME, medical devices and supplies, prosthetics and appliances, including cochlear implants. Limit of four surgical bras following mastectomy per benefit period; LVAD covered only as bridge to heart transplant. Excludes items for personal hygiene, environmental control or convenience; exercise equipment; repair and replacement due to misuse, malicious breakage, or gross neglect, lost or stolen items; adhesive tape, Band-Aids, cotton-tipped applicators; arch supports; doughnut cushions; hot packs, ice bags; vitamins; medinjectors; air conditioners; cold pack pump; raised toilet seats; rental of equipment if the member is in a facility that is expected to provide such equipment; translift chairs; treadmill; tub chair used in shower; dentures replacing teeth or structures directly supporting teeth; dental appliances; elastic stockings, garter belts, arch supports, and corsets; artificial heart implants; wigs (except following cancer treatment); penile prosthesis in men suffering impotency that results from disease or injury; orthopedic shoes (except therapeutic shoes for diabetics); foot support devices such as arch supports and corrective shoes, unless they are an integral part of a leg brace; standard elastic stockings, garter belts, and other supplies not specially made and fitted.
Oklahoma	Coverage not detailed.
Oregon	\$5,000 per year. Exceptions to this limitation are EHBs such as prosthetics and orthotic devices, oxygen and oxygen supplies, diabetic supplies, wheelchairs, and breast pumps. Medical foods for the treatment of inborn errors of metabolism are also exempt from this limitation. Benefits exclude hospital-grade breast pumps.
Pennsylvania	\$2,500 per year. Precertification required for out-of-network care. Benefits will be reduced by 50 percent per service or supply if precertification is not obtained.

(continued)

Appendix Table 4. (continued)

State	Details of Coverage
Rhode Island	<p>DME is equipment that can withstand repeated use, is primarily and customarily used to serve a medical purpose, is not useful to a person in the absence of an illness or injury, and is for use in the home. DME items may be classified as rental or purchased items. A DME rental item is billed on a monthly basis for a specific period of months, after which the item is considered paid up to allowance. Allowance for a rental DME item will never exceed allowance for a purchased DME item. Preauthorization is recommended for certain items. Repairs and supplies to rental equipment are included in our rental allowance. Preauthorization is recommended for replacement and repairs of purchased DME. Includes wheelchairs, hospital beds, and other DME used only for medical treatment; replacement of purchased equipment that is needed due to a change in your medical condition. Excludes items found in the home that do not need a prescription and are easily obtainable, such as adhesive bandages, elastic bandages, gauze pads, and alcohol; supplies prescribed primarily for the convenience of the member or the member's family, duplicate DME or medical supplies for use in multiple locations, or any DME or medical supplies used primarily to assist a caregiver; DME that does not directly improve the function of the member; pillows or batteries, except when used for the operation of a covered prosthetic device; items whose sole function is to improve the quality of life or mental well-being; repair or replacement of DME when under warranty, covered by the manufacturer, or during the rental period; repair charges to repair rental items.</p>
South Carolina	<p>Includes orthotics, medical equipment and supplies that have exclusive medical use and are medical in nature, including wheelchairs, hospital-type beds, prosthetic devices, walkers, oxygen, respirators, etc. Excludes TENS unit; adjustable cranial orthosis as referenced in contract; bioelectric, microprocessor- or computer-programmed prosthetic components; air conditioners, whirlpool baths, spas, (de)humidifiers; wigs; fitness supplies; vacuum cleaners, air filters; common first aid supplies; manual or motorized wheelchairs or power-operated scooters for mobility outside the home setting.</p>
South Dakota	<p>Equipment that is primarily and customarily manufactured to serve a medical purpose, including diabetic supplies and prosthetic limbs. Excludes orthotics, wigs or hair pieces, pools, whirlpools, spas, common first aid supplies, and health club memberships.</p>
Tennessee	<p>Includes medically necessary and appropriate medical equipment or items that in the absence of illness or injury are of no medical or other value to you, can withstand repeated use in an ambulatory or home setting, require the prescription of a practitioner for purchase, are approved by the FDA for the illness or injury for which it is prescribed, and are not solely for convenience. Maximum allowable rental charge not to exceed the total maximum allowable charge for purchase. If renting the same type of equipment from multiple DME providers, and the total rental charges from the multiple providers exceed the purchase price of a single piece of equipment, you will be responsible for amounts in excess of the maximum allowable charge for purchase. Includes the repair, adjustment, or replacement of components and accessories necessary for the effective functioning of covered equipment; supplies and accessories necessary for the effective functioning of covered DME; the replacement of items needed as the result of normal wear and tear, defects, or obsolescence</p>

Appendix Table 4. (continued)

State	Details of Coverage
Texas	and aging. Insulin pump replacement is covered only for pumps older than 48 months and only if the pump cannot be repaired. Excludes charges exceeding the total cost of the maximum allowable charge to purchase the equipment; unnecessary repair, adjustment or replacement or duplicates of any such equipment; supplies and accessories that are not necessary for the effective functioning of the covered equipment; replacements for equipment lost, damaged, stolen, or prescribed as a result of new technology; items that require or are dependent on alteration of home, workplace, or transportation vehicle; motorized scooters, exercise equipment, hot tubs, pool, saunas; "deluxe" or "enhanced" equipment; computerized or gyroscopic mobility systems, roll-about chairs, geriatric chairs, hip chairs, and seat lifts of any kind; patient lifts, auto tilt chairs, air fluidized beds, or air flotation beds, unless approved by case management.
Utah	Coverage not detailed. Includes one breast prosthetic per affected breast every two years (requires preauthorization); eye prosthetic once per affected eye every five years; one lens for the affected eye following eligible corneal transplant surgery; contact lenses for documented keratoconus may be approved as medically necessary; one pair of ear plugs within 60 days following eligible ear surgery; continuous passive motion machine rentals may be approved for up to 21 days rental only for total knee or shoulder arthroplasty; wheelchairs require preauthorization through medical case management and are limited to one power wheelchair every five years; knee braces are limited to one per every three years. Excludes foot orthotics; training and testing in conjunction with DME or prosthetics; more than one lens for each affected eye following surgery for corneal transplant; DME that is inappropriate for the patient's medical condition; diabetic supplies, such as insulin, syringes, needles (covered by pharmacy benefits); equipment purchased from nonlicensed providers; used DME; TENS units; neuromuscular stimulator; H-wave electronic devices; sympathetic therapy stimulators; limb prosthetics; machine rental or purchase for the treatment of sleep disorders; support hose for phlebitis or other diagnosis.
Vermont	Includes supplies and equipment necessary for administration, orthotics (if approved), prosthetics, and devices. Threshold applies. Some durable medical equipment and supplies require prior approval.
Virginia	Includes DME, medical devices and supplies, prosthetics and appliances, including cochlear implants. Excludes those items that have both a therapeutic and nontherapeutic use, including exercise equipment; air conditioners, dehumidifiers, humidifiers, and purifiers; hypoallergenic bed linens; whirlpool baths; handrails, ramps, elevators, stair glides; telephones; adjustments made to a vehicle; foot orthotics; changes made to home or place of business; repair or replacement of equipment lost or damaged through neglect; over-the-counter convenience and hygienic items including adhesive removers, cleansers, underpads, and ice bags.
Washington	Coverage not detailed.
West Virginia	Includes purchase or rental at insurer's option when prescribed by providers practicing within the scope of their license, including orthotics and prosthetics. Excludes dental appliances; elastic bandages, garter belts, or similar supplies; orthopedic shoes; items not serving a medical purpose; items not able to withstand repeated use. All covered services must be medically necessary unless otherwise specified.

(continued)

Appendix Table 4. (continued)

State	Details of Coverage
Wisconsin	<p>One item per three years, up to \$2,500 per year for nonessential DME. Includes equipment to assist mobility, such as a standard wheelchair; standard hospital-type bed; oxygen and the rental of equipment to administer oxygen (including tubing, connectors, and masks); delivery pumps for tube feedings (including tubing and connectors); braces, including necessary adjustments to shoes to accommodate braces (braces that stabilize an injured body part and braces to treat curvature of the spine are considered DME and are covered; braces that straighten or change the shape of a body part are orthotic devices and are excluded from coverage. Dental braces are also excluded from coverage); mechanical equipment necessary for the treatment of chronic or acute respiratory failure (except that air conditioners, humidifiers, dehumidifiers, air purifiers and filters, and personal comfort items are excluded from coverage); burn garments; insulin pumps and all related necessary supplies as described under diabetes services; external cochlear devices and systems (benefits for cochlear implantation are provided under the applicable medical/surgical benefit categories). Excludes prescribed or nonprescribed medical supplies and disposable supplies; compression stockings, ACE bandages, gauze, and dressings, urinary catheters, tubings, and masks unless necessary for the effective use of covered DME; devices used specifically as safety items or to affect performance in sports-related activities; blood pressure cuff and monitor; enuresis alarm; nonwearable external defibrillator; trusses; ultrasonic nebulizers; devices and computers to assist in communication and speech except for speech aid devices and tracheo-esophageal voice devices covered under DME; oral appliances for snoring; any device, appliance, pump, machine, stimulator, or monitor that is fully implanted into the body; repairs and replacement due to misuse, malicious damage, or gross neglect or to replace lost or stolen items. Includes cochlear implants.</p>
Wyoming	<p>Includes rental or purchase, initial fitting and adjustments, repair and replacement, used and refurbished equipment, diabetic supplies, therapeutic devices (e.g., hypodermic needles and syringes), oxygen, and onsite and take-home medical and surgical supplies. Excludes support devices for the foot, including flat foot conditions, for shoe inserts; deluxe motorized equipment, electronic speech aids, robotization devices, robotic prosthetics; dental appliances; artificial organs; personal hygiene and convenience items such as air conditioner, humidifiers, or physical fitness equipment; wigs or artificial hairpieces, or hair transplants or implants, regardless of whether there is a medical reason for hair loss.</p>

Endnotes

- 1 Specifically, the 12th International Conference on Grey Literature at Prague issued the following definition in December 2010: “Grey literature stands for manifold document types produced on all levels of government, academics, business and industry in print and electronic formats that are protected by intellectual property rights, of sufficient quality to be collected and preserved by library holdings or institutional repositories, but not controlled by commercial publishers—i.e., where publishing is not the primary activity of the producing body.” Schöpfel, Joachim. “Towards a Prague Definition of Grey Literature,” in *Twelfth International Conference on Grey Literature: Transparency in Grey Literature. Grey Tech Approaches to High Tech Issues*, (Prague, December 6–7 2010).
- 2 For our literature review, we included all available research that empirically analyzes the impact of the ACA for people with disabilities. We focused on ACA provisions most relevant to people with disabilities: Medicaid expansion, health insurance marketplaces, and long-term services and supports (LTSS) options. We also included empirical literature on the dependent coverage provision for young adults. We excluded most studies that analyze the effect of the ACA on the general population without specifically addressing the people with disabilities’ situation (some of this research is mentioned when comparing findings for people with disabilities with those for all adults). We also excluded studies that discuss the potential effect of the ACA on people with disabilities but that do not conduct an empirical analysis.
- 3 The Community First Choice option allows States to provide home and community-based attendant services and supports to eligible Medicaid enrollees under their State Plan. This State Plan option was established under the ACA. <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/community-first-choice-1915-k.html>.
- 4 See, for example, CMCS Informational Bulletin, “Updates to the Section 1915 © Waiver Instructions and Technical Guide regarding employment and employment related services,” September 16, 2011. <https://downloads.cms.gov/cmssgov/archived-downloads/CMCSBulletins/downloads/CIB-9-16-11.pdf>.
- 5 One state (Colorado) offered both an ABP aligned to its standard Medicaid plan and a commercial plan and it therefore counted twice.
- 6 Kaiser Family Foundation. “Health Reform Implementation Timeline.” Accessed September 10, 2015. <http://kff.org/interactive/implementation-timeline/>.
- 7 Kaiser Family Foundation. “Status of State Action on the Medicaid Expansion Decision.” Last modified June 26, 2015. <http://kff.org/health-reform/state-indicator/state-activity-around-expanding-medicaid-under-the-affordable-care-act/>.
- 8 EHBs consist of ten categories that QHPs, most other forms of private insurance, and benefit plans for individuals included in the Medicaid expansion must cover.
- 9 These totals combine partnership exchanges and federally supported marketplaces into the middle category of jointly operated marketplaces. See Kaiser Family Foundation. “State Health Insurance Marketplace Types, 2015.” Accessed September 10, 2015. <http://kff.org/health-reform/state-indicator/state-health-insurance-marketplace-types/>.
- 10 Half of the informants were people with disabilities or individuals caring for family members or others with disabilities.
- 11 One state (Colorado) offered both an ABP aligned to its standard Medicaid plan and a commercial plan and it therefore counted twice.

- 12 Shartzter, Adele, Genevieve M. Kenney, and Stephen Zuckerman. "Quick Take: Uninsurance Rate Halved for Adults with Chronic Conditions." Health Reform Monitor Survey. Washington, DC: Urban Institute, 2015. <http://hrms.urban.org/quicktakes/Uninsurance-Rate-Halved-for-Adults-with-Chronic-Conditions.html>.
- 13 The number of states with approved Spas was provided by HHS staff.
- 14 A number of studies have discussed possible implications for people with disabilities. See for instance Rosenbaum, Sara, Joel B. Teitelbaum, and Katherine Hayes. "Crossing the Rubicon: The Impact of the Affordable Care Act on the Content of Insurance Coverage for Persons with Disabilities." *Notre Dame Journal of Ethics and Public Policy* 25 (2011): 527–62 and Mechanic, David. "Seizing Opportunities under the Affordable Care Act for Transforming the Mental and Behavioral Health System." *Health Affairs* 31, 2 (2012): 376–82. Similarly, Musumeci et al. uses three profiles of people with disabilities to explain how the ACA might affect different groups of people with disabilities, see Musumeci, MaryBeth, Julia Paradise, Erica Reaves, and Henry Claypool. "Benefits and Cost-Sharing for Working People with Disabilities in Medicaid and the Marketplace." Issue brief, Kaiser Family Foundation, 2014.
- 15 See, for example, Brault, Matthew W. "Americans with Disabilities: 2010." Current Population Reports No. P70-131, US Census Bureau, Washington, DC, 2012. He uses the 2010 American Community Survey to estimate a disability prevalence rate of 10.2 percent among individuals ages 15 to 24 compared with a disability prevalence rate of 16.6 percent among individuals ages 21 to 64.
- 16 The 12th International Conference on Grey Literature at Prague issued the following definition in December 2010: "Grey literature stands for manifold document types produced on all levels of government, academics, business and industry in print and electronic formats that are protected by intellectual property rights, of sufficient quality to be collected and preserved by library holdings or institutional repositories, but not controlled by commercial publishers—i.e., where publishing is not the primary activity of the producing body" Schöpfel, "Towards a Prague Definition of Grey Literature."
- 17 Experts followed for review include Yaa Akosa Antwi, Department of Economics, Indiana University-Purdue University at Indianapolis; Matthew Brault, US Census Bureau; Joel Cantor, Institute for Health, Health Care Policy, and Aging Research, Rutgers University; Jonathan Gruber, Department of Economics, Massachusetts Institute of Technology; Stephen Kaye, School of Nursing, University of California, San Francisco; Andrew Mulcahy, RAND Corporation; MaryBeth Musumeci, Kaiser Family Foundation; Shirley Porterfield, School of Social Work, University of Missouri-Saint Louis; Brendan Saloner, Bloomberg School of Public Health, Johns Hopkins University; Benjamin Sommers, Department of Health Policy and Management, Harvard University; and Edith Walsh, Director of Aging, Disability, and Long-Term Care, RTI International.
- 18 See Centers for Medicare and Medicaid Services (CMS). "Approved Demonstrations—Signed MOUs." Accessed September 10, 2015. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/ApprovedDemonstrations-SignedMOUs.html>. Researchers need to submit a proposal to be able to use early release microdata and can only access this data at CDC's Research Data Center in Hyattsville, Maryland.
- 19 National Center for Health Statistics. "National Health Interview Survey, 2014: Public-use data file and documentation." Accessed September 10, 2015. http://www.cdc.gov/nchs/nhis/quest_data_related_1997_forward.htm or National Health Interview Survey. 2015. "2014 NHIS Questionnaire." Division of Health Interview Statistics, National Center for Health Statistics, Hyattsville, MD. The CDC has released analyses of insurance coverage with tabulations based on age, gender, race or ethnicity, and income as a percentage of the FPL, but these analyses do not tabulate results on the basis of health status or disability. See Cohen, Robin A., and Michael E. Martinez. "Health Insurance Coverage: Early Release of Estimates From the National Health Interview Survey, January–March 2014." U.S. Department of Health and Human Services, Centers for Disease Control and Prevention, and National Center for Health Statistics, Washington, DC, September 2014. <http://www.cdc.gov/nchs/data/nhis/earlyrelease/insur201409.pdf>.
- 20 See Iezzoni, Lisa I., Stephen G. Kurtz, and Sowmya R. Rao. "Trends in Mammography over Time for Women with and without Chronic Disability." *Journal of Women's Health* 24, 7 (2015): 593–601; Iezzoni, Lisa I., Jun Yu,

- Amy J. Wint, Suzanne C. Smeltzer, and Jeffrey L. Ecker. "Health Risk Factors and Mental Health among US Women with and without Chronic Physical Disabilities by whether Women Are Currently Pregnant." *Maternal and Child Health Journal* 19, 6 (2015): 1364–75; Qin, Jin, Kristina A. Theis, Kamil E. Barbour, Charles G. Helmick, Nancy A. Baker, and Teresa J. Brady. "Impact of Arthritis and Multiple Chronic Conditions on Selected Life Domains—United States, 2013." *Morbidity and Mortality Weekly Report* 64, 21 (2015): 578–82; Sharts-Hopko, Nancy C. "Mental Health Status Indicators and Vision Status among Adult Women Respondents to the 2010–2013 National Health Interview Surveys." Paper presented to Sigma Theta Tau International's 26th International Nursing Research Congress, San Juan, Puerto Rico, July 23–27 2015; and Woodard, Kedra. "Association of Glucosamine and/or Chondroitin Use with Reports of Improved Health and Joint Pain among Individuals with Arthritis, National Health Interview Survey (NHIS) 2012." Thesis for Master of Public Health, Georgia State University, 2015 for more information.
- 21 Studies on barriers to health care access typically show substantial barriers for people with disabilities. Recent studies include, for instance, Drainoni, Mari-Lynn, Elizabeth Lee-Hood, Carol Tobias, Sara S. Bachman, Jennifer Andrew, and Lisa Maisels. "Cross-Disability Experiences of Barriers to Health-Care Access: Consumer Perspectives." *Journal of Disability Policy Studies* 17, 2 (2006): 101–15; Goin, Dana, and Sharon K. Long. "Health Care Access and Cost Barriers for Adults with Physical or Mental Health Issues: Evidence of Significant Gaps as the ACA Marketplaces Opened Their Doors." Health Reform Monitoring Survey brief. Washington, DC: The Urban Institute, 2014; and Iezzoni, Lisa I., Austin B. Frakt, and Steven D. Pizer. "Uninsured Persons with Disability Confront Substantial Barriers to Health Care Services." *Disability and Health Journal* 4, 4 (2011): 238–44.
 - 22 Sommers, Benjamin D., Genevieve M. Kenney, and Arnold M. Epstein. "New Evidence on the Affordable Care Act: Coverage Impacts of Early Medicaid Expansions." *Health Affairs* 33, 1 (2014): 78–87.
 - 23 Specifically, they used Maine, New Hampshire, Vermont, Massachusetts, Rhode Island, New York, Pennsylvania, and New Jersey as comparison states for Connecticut and Virginia as the comparison state for Washington, DC.
 - 24 This group includes all respondents who answered yes to at least one disability-related question, which included items related to sensory, physical, mental, self-care, outside-of-home, and employment disabilities. About 20 percent of all people in the sample reported such health-related limitation.
 - 25 In addition, most of the new enrollees in Washington, DC, were previously insured through a local program called Health Alliance.
 - 26 Shartzter, Adele, Genevieve M. Kenney, and Stephen Zuckerman. "Quick Take: Uninsurance Rate Halved for Adults with Chronic Conditions." Health Reform Monitory Survey. Washington, DC: Urban Institute, 2015. <http://hrms.urban.org/quicktakes/Uninsurance-Rate-Halved-for-Adults-with-Chronic-Conditions.html>.
 - 27 They define adults with chronic conditions as respondents who have one of the following conditions: asthma, chronic bronchitis, or chronic obstructive pulmonary disorder; diabetes; epilepsy; heart attack; heart disease; and high blood pressure.
 - 28 See Long, Sharon K., Michael Karpman, Genevieve M. Kenney, Stephen Zuckerman, Douglas Wissoker, Adele Shartzter, Nathaniel Anderson, and Katherine Hempstead. "Taking Stock: Gains in Health Insurance Coverage under the ACA as of March 2015." Health Reform Policy Survey brief. Washington, DC: The Urban Institute, 2015. The decline in the uninsurance rate among all nonelderly adults is 7.5 percentage points in absolute terms, slightly higher than the 6.7 percentage point decline report by Shartzter, Kenney, and Zuckermann. The relative decline is nonetheless larger for people with chronic health conditions because their pre-implementation uninsurance rate in 2013 is lower.
 - 29 See Centers for Medicare and Medicaid Services (CMS). "Approved Demonstrations—Signed MOUs." Accessed September 10, 2015. <https://www.cms.gov/Medicare-Medicaid-Coordination/Medicare-and-Medicaid-Coordination/Medicare-Medicaid-Coordination-Office/FinancialAlignmentInitiative/ApprovedDemonstrationsSignedMOUs.html>.
 - 30 Musumeci, MaryBeth. "Financial and Administrative Alignment Demonstrations for Dual Eligible Beneficiaries Compared: States with Memoranda of Understanding Approved by CMS." Issue brief, Kaiser Family Foundation, 2014.

- 31 E-mail conversation with the primary investigator, Edith Walsh, May 4, 2015. For the evaluation plan, see Walsh, Edith G. "Measurement, Monitoring, and Evaluation of State Demonstrations to Integrate Care for Dual Eligible Individuals: Aggregate Evaluation Plan." Report to the Center for Medicare and Medicaid Innovation, Centers for Medicare and Medicaid Services, 2013.
- 32 See Craver, Gerald, Meredith Lee, Sarah Broughton, Alison Cuellar, and Gilbert Gimm. "Commonwealth Coordinated Care: Notes from the Field—April 2014." Virginia Department of Medical Assistance Services and George Mason University, 2014.
- 33 For example, a report from focus group interviews in Massachusetts included just three interviewees using LTSS services and none of them had met with a coordinator at that point. See Fishman, Jennie, and Alexis Henry. "The One Care Early Indicators Project—Preliminary Findings from a Focus Group with Early Self-Selected One Care Enrollees." Report of focus group held in Boston, MA, December 16, 2013. University of Massachusetts Medical School. <http://www.mass.gov/eohhs/docs/masshealth/onecare/eip-focus-group/eip-focus-group-1-opt-ins-summary-report.pdf>.
- 34 See Craver, Gerald, Meredith Lee, and Sarah Broughton. "Review of Commonwealth Coordinated Care Beneficiary Focus Groups (CY 2014)." PowerPoint document. Virginia Department of Medical Assistance Services, Richmond; Dickson, 2015; Virgil. "Future of Dual-Eligible Demonstrations Questioned Due to Low Enrollment." *Modern Healthcare*. April 21 2015; and Ingram, Carolyn. "Engaging Consumers in Care." Presentation to Cal MediConnect Providers Summit, Los Angeles, January 21 2015. www.calduals.org/wp-content/uploads/2015/01/January-21-2015-Providers-Summit-Session-3A.pdf.
- 35 CMS approved California's SPA under the condition that California would revise it to reflect the then-newly established institutional level-of-care eligibility criteria. The revised SPA went into effect July 1, 2013.
- 36 Sebelius, Kathleen. "Community First Choice: Interim Report to Congress." Department of Health and Human Services, Office of the Secretary, Washington, DC, 2014. <http://www.medicaid.gov/medicaid-chip-program-information/by-topics/long-term-services-and-supports/home-and-community-based-services/downloads/community-first-choice-interim-report-to-congress.pdf>.
- 37 *Ibid.*, p.9.
- 38 For a summary of the evaluation research plan, see Lowell, Kristina Hanson, and Gretchen Williams Torres. "Interim and Final Report to Congress on the Community First Choice Option." Report for the Centers for Medicare and Medicaid Services. National Opinion Research Center, University of Chicago. Accessed September 10, 2015. <http://www.norc.org/Research/Projects/Pages/interim-and-final-report-to-congress-on-the-community-first-choice-option.aspx>.
- 39 A few studies report results separately for young adults ages 19 to 22 and those ages 23 to 25 because young adults under 23 years of age could typically stay on their parents' insurance before 2010 if they were in college. In this report we ignore that distinction, focusing exclusively on results for adults ages 19 to 25.
- 40 O'Hara, Brett, and Matthew W. Brault. "The Disparate Impact of the ACA-Dependent Expansion across Population Subgroups." *Health Services Research* 48, 5 (2013): 1581–92.
- 41 The relative decline is obtained by dividing the absolute decline (6 percentage points) by the initial uninsurance level (30 percentage points). McMorro et al. reported a similar uninsurance rate of 30 percent to 35 percent for young adults in 2009 and the first two quarters of 2010. See McMorro, Stacey, Genevieve M. Kenney, Sharon K. Long, and Nathaniel Anderson. "Uninsurance among Young Adults Continues to Decline, Particularly in Medicaid Expansion States." *Health Affairs* 34, 4 (2015): 616–20.
- 42 Cantor, Joel C., Alan C. Monheit, Derek DeLia, and Kristen Lloyd. "Early Impact of the Affordable Care Act on Health Insurance Coverage of Young Adults." *Health Services Research* 47, (2012): 1773–90; and Sommers, Benjamin D., and Richard Kronick. "The Affordable Care Act and Insurance Coverage for Young Adults." *Journal of the American Medical Association* 307, 9 (2012): 913–14. Both studies use the Current Population Survey Annual Social and Economic (March) Supplement from the mid-2000s to 2010.
- 43 See Sommers, Benjamin D, Thomas Buchmueller, Sandra L Decker, Colleen Carey, and Richard Kronick. "The Affordable Care Act Has Led to Significant Gains in Health Insurance and Access to Care for Young Adults."

- Health Affairs* 32, (2013): 165–74. They report that the uninsurance rate dropped by 4.1 percentage points in the last quarter of 2010 and first quarter of 2011 compared with pre-implementation levels but by 7.2 percentage points when the researchers compared the second and third quarter of 2011 to pre-implementation levels.
- 44 Antwi, Yaa Akosa, Asako S. Moriya, and Kosali Simon. “Effects of Federal Policy to Insure Young Adults: Evidence from the 2010 Affordable Care Act’s Dependent-Coverage Mandate.” *American Economic Journal: Economic Policy* 5, 4 (2013): 1–28.
- 45 Saloner, Brendan, and Benjamin Lê Cook. “An ACA Provision Increased Treatment for Young Adults with Possible Mental Illnesses Relative to Comparison Group.” *Health Affairs* 33, 8 (2014): 1425–34. They identified individuals with potential mental health care needs as respondents who expressed serious mental distress in the previous year using a six-item scale that included questions about symptoms of depression and anxiety.
- 46 Porterfield, Shirley L., and Jin Huang. “Health Insurance and Access to Care among Young Adults with Disabilities: Impacts of the Affordable Care Act.” Paper presented at the 10th World Congress of the International Health Economics Association, Dublin, UK. 2014.
- 47 These results are currently not publicly available and were graciously shared by Shirley Porterfield in the form of presentation slides.
- 48 Antwi, Yaa Akosa, Asako S. Moriya, and Kosali Simon. “Effects of Federal Policy to Insure Young Adults: Evidence from the 2010 Affordable Care Act’s Dependent-Coverage Mandate.” *American Economic Journal: Economic Policy* 5, 4 (2013): 1–28.
- 49 Sommers, Benjamin D, Thomas Buchmueller, Sandra L Decker, Colleen Carey, and Richard Kronick. “The Affordable Care Act Has Led to Significant Gains in Health Insurance and Access to Care for Young Adults.” *Health Affairs* 32, 1 (2013): 165–74.
- 50 Antwi, Yaa Akosa, Asako S. Moriya, and Kosali Simon. “Effects of Federal Policy to Insure Young Adults: Evidence from the 2010 Affordable Care Act’s Dependent-Coverage Mandate.” *American Economic Journal: Economic Policy* 5, 4 (2013): 1–28.
- 51 Porterfield, Shirley L., and Jin Huang. “Health Insurance and Access to Care among Young Adults with Disabilities: Impacts of the Affordable Care Act.” Paper presented at the 10th World Congress of the International Health Economics Association, Dublin, UK, 2014.
- 52 Saloner, Brendan, and Benjamin Lê Cook. “An ACA Provision Increased Treatment for Young Adults with Possible Mental Illnesses Relative to Comparison Group.” *Health Affairs* 33, 8 (2014): 1425–34.
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- 55 Mulcahy, Andrew, Katherine Harris, Kenneth Finegold, Arthur Kellermann, Laurel Edelman, and Benjamin D. Sommers. “Insurance Coverage of Emergency Care for Young Adults under Health Reform.” *New England Journal of Medicine* 368, 22 (2013): 2105–12.
- 56 Scott, John W., Benjamin D. Sommers, Thomas C. Tsai, Kirstin W. Scott, Aaron L. Schwartz, and Zirui Song. “Dependent Coverage Provision Led to Uneven Insurance Gains and Unchanged Mortality Rates in Young Adult Trauma Patients.” *Health Affairs* 34, 1 (2015): 125–33.
- 57 Barbaresco, Silvia, Charles J. Courtemanche, and Yanling Qi. “Impacts of the Affordable Care Act Dependent Coverage Provision on Health-Related Outcomes of Young Adults.” NBER Working Paper No. 20148, National Bureau of Economic Research, Boston, MA, 2014.
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- 62 O'Hara, Brett, and Matthew W. Brault. "The Disparate Impact of the ACA-Dependent Expansion across Population Subgroups." *Health Services Research* 48, 5 (2013): 1581–92.
- 63 Sommers, Benjamin D., and Richard Kronick. "The Affordable Care Act and Insurance Coverage for Young Adults." *Journal of the American Medical Association* 307, 9 (2012): 913–14.
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- 65 Mulcahy, Andrew, Katherine Harris, Kenneth Finegold, Arthur Kellermann, Laurel Edelman, and Benjamin D. Sommers. "Insurance Coverage of Emergency Care for Young Adults under Health Reform." *New England Journal of Medicine* 368, 22 (2013): 2105–12.
- 66 Scott, John W., Benjamin D. Sommers, Thomas C. Tsai, Kirstin W. Scott, Aaron L. Schwartz, and Zirui Song. "Dependent Coverage Provision Led to Uneven Insurance Gains and Unchanged Mortality Rates in Young Adult Trauma Patients." *Health Affairs* 34, 1 (2015): 125–33.
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- 68 Specifically, because of the provision, young adults as a whole were more likely to have a primary care doctor and less likely to forgo medical care because of costs. See Barbaresco, Silvia, Charles J. Courtemanche, and Yanling Qi. "Impacts of the Affordable Care Act Dependent Coverage Provision on Health-Related Outcomes of Young Adults." NBER Working Paper No. 20148, National Bureau of Economic Research, Boston, MA, 2014. General hospital visits increased by 3.5 percent, with mental health–related visits increasing by 9.0 percent. See Antwi, Yaa Akosa, Asako S. Moriya, and Kosali Simon. "Access to Health Insurance and the Use of Inpatient Medical Care: Evidence from the Affordable Care Act Young Adult Mandate." NBER Working Paper No. 20202, National Bureau of Economic Research, Boston, MA, 2014. There is also evidence that affordability of health care improved. Busch, Golberstein, and Meara examined large out-of-pocket expenses, defined as yearly expenses exceeding \$500 or \$1,500, and found that annual expenses exceeding \$1,500 declined by 2.4 percentage points. See Busch, Susan H., Ezra Golberstein, and Ellen Meara. "ACA Dependent Coverage Provision Reduced High Out-of-Pocket Health Care Spending for Young Adults." *Health Affairs* 33, 8 (2014): 1361–66. Only one study, by Kotagal et al., did not find evidence of greater access to health care (in terms of physician visits or self-reported affordability of prescription medication) because of the provision. See Kotagal, Meera, Adam C. Carle, Larry G. Kessler, and David R. Flum. "Limited Impact on Health and Access to Care for 19- to 25-Year-Olds Following the Patient Protection and Affordable Care Act." *JAMA Pediatrics* 168, 11 (2014): 1023–29.
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- 72 Antwi, Yaa Akosa, Asako S. Moriya, and Kosali Simon. "Effects of Federal Policy to Insure Young Adults: Evidence from the 2010 Affordable Care Act's Dependent-Coverage Mandate." *American Economic Journal: Economic Policy* 5, 4 (2013): 1–28.
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- 76 Blumberg, Linda J., John Holahan, Genevieve M. Kenney, Matthew Buettgens, Nathaniel Anderson, Hannah Recht, and Stephen Zuckerman. "Measuring Marketplace Enrollment Relative to Enrollment Projections: Update." Health Policy Center policy brief. Washington, DC: The Urban Institute, 2014.
- 77 Blumberg, Linda J., John Holahan, Genevieve M. Kenney, Matthew Buettgens, Nathaniel Anderson, Hannah Recht, and Stephen Zuckerman. "Measuring Marketplace Enrollment Relative to Enrollment Projections: Update." Health Policy Center policy brief. Washington, DC: The Urban Institute, 2014.
- 78 See Kaiser Family Foundation. "Section 1915(k) Community First Choice State Plan Option." Accessed September 10, 2015. <http://kff.org/medicaid/state-indicator/section-1915k-community-first-choice-state-plan-option/>.
- 79 See Kaiser Family Foundation. "Financial and/or Administrative Alignment Demonstrations for Dual Eligible Individuals (or 'Duals Demonstrations')." Accessed September 10, 2015. <http://kff.org/health-reform/state-indicator/financial-andor-administrative-alignment-demonstrations-for-dual-eligible-individuals-or-duals-demonstrations-2/>.
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- 81 Garfield, Rachel, Anthony Damico, Jessica Stephens, and Saman Rouhani. "The Coverage Gap: Uninsured Poor Adults in States That Do Not Expand Medicaid—An Update." Issue brief, Kaiser Family Foundation, 2015.
- 82 "Guaranteed issue" and "community rating" refer respectively to prohibitions against denying coverage and varying premiums on the basis of consumers' health status.
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- 85 CMS SPA approval letters were referred to for the following states: Arkansas, California, Delaware, Michigan, New Mexico, and West Virginia.
- 86 For Appendix Table 2, these states are Arizona, Colorado, the District of Columbia, Hawaii, and Kansas. In Appendix Table 3, these states are Arizona, Arkansas, California, the District of Columbia, and Rhode Island. In Appendix Table 4, these states are Connecticut, the District of Columbia, Kansas, Michigan, Rhode Island, and Washington.
- 87 So-called grandfathered plans are exempt from meeting EHB requirements. Such plans have not made any significant changes to their benefits or out-of-pocket cost-sharing rules since the ACA's enactment.
- 88 HealthCare.gov. "Habilitative/Habilitation Services." Accessed September 10, 2015. <https://www.healthcare.gov/glossary/habilitative-habilitation-services/>.
- 89 In states that have separate limits for habilitative and rehabilitative services, the total number of visits for habilitative and rehabilitative services combined is significantly greater than the combined total in states that retain a combined limit. This may result from state policymakers' or insurers' resistance to drastically decrease the total number of visits available for rehabilitation, compared to pre-ACA coverage. For example, suppose a state's benchmark plan covers 40 rehabilitation visits but not habilitative services. Under current regulations, separate rather than combined limits apply to habilitative and rehabilitative services, and habilitative services must be comparable to coverage of rehabilitation. If that state wishes to retain the previous 40-visit coverage of rehabilitation, it will need to cover 40 visits for habilitative services as well.
- 90 The category in which autism services is listed can affect the total amount of coverage available. If autism services are listed separately from habilitative services, they are not subject to caps on habilitative services, a situation which increases the total volume of covered visits. On the other hand, if autism coverage has a separate cap that is more stringent than the cap for all habilitation services, some people with autism may be denied necessary care if autism services are treated as a separate category of coverage.

- 91 The Center for Consumer Information & Insurance Oversight (CCIIO). "Information on Essential Health Benefits (EHB) Benchmark Plans." Centers for Medicare and Medicaid. Accessed September 10, 2015. www.cms.gov/CCIIO/Resources/Data-Resources/ehb.html; and Centers for Disease Control and Prevention (CDC). "The National Health Interview Survey Early Release Program." <http://www.cdc.gov/nchs/nhis/releases.htm>.
- 92 HealthCare.gov. "Rehabilitative/Rehabilitation Services." Accessed September 10, 2015. www.healthcare.gov/glossary/rehabilitative-rehabilitation-services/.
- 93 The first phase of cardiac or pulmonary rehabilitation is an inpatient program that includes analysis of daily functioning and postoperative education; the second phase transitions the patient from hospital to home and includes the development of a light aerobic exercise plan; and the third phase is an outpatient program that includes a more robust exercise program and long-term preventative goal setting.
- 94 Livermore, Gina, Denise Whalen, Sarah Prenovitz, Raina Aggarwal, and Maura Bardos. "Disability Data in National Surveys." Report for the US Department of Health and Human Services, Office of Disability, Aging, and Long-Term Care Policy, Mathematica Policy Research, Washington, DC, 2011.
- 95 See US Census Bureau's 2014 Release Schedule at www.census.gov/programs-surveys/acs/news/data-releases/2014/release-schedule.html for the 2014 ACS schedule. The 2014 Current Population Survey Annual Social and Economic Supplement Research Files, which are based on the 2013 survey, was released on January 13, 2015. See www.census.gov/newsroom/press-releases/2015/cb15-tps04.html.
- 96 Marlay, Matthew. "Introducing the New Survey of Income and Program Participation (SIPP)." Presentation to the 2015 annual meeting of the Population Association of America, San Diego, CA. 2015. The Panel Study for Income Dynamics also contains information about health insurance coverage and disability but is only conducted every other year, with the next wave being for 2015. http://www.census.gov/content/dam/Census/programs-surveys/sipp/about/SIPP_Health_Insurance_Brochure_APPROVED.pdf?cssp=SERP.
- 97 See Centers for Disease Control and Prevention (CDC), 2015, "Disability and Health—Key Findings: Persons with Disabilities as an Unrecognized Health Disparity Population." Last modified March 31, 2015. www.cdc.gov/ncbddd/disabilityandhealth/features/unrecognizedpopulation.html
- 98 Krahn, Gloria L., Deborah Klein Walker, and Rosaly Correa-De-Araujo. "Persons with Disabilities as an Unrecognized Health Disparity Population." *American Journal of Public Health*, 105, S2 (2015): S198–S206.
- 99 If available, administrative records from states (e.g., on Medicaid backlogs) might also shed light on some of these questions, as could survey data showing different outcomes for states pursuing different policies.



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