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In 2008, the year Barack Obama was elected President, the number of people in the United States without health insurance was 46.3 million.\textsuperscript{1} This number had been growing annually and there was no evidence that the trajectory would or could reverse. Estimates suggest that individuals without insurance or without enough coverage, received $57.4 billion of uncompensated care in that year.\textsuperscript{2} President Obama decided that comprehensive health reform legislation had to be a top priority of his administration. The Affordable Care Act (ACA) will most likely be his primary domestic legacy.
How to make the American health care system work better and ensure that the costs of health care did not bankrupt a family are not new queries. As long ago as 1912, Theodore “Teddy” Roosevelt campaigned on a platform of a national health insurance.\(^3\) It was his belief that no country could remain strong if the citizens were sick and poor. Since there had been so little medical professionals could do for patients, medical fees were not astronomical and the push was not strong enough to trigger action.

In 1929, Baylor Hospital in Dallas, Texas, offered Dallas teachers the opportunity to have insurance that would cover 21 days of hospitalization per year for only 50 cents per month. This seed eventually grew into Blue Cross. A group of doctors, economists, and hospital administrators spent five years working on the independent Committee on the Costs of Medical Care, and in 1932, published a report recommending health care should be available to all.\(^4\)

The impact of the Great Depression sparked President Franklin D. Roosevelt to begin the push for Social Security and he wanted it to include a national health insurance approach. In 1935, this social insurance program was signed into law, but national health insurance was not included and Mr. Roosevelt did not have further opportunity to advance that part of his agenda. As World War II expanded, President Roosevelt felt it necessary to establish wage and price controls as part of an emergency response. Since employers could not increase wages, they could “sweeten the pot” for their employees with added benefits, such as health insurance. This evolved into a workplace perk and following the war, the Revenue Act of 1954 deemed employers’ contributions to employee health insurance to be tax-exempt income.\(^5\)

During the administration of President Lyndon B. Johnson, Medicare was established to address health insurance for people over age 65, since many were retired and no longer had the coverage of an employer.
sponsored plan. Medicare and Medicaid were amendments to the Social Security Act of 1935 and were signed into law on July 30, 1965, becoming Title XVIII and XIX of Public Law 89-97, respectively. It is interesting to note that in 1971, Senator Edward M. Kennedy (D-Mass.), sponsored legislation that would have created a payroll tax-funded national insurance plan. His efforts were countered by President Richard Nixon’s Comprehensive Health Care Plan of 1974. This proposal, which was based in the private insurance market, included an employer mandate, financial assistance for those who couldn’t afford the premiums, a ceiling on out-of-pocket expenses, and would have eliminated pre-existing conditions as a reason an insurance company could refuse to cover an individual. The plan included coverage of treatment for mental illness, alcoholism, and drug addiction. President Nixon’s efforts to overhaul the health care system were derailed not only due to political and personal scandal but also an ideological divide that may have foreshadowed the more recent battle to pass the ACA.

President William J. Clinton, early in his first term, began looking for a way to reduce the rising number of uninsured Americans. In 1993, President Clinton and First Lady Hillary Clinton led the charge to develop a proposal for universal coverage that included an employer mandate and an individual mandate. Congress was divided on the approach and the plan never came to a vote in either the House or Senate, though the volume of the fervor showed deeply held opinions on all sides.

Through the last years of the George W. Bush administration, there were a number of hearings in both the House and Senate on the issue of people without insurance and health care access. During this time, there was no major push to pass comprehensive health care reform.

President Obama chose a different path to address health reform. Early in his administration, he laid out broad principles that any health reform law should address and left the writing of legislation to Congress. The House passed a reform bill, H.R. 3962, the Affordable Health Care for America Act in November 2009. That bill was sent to the Senate for consideration but was never assigned to Senate committees. Independent of the House-passed bill, two Senate committees, the Health, Education, Labor and Pensions (HELP) and the Finance Committee, began working on differing approaches to the issue. Senator Edward Kennedy, Chair of the HELP Committee and his staff, provided the drive and expertise that ultimately resulted in the Patient Protection and Affordable Care Act, H.R. 3590, the bill which passed the Senate on December 24, 2009.

The House debated the Patient Protection and Affordable Care Act but recognized that if it was amended, the bill would have to return to the Senate. Due to Senator Kennedy’s death and his successor, Senator Scott Brown, being Republican, that body no longer had the necessary 60 Democratic votes for cloture or passage. After a series of discussions, compromises, and Executive Order 13535, pertaining to federal funding for abortion, the House did pass H.R. 3590, so there was no need for a House-Senate conference. However, the House also passed a new piece of legislation, H.R. 4872, The Health Care and Education Reconciliation Act to “amend” the Senate bill. Subsequently, the Senate passed this bill as well.

President Obama signed H.R. 3590, the Patient Protection and Affordable Care Act into Public Law 111-148 on March 23, 2010. He signed H.R. 4872, the Health Care and Education Reconciliation Act, Public Law 111-152 on March 30, 2010. These two bills together are now informally known as the Affordable Care Act (ACA).
The ACA triggered the largest overhaul of the American health care system since Medicare and Medicaid were put into place in 1965. These changes include:

- the requirement that everyone have health insurance or pay a penalty (individual mandate),
- the requirement that employers of over 50 workers provide insurance coverage to all full time employees or pay a penalty (employer mandate),
- the provision of a subsidy to help cover the cost of premiums for certain individuals purchasing insurance,
- the expansion of Medicaid to those under 133 percent of poverty (a Supreme Court decision later gave states the choice of whether to expand Medicaid),
- the creation of a marketplace where insurance plans can be monitored, compared and purchased,
- the requirement that insurance companies cover everyone with minimum health benefits,
- the prohibition of denial of coverage on the basis of a preexisting condition, and
- the prohibition of coverage decisions and rate differentials based on health condition or gender.

The ACA required each state to create an insurance exchange or marketplace where an individual could purchase a federally qualified insurance plan (QHP) which includes a package of essential benefits, and have access to the federal subsidies to relieve the financial burden. By January 2016, four different kinds of marketplaces had evolved:

- a state-based marketplace,
- a federally-facilitated marketplace,
- a state-federal partnership (state does in-person consumer activities and other functions but most functions are managed by HHS), and
- a federally-supported marketplace (state runs marketplace but technology platform is federal).\textsuperscript{14}

The essential health benefits (EHB) are the categories of services or the 10 “buckets” of benefits that must be included in any insurance plan:

1. ambulatory, outpatient patient services;
2. inpatient hospital services;
3. maternity and newborn care;
4. emergency care;
5. prescription drugs;
6. mental health and substance use disorder services, including behavioral health services;
7. rehabilitative and habilitative services and devices;
8. laboratory services;
9. preventive and wellness services; and
10. pediatric care including dental and vision coverage.

The ACA directed the U.S. Department of Health and Human Services (HHS) to define the specific elements of the EHBs. HHS asked each state to choose a base or “benchmark” plan as a place to start those definitions for that state. A state could choose from four types of plans for the benchmark:\textsuperscript{15}
one of the state’s three largest state employee plans,

one of the three largest plans, by enrollment, in the state’s small-group market,

the state’s largest non-Medicaid HMO, or

one of the three largest Federal Employees Health Benefit Program options.

Half of the states simply did not choose a benchmark plan. HHS then determined that the default would be the largest small-group plan in the state. Not surprisingly, 45 out of 50 states ended up with a small-group plan as their benchmark. States had an incentive to utilize one of the small-group plans because these plans already incorporated the state’s mandated services. If the state’s mandates were less than what was required by the federal EHB, the state should add to the necessary benefits in the benchmark to be sure those EHB requirements were met. If the state’s mandates were adopted after January 1, 2012, and were more than what is required in the EHB package, the state would have to defray the costs of those required services over the level set in the federal package. Any discussion of essential health benefits is affected by this tension between coverage and cost.

From 2014–2016, the EHBs have been an amalgam of each state’s mandates that were in place as of December 2011 and the benchmark the state chose for the default. This process has led to a wide range
of benefit packages across the country, differing in amount, duration and scope of benefits for certain services. All the EHB packages include the 10 broad categories listed above, but they also may contain a variety and range of state mandates which results in packages that differ from state-to-state. States were given the opportunity to select a different benchmark for the year of 2017 by the deadline of June 1, 2015. The choice was made among the plans available in the state during 2014.

The ACA also created four levels or kinds of plans that can be sold in the marketplaces, referred to as the “metal” levels—bronze, silver, gold and platinum. In all of these plans, the essential health benefits must be offered. These levels were designed to help individuals know what the actuarial value of the plan is (how much the insurance plan would cover) and how much of the costs would be an individual’s responsibility. This calculation takes into account the plan’s monthly premium, deductible, copayments, coinsurance and out-of-pocket maximum. The four levels are:

- **bronze**—the health plan pays about 60 percent of the costs and the individual pays about 40 percent,
- **silver**—the health plan pays about 70 percent of the costs and the individual pays about 30 percent,
- **gold**—the health plan pays about 80 percent of the costs and the individual pays about 20 percent, and
- **platinum**—the health plan pays about 90 percent of the costs and the individual pays about 10 percent.

The differences are predominately in the size of monthly premiums and the expectation of the amount of out-of-pocket expenses. The higher the metal tier, the higher the premium is likely to be. Federal assistance for premiums is based on the second lowest silver plan available and the cost sharing support is only available for the purchase of silver plans.

In all of these plans, the essential health benefits must be offered.
Question—Are people getting the benefits expected?

When states opened their marketplaces on October 1, 2014, many details including the definition of what specific services would be included in certain benefits had not been completed. In 2013, only 2 percent of individual insurance plans were providing coverage for all 10 of the essential health benefit “buckets”. Eighteen percent of the plans did not have a prescription drug benefit, 15 percent did not include rehabilitative and habilitative services, 39 percent did not cover mental health treatment and 46 percent of the plans did not cover substance abuse services. The ensuing years have provided some insight into the variations from state-to-state, but there is not clarity on the definitions of benefits and what specific services are covered.

For many citizens, the ACA enabled them to purchase coverage for the first time. In the past, health insurance was either too expensive, did not include the benefits that were needed to manage the individual’s health, or unavailable because of a pre-existing condition. Even with the explicit 10 buckets of essential health benefits, it is not yet confirmed that individuals can access the coverage they need. As a leading non-profit provider of services for individuals of all ages with autism, developmental disabilities, physical and mental disabilities, and other special needs, Easterseals believes that how the benefits actually play out needs to be explored. Thus, we have strived to understand how the ACA is playing out in the lives of real people.

We focused our efforts on four key areas—prescription drugs, mental health services, behavioral health services, and rehabilitative and habilitative services.

- **Prescription Drugs:** According to the CDC, in a compilation of trends entitled *Health, United States, 2014*, between the years 2009 and 2012, nearly half (48.7 percent) of the people surveyed had taken a prescription drug in the last 30 days. Those numbers imply that the structure of pharmaceutical coverage in insurance plans and the appeals process has a profound effect on access and adherence. It is essential that a consumer know what drugs are covered, what the out-of-pocket costs may be and whether prior authorization or step therapy is required before a medicine will be covered.

- **Mental Health Services:** Approximately one in five adults experiences mental illness in any given year, according to the National Institute of Mental Health. Depression is estimated to cause 200 million lost workdays each year and may cost employers between $17 million and $44 million. The practical definition and application of what is meant by “mental health services” and how that manifests in different benchmark plans in different states will help us lay the ground work to determine if the needs of the patients are being met. This may assist people with disabilities and their advocates to ensure that children and adults can access appropriate treatments, medicines and other supports.
Behavioral Health Services: As one example of behavioral health needs, CDC published a study in 2010 on the prevalence of autism spectrum disorder (ASD) in children eight years of age. In the selected 11 communities, they reported that 1 child out of 68 had been diagnosed with autism. The kind of services that would be available to a child with this diagnosis would fall into this category. This need has been identified by 34 states plus the District of Columbia that have insurance laws that preceded the ACA, establishing specific benefits for people with autism. Examining the experience of individuals will help clarify the definition of this category, and how this constellation of services interacts with the EHB requirements will illuminate what is available to an individual in need of this care.

Rehabilitative and Habilitative Services:
- Rehabilitative services have been historically offered by many insurance plans. These benefits help an individual retain or learn a skill again. Examples are physical therapy following a broken leg or speech therapy following a stroke. According to the CDC, 34 percent of those hospitalized for stroke in 2009 were under age 65.
- Habilitative services, especially for children with developmental disabilities, are key to learning a skill for the first time. In 2008, nearly one in seven children experienced a physical or mental health condition that led to some level of developmental disability. These efforts can make the difference between a dependent and an independent life. These services may include assisting a child with cerebral palsy learn to walk. The lack of specificity about such services in each state’s plan led to deep variation in the quality and ability of services to help an individual learn new skills.

In 2008, nearly one in seven children experienced a physical or mental health condition that led to some level of developmental disability.
Literature Review

Following is a sample of studies regarding the marketplaces, how they work and if the care needed is available. While studies that cover all the areas of experience focused on in this project were not located, efforts around any one of the buckets still provide insight as to how the marketplaces, the EHBs, and real life interact. This is by no means an exhaustive list, but may provide a snapshot of how this change has unfolded in the just over two years the EHBs have defined marketplace policies and the diversity of the research available.

Prescription Drugs

- Supporting Informed Decision-Making in the Health Insurance Marketplace: A Progress Report, National Partnership for Women & Families, February 10, 2015. This analysis was designed to review the Federally-facilitated Marketplace and all 14 state-based marketplaces during the second open enrollment period and provide a status update for how well their websites were helping consumers make informed choices about their health plans. The report provided insight into several elements of the plan choice process, and touched specifically on the tools available to consumers to compare plans based on prescription drug coverage. Of note, the report highlighted the Colorado marketplace website’s integrated prescription drug directory which allows consumers to quickly and easily compare plans depending on whether their drugs are covered or not. During the open enrollment period for 2015 plans, Colorado was the only state with such a tool.

- Impact of the Health Insurance Marketplace on Participant Cost Sharing for Pharmacy Benefits, Milliman, Inc. for PhRMA, May 13, 2014. This analysis looked at the differences between health care benefit designs offered in the exchanges and health care benefit designs in typical employer-sponsored plans. The study confirmed that overall cost sharing is 38 percent higher in the Silver exchange plans than in the employer-sponsored plans due to the lower actuarial value of the exchange plans. It also supported the premise that a combined deductible (medical and pharmacy together) will impose higher member cost sharing for the pharmacy benefit than an employer plan. The study found that cost sharing for prescription drugs was 130 percent higher in silver exchange plans with a combined deductible as compared to employer plans. This study was not designed to look at the effect of higher cost sharing on compliance.

- Cancer Drug Coverage and Transparency in Health Insurance Marketplace Plans, American Cancer Society Cancer Action Network (ACS CAN), November 2015. This analysis looked at the coverage of cancer drugs in the marketplaces of six states. The study reported that cancer drugs are covered by the vast majority of plans in the marketplace, but the links to the formularies are not always correct or updated. Information about coverage of intravenous drugs remains obscure.
and many cancer drugs, including generics, were on the highest cost-sharing tier. Coinsurance (a percentage of the cost), rather than copayments (a flat fee) is used in between 73 and 100 percent of the plans examined. Accessing this type of information will allow a consumer to make the best choice for their circumstances.

**Mental Health and Behavioral Health Services**

- **A Tale of Two States: Do Consumer See Mental Health Insurance Parity When Shopping on State Exchanges?** K. Berry, H. Huskamp, H. Goldman, C. Barry, *Psychiatric Services*, Vol. 66, No. 6, June 1, 2015. This study looked at the mental health benefits in two state-based exchanges during the first open enrollment period to determine whether the benefits met the requirements for mental health parity. The analysis focused on the information presented to consumers, since that is how people would choose a plan. This study found inconsistencies between plans. Some consistency existed on the use of prior authorization for some services. The study suggested that monitoring the exchanges for whether they meet the parity requirements will continue to be necessary and beneficial to assure fair and efficient operation of the insurance markets.

- **Comparison of Benefits and Cost Sharing in Children’s Health Insurance Programs (CHIP) to Qualified Health Program**, A. Bly, J. Lerche, K. Rustagi, Wakely Consulting Group, July 2014. This comparison looked at the benefits available in a wide range of categories, including autism and applied behavioral analysis (ABA) across states and the children's health insurance program (CHIP) vs. the exchange programs. It concluded that the differing range of coverage, duration and costs supports the need to be wary about generalizing from state to state when discussing the effectiveness of coverage.

**Rehabilitative and Habilitative Services**

- **Analysis of Rehabilitation and Habilitation Benefits in Qualified Health Plans**, prepared by the American Occupational Therapy Association, October 2014. This study looked at the silver plan’s Statement of Benefits and Coverage for each carrier selling in five states. It concluded that consumers did not have access to adequate information about rehabilitative and habilitative benefits to make informed choices. It also raised concerns about whether states were complying with EHB standards for coverage under this benefit category.

- **Quality Health Care for Children and the Affordable Care Act: A Voltage Drop Checklist**, Cheng, P. Wise, N. Halfon, *Pediatrics*, October 2014, Vol. 134, Issue 4. This analysis looked at the elements of differing benchmarks and created an organizing tool and state checklist to help compare what is available in a select state. The authors presented the checklist to support the premise that having insurance coverage is necessary to good quality care, but is not the only factor necessary to accomplish the goal. Other factors include enrollment in insurance, the services and providers covered, consistent presence of primary care, and an informed choice of plans, clinicians and institutions covered.

These and other studies point to the difficulty in drawing conclusions either from one state to another or from one category of benefits to another. The impact of the numerous factors involved in each state's history of insurance regulation paired with the requirements of the ACA creates unique circumstances and the need for good presentation of information on a state-by-state, plan-by-plan, benefit-by-benefit basis. When looking at the quality of any given state's exchange and essential health benefits package, generalization or extrapolation from one state to another is not possible.
The Project

Easterseals wanted to explore the practical implementation of the ACA. The goal of this project is to gather information about the experience of those who have purchased insurance through the marketplace, in a subset of states, with the focus on three selected "buckets" of the EHB package which are

- prescription benefits,
- mental health and behavioral health services, and
- rehabilitative and habilitative services.

States Selected

Six states were chosen on which to focus. These states were home to Easterseals affiliates that provided health services. We also wanted states that used different models for administering its marketplace. The states selected to be part of this project were

- Connecticut—state-based marketplace;
- Florida—federally-facilitated marketplace;
- Indiana—federally-facilitated marketplace;
- Iowa—state-federal partnership marketplace;
- Michigan—state-federal partnership marketplace; and
- Texas—federally-facilitated marketplace.

The Survey

An online survey tool was used to gather this information (Index A). The survey was sent out on two occasions, first during the month of August 2015 and then again during November 2015. The survey took 15 minutes or less to fill out and had space for individual comments (Index B).

The survey was disseminated with the assistance of the Chief Executive Officers (CEOs) of the Easterseals affiliates (Index C). They were asked to identify groups including people who had purchased their insurance through the exchanges and share the questionnaire. This could include client lists, community organizations, coalitions, church membership lists, Scout groups, the YMCA, neighborhood lists, or recreational teams. One affiliate suggested board members forward the survey through lists to which they have access. The request was also made that the survey be placed on affiliate Facebook pages and/or websites, shared in newsletters, and in blog postings. Another suggestion was to encourage any individual who filled out the survey to feel free to forward it on to others.

In order to expand the circle that might include eligible individuals for this study, a number of national organizations were engaged in discussions about the issues at hand. Discussions with the advocates from these groups helped clarify what information might be beneficial and in which benefits they were interested in finding out more about usage. These groups were asked to disseminate the survey through their channels in the selected states as appropriate. Groups posted the survey on their website, sent it out through their local chapter leaders and used their mailing lists. A list of these supportive organizations is included in this report (Index D).
Findings

Overview

It was difficult to obtain a high response rate. This survey garnered 304 responses. The survey did, however, provide new information about how individuals view their experience in the exchanges (Index E). It is important to note that approximately half of the respondents purchased insurance through the marketplace. It is positive news that as of January 31, 2016, the end of the most recent open enrollment period, HHS reports that 12.7 million people had purchased insurance plans or re-enrolled in their plan through the exchanges in all 50 states and the District of Columbia. The exchanges continue to be viable sources of purchasing insurance nationwide.

Because the sample did not come evenly from the six states targeted, comparing the state-run, federally-facilitated, and state-federal partnership types of exchanges is difficult. Strong showings come from Florida and Texas which were federally-facilitated marketplaces, as well as Connecticut which is a state-based marketplace. There were not enough responses to draw conclusions about the impact of the type of administration of the marketplace on the experience of the customers from Iowa and Michigan, the two state-federal partnership exchanges. We can conclude, however, that the EHBs, even after they are filtered through different state benchmarks, different administration models and different definitions, fall within a range that is more alike than not alike.

If information from this survey or a similar effort, is to be used further, it will be important to capture more respondents to provide more data. For example, the respondents did not offer much about the experience of their children and the insurance plans sold in the exchanges, which, particularly in the arena of behavioral therapies, would have been a group that may have provided insight into the impact of early intervention, obstacles to getting care and the range of services available in exchange plans.

The population of families that have children receiving mental health, behavioral health, or habilitative services may need to be accessed through a different dissemination tool. An increased number of responses would have provided a clearer sense of their experience.

The following questions and responses from those who had purchased insurance coverage in an exchange in one of the six selected states.

Q: Do you qualify for federal tax credits/subsidies to help cover the cost of the premiums for this plan?

Well more than half (65 percent) of the respondents qualified for the financial support available. The subsidy is available to an individual or family with an income between 100 percent and 400 percent of the poverty line. The federal poverty line in 2015 was $11,770 for an individual and $24,250 for a family of four. Determining whether the subsidy or tax credit was utilized to purchase a plan in the marketplace was to learn something about the income level of those responding and if their experiences differed. Even though the responses were pretty evenly split between those receiving a subsidy and those paying the full premium to purchase a plan, that factor did not appear to influence other experiences in the process. Once the insurance has been obtained, the experience seems less affected by the financial details and more likely to be judged by the responsiveness of the plan to the needs of the individual or family member.

One comment that references that subsidy structure was My husband is a full time student at a local university and I make $38,000 per year at a non-profit. Insurance through work is prohibitively expensive for my spouse so we bought his on the exchange. For a 27 year old healthy man...we pay $150 per month. I believe the Affordable Care Act to be a helpful step in the right direction.
Q: Overall, how satisfied are you with the care and services available through this insurance product?

The responses on satisfaction were pretty well evenly split across the range of options on a scale of 1-5 with “1” being “very dissatisfied” and “5” being “very satisfied”. The questionnaire sought to get a sense of whether the “customers” of the marketplace were satisfied with their overall experience. Given the diversity of people and their circumstances, the different types of state benchmarks, the range of levels of plans (bronze, silver, gold, platinum), it is not a surprise that the level of satisfaction was also wide-ranging. There was a slightly higher number of respondents on the “very dissatisfied” end of the scale (26), responses in each category were pretty evenly distributed after the weakest response in the “very satisfied” category (10). There were 22 responses in the “satisfied” category, 27 in the “neutral” range and 22 in the “dissatisfied” group.

These two responses from Florida show the range of opinions.

I’ve had no problem. As a small business owner with a pre-existing condition, I’m very thankful for it.

And Cost are extremely high for our income level which means that even with the amount that is subsidized it is more than we can afford and we have a high deductible plan. My family only uses the preventive services but pay far more than a family with no health issues should pay.

Pharmacy Benefit Section

Q: Have adults in your family used the pharmacy benefit through this plan?

Q: Have your children used the pharmacy benefit through this plan?

Of the respondents, nearly two-thirds had experience with the pharmaceutical benefit, but only a small number had accessed this benefit for their children, so the following information is primarily reporting the experience of an insurance plan for an adult.

Q: Were you able to access information about specific pharmaceuticals, including the prior authorization process, estimated costs and tiering information before the health insurance was purchased?

Q: Was this information available after enrollment?

Just less than half (46 percent) of the respondents reported that they were able to access information about coverage of specific drugs and also the cost sharing and utilization management required for specific medicines. There has been concerns raised as to whether people shopping for insurance in the marketplace were able to evaluate alternative plans on such characteristics as pharmaceuticals covered (formulary), cost sharing, and process (e.g. prior authorization and tiering). For those that responded to the survey, it broke about even as to whether the potential customers were able to locate this information prior to purchase.

It is interesting to note that after the purchase, there was a great improvement on this front and the majority of individuals (78 percent) reported being able to find the information after signing up. It cannot be known from this survey whether this is an issue of the presentation of the plan or the perspective of the applicant.

A comment from one of the respondents in Texas makes this clear. The response to your question about pharmaceuticals should not be a simple “yes” or “no” as it is more complicated than that. There are plan specific limitations that are not clearly explained prior to enrollment and it is often very difficult to tell what is covered and not covered.

Or this comment from a Florida participant in the survey: Not happy with the drug portion, as I went to get a certain prescription filled for my fibromyalgia, the plan would not cover it unless I tried a different medication first.... Should not be this way!
Q: Has your health care provider suggested/prescribed specific drugs/medicine that are not covered in your health plan?

Just less than half of the respondents had experienced their provider having prescribed a drug that was not covered by the formulary of a given insurance plan. While 46 percent of the individuals had been faced with the coverage issue, only one-third of the respondents knew that there was an appeals process for access to a specific pharmaceutical.

Prior to the passage of the ACA, the ability to appeal decisions made by an insurance plan could vary from state-to-state, by the type of insurance someone had and whether the plan was employer sponsored or purchased by the individual. With the advent of the ACA, a minimum level of appeal rights are guaranteed.

An appeal refers to challenging an insurance plan’s decision to deny an individual coverage for a benefit that is covered under the plan. That is, if a plan decides not to pay for a covered benefit or to reduce or end payment for a covered service.

An exception to a coverage decision is utilized when an individual requests coverage for a medicine that is not on the health plan’s formulary.

The final Notice of Benefits Payment Parameters (NBPP) rule for 2017 allows states to use their internal appeal/external review process for exceptions requests as long as that appeal process includes an internal review, an external review, the ability to expedite a review, and timeframes the same as or shorter than those under the exceptions process rules.37 Those timeframes are that determinations for standard exceptions requests must be provided with 72 hours following the receipt of a request or within 24 hours following the receipt of a request for an expedited review.

This would seem to point to the need for well written, understandable, and accessible information in the insurance plans about what benefits are covered and how to request an appeal or exception. People should be able to access the specific prescription drug that their provider has ordered, or be able to find instructions to seek either an exception or an appeal, if necessary, to access a particular pharmaceutical.

As one of the respondents from Florida explained it: We are not happy that prescriptions that the doctor has prescribed for my husband have been denied by the insurance company. They shouldn’t be telling the doctors what they can prescribe to their patients. I also don’t like that they will only pay for generic prescriptions. This is also a big problem.

Q: Was there copayment/coinsurance required to be able to get a prescription?

Q: Was there copayments/coinsurance that were so high that you could not fill the prescription?

Over 90 percent of those responding to the survey were required to pay a copayment or coinsurance to get prescriptions and about nearly half of them felt the added cost made it difficult for them to access the medication. The high cost sharing in the exchange plans raises concerns about adherence.

Mental Health Benefit Section

For the purposes of the questionnaire, the mental health benefit was defined as covered access to mental health professionals and substance use disorder treatments.

Q: Has an adult in your family used mental health benefits through this plan?

Q: Have your children used mental health benefits through this plan?

Of the respondents, about 20 percent had utilized the mental health benefits that are the focus of this section. The use of the benefit for children was 10 percent.
Q: Did your mental health provider suggest/prescribe more visits for you than the insurance plan covered?

Q: Did your mental health provider suggest/prescribe more visits for your child than the insurance plan covered?

Less than 20 percent of the respondents experienced the request of a provider for more visits than the insurance plan covered and only a very few confronted this in their children's experience.

Q: Has your mental health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?

About 20 percent of individuals who answered the question had specific therapies/services prescribed that were not covered by the plan.

Q: Was there copayment/coinsurance required for you to access this benefit under the plan?

Q: Was their copayment/coinsurance that was required to be paid to access this benefit for your child under the plan?

Approximately half of those who shared their experiences had to pay a copayment to access the mental health benefit for an adult and 25 percent reported a copayment required for mental health treatment for their children.

The experience of a participant in Texas was described as: *It was easy to sign up for, but the (for me) ‘affordable coverage plans’ had such high copayments and then there was no mention of mental health benefits anywhere online, but there was just one single page in the booklet that arrived a couple weeks later.*

Q: Did your behavioral health provider suggest/prescribe more visits for you than the insurance plan covered?

Q: Did your behavioral health provider suggest/prescribe more visits for your child than the insurance plan covered?

Q: Has your behavioral health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?

In this benefit category, about 12 percent had experience with a provider requesting more visits then the plan would cover for either adults or children. Less than 10 percent reported dealing with therapies that were not covered at all by the plan.

Behavioral Health Benefit Section

The definition of the behavioral health benefits for the purpose of this survey is access to professionals with a goal of changing behavior, examples would be treatment of autism or psychotherapy.

Q: Have adults in your family used behavioral health benefits through this plan?

Q: Have your children used behavioral health benefits through this plan?

About 10 percent of the respondents had accessed the behavioral health benefits through the plans purchased in the exchanges and of those who did, most were adults only a very small sample sought out these benefits for their children.

Q: Did your behavioral health provider suggest/prescribe more visits for you than the insurance plan covered?

Q: Did your behavioral health provider suggest/prescribe more visits for your child than the insurance plan covered?

Q: Has your behavioral health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?
Q: Was there copayments/coinsurance required for you to access this benefit under the plan?

Q: Was there copayments/coinsurance required to access this benefit for your child under the plan?

About half of the participants were required to pay a copayment to access behavioral benefits for adults, but less than 20 percent paid a copayment when the benefits were for children.

One of the comments from Florida reported, *Deductibles were too high or coverage not provided for services such as Applied Behavior Analysis (ABA).*

**Rehabilitative and Habilitative Services Section**

Rehabilitative services were defined as services to restore functional capacity, minimize limitations on physical and cognitive functions and maintain or prevent deterioration of functioning.

Habilitative services were defined as helping a person keep, learn, or improve skills and functioning for daily living; (e.g. physical therapy with a child that isn’t walking or speech therapy for a child). These services may include training of individuals with mental and physical disabilities to enhance functional development.

Q: Have adults in your family used rehabilitative or habilitative services through this plan?

Q: Have your children used rehabilitative or habilitative services through this plan?

Just less than one-third of the participants reported having paid a copayment to access this benefit and less than 10 percent had paid a copayment when the care was for their children.

One of the Michigan respondents described the experience as: *The plan was purchased to supplement Medicare because I have a chronic health condition that has disabled me, unfortunately the services I require are considered habilitative because of my condition…I have to pay, which averages $200–$500 per month. Not affordable for this benefit.*
Recommendations

1. **Advocates must monitor the impact of copayments and coinsurance to determine if they are a barrier to access.** Although it is not surprising, there was a negative response to copayments/coinsurance in the pharmaceutical arena and across other types of benefits. There was some acknowledgement that the cost is worth it for access to the benefit, but overall, there is concern that the cost of the copayments/coinsurance could be an obstacle to obtaining medication or a type of care.

2. **Plans must provide clear and accessible plan information that includes all formularies and costs.** The survey found there is a lack of information about an insurance plan before it was purchased, but reported the information was available after purchase had been made. The important thing here is that people are signing up for a plan that they may not be fully acquainted with, but seek more information after the purchase. Whether it is the estimated costs, prior authorization, the step-therapy requirements, just to name a few, we would like to suggest more work be done to assure that information is easily accessible and accurate. Efforts may be directed at the National Association of Insurance Commissioners as they look at options or state legislatures. In addition, continued oversight at the federal level of what is required in the presentation of plans is important. Positive changes are apparent, but there is still work to be done. An in-depth discussion of improving consumer choices is detailed in the Clear Choices white paper, providing structured and practical recommendations.

3. **Plans must provide clear and accessible information about the appeals process.** This recommendation surfaced clearly with the pharmacy benefit, but also applies to the mental health and behavioral health benefits and the rehabilitative and habilitative benefits. More information may be needed for individuals to be able to appeal a decision by an insurance plan or seek an exception to attain coverage of benefits not included in the plan. Whether this is for a prescribed drug, the number of visits to a mental health professional or the number of times the individual can see a physical therapist, there are processes to be followed to appeal or seek an exception to a coverage determination, but an individual must know those processes exist to take full advantage of what is allowed under the law. Good information about the right to talk with your insurance company if there is a discrepancy in what has been prescribed, or what is being covered and to appeal or seek an exception to that decision is very important.

4. **Consumers need more education about the essential health benefits package and its breadth of coverage.** The shift to an essential health benefits package in any individual or small group insurance product sold inside the exchanges, and outside, is still relatively new. This survey showed that few respondents having sought mental health or behavioral health benefits or rehabilitative or habilitative services for children. This raises the concern that some consumers may not realize that these benefits are not part of their insurance policy. A campaign to educate individuals buying in the exchange could include basic information about what should be in every plan, what can differ, where cost-sharing information is found, how the appeals process works. The ACA will require ongoing education of those who utilize the exchanges and a basic primer on what to look for in a plan might be a good place to start.
Opportunities for Action

A wide range of opportunities—or challenges—exist for modifications of the EHB package and the rules that define the plans and exchanges. Rules governing the EHB will have an influence over how well the benefits package meets the needs of exchange plan beneficiaries over time. The number of places for potential modification makes it imperative to track policy changes at the state and federal level, as well as other points of influence in the insurance market, to have a sense of what is the reality.

Congress

There is always the possibility of tweaking or altering the EHB package, either to improve the coverage of these buckets or to modify the structure of the benefits. Any type of alteration to the minimum essential requirements weakens the chances that the 10 essential health benefits remain intact. Of the benefits that this report focuses on, it is most likely that the prescription drugs benefit would remain available, but it seems that such benefits as behavioral and habilitative services, which struggle to be defined under the best circumstances, could be vulnerable to being weakened. A sampling of bills introduced in the 114th Congress that have the potential to change the EHB package include:

- S.254 (Small Business Health Relief Act of 2015) deems high deductible plans meet the essential health benefit requirements if the individual also has enrolled in a health savings account, and reduces the minimum benefit standard.
- S.1016 (Preserving Freedom and Choice in Health Care Act) repeals the need for individuals to have minimum essential coverage and gives states the jurisdiction to define essential health benefits. This bill would shift the requirement of defining a benefits package to the 50 states.
- S.1099/H.R.1624 (Protecting Affordable Coverage for Employees Act (PACE) Act of 2015) redefines employers with 51–100 employees as large employers and thereby eliminates the requirement for minimum essential coverage (the EHB package).
- H.R.1234 (Medical Freedom Act of 2015) repeals patient protections in ACA (e.g. lifetime and annual limits, prohibition of preexisting condition exclusions, guarantee of renewability). This bill would not only eliminate the minimum coverage, but would allow the exclusion of people with known illnesses from coverage.

Federal Agencies

Given the role that federal agencies play in the interpretation and implementation of the ACA, it is important to identify where policy decisions could be made. Tracking the rules process, the directives and guidance from the agency of jurisdiction would allow input or comments on proposed changes that may affect the minimum benefits package. A number of agencies have an impact on the ACA’s implementation. They include:

- HHS, Center for Consumer Insurance Information and Oversight (CCIIO): Oversees implementation of the ACA as it affects private health insurance and EHBs.
- HHS, Office of Civil Rights: Enforces the non-discrimination protections in Section 1557 of the ACA, which applies existing civil rights laws to federal health programs.
- Office of Management and Budget (OMB): Monitors and tracks the costs of benefits, exchanges, competition’s effect, focuses on figures and facts.
- Office of Personnel Management (OPM): Administers the Multistate Plans in the marketplaces, makes decisions about the mechanics and content of these plans. These plans are under contract with OPM and must meet state requirements for benefit packages where they are sold.
Federal Annual Reviews of EHB-related Plans, Regulations

The implementation of the ACA includes information and documents that are sent out annually and are updated each year before they are utilized. This creates an opportunity for input to reduce confusion and improve communication with insurance plans and marketplaces. These include:

- **Notice of Benefit and Payment Parameters:** Out in late fall each year, October-November, annual rule through which CMS sets out policy for the coming years.
- **Letter to Issuers:** Late December/January each year—CMS provides operational and technical guidance to issuers of insurance plans that seek to be Qualified Health Plans.

State Legislation

States have a varying amount of influence on the plans sold in their state exchanges, but for some states, that impact is profound, particularly those with a state-based or state-partnership exchange. An effort made by the state legislature to alter the make-up or structure of the benefit package can strongly influence what people get for coverage in that state. Here are some examples of state legislation that was debated but not adopted:

- **Connecticut**
  - CT S.811 (2015) affects the state exchange, requires easily readable format for a) clear list of covered drugs and coverage exclusions; b) restrictions on quantity of a covered benefit, including prescription drugs; c) description of how prescription drugs are included or excluded from deductible; d) dollar amount of copayment and percentage of coinsurance; e) information about pre-authorization or step therapy requirements.
  - CT S.24 (2015) requires the provision of certain information concerning health insurance policy benefits, and requires the insurance commissioner to evaluate insurers compliance with the ACA.

- **Florida**
  - FL S.784 (2015) The Right Medicine, Right Time Act, creates the Clinical Practices Review commission, requires a managed care plan that establishes a prescribed drug formulary or preferred drug list to provide a broad range of therapeutic options to the patient, and requires sufficient clinical evidence to support a proposed coverage limitation at the point of service.

- **Iowa**
  - IA H.349 (2016) prohibits a health carrier that offers coverage required by the ACA through the EHB package from using a plan benefit design that discriminates against an enrollee on specified bases, and provides that the commissioner of insurance may adopt rules to administer the provision.

- **Michigan**
  - MI S.354 (2015) requires insurers and HMOs to ensure timely diagnosis and treatment of autism spectrum disorder and require an adequate participating provider network.

- **Texas**
  - TX S.332 (2015) prohibits a health benefit plan issuer or pharmacy benefit manager from including a drug on a maximum allowable cost list unless the drug meets certain specification, and requires certain disclosures.
  - TX H.1621 (2015) provides a notice of adverse determinations by utilization review agents regarding the denial of prescription drugs or intravenous infusions must include an enrollee’s right to an immediate review and the procedures to obtain the review and a timetable for patient notification.
Other Points of Influence

Because states have historically had jurisdiction over most insurance products, there are non-governmental bodies that have influence on state agencies, legislatures and governors in the way an insurance market may be run. The National Association of Insurance Commissioners (NAIC) provides state guidance through the development of model laws and regulations of which each state has the option of selecting certain sections to adopt or adopting as a whole. For example, the Health Carrier Prescription Drug Benefit Management Model Act (# 22) provides guidelines for the establishment, maintenance and management of prescription drug formularies in plans sold at the state level. This model was developed in 2003 and has not been updated since the passage of the ACA. Model 22 has been open for updating, and the first round of comments were due January 22, 2016. The current focus of Model 22 is on transparency and accessibility of formulary information. If a revised version of this model law, or any subsequent model law, is adopted by the NAIC, it could directly and profoundly impact how subsequent rules that govern EHB’s are developed at the state and federal level.

Examples of Changes in the EHB Package that Have Been Made for the 2016 and 2017 Plan Years

Over the past several years, discussion with federal agencies about how to improve the EHB package have led to concrete changes in the way HHS views this collection of benefits. There are two very specific examples that relate to the benefits that are being focused on in this paper.

First, a uniform definition of habilitative services was included in the Notice of Benefit and Payment Parameters for 2016, final rule. While prior to 2014, plans were able to provide coverage of habilitative services similarly to rehabilitative benefits, concerns had been raised that this was an inadequate means of definition. To ensure adequate coverage and clarify the difference between habilitative and rehabilitative services, distinct language was included in the final rule. That language in the rule states that health plans must:

Cover health care services and devices that help a person keep, learn or improve skills and functioning for daily living (habilitative services). Examples include therapy for a child who is not walking or talking at the expected age. These services may include physical and occupational therapy, speech-language pathology and other services for people with disabilities.

If a state chooses to be more protective of an enrollee, they can go beyond these minimum standards, but they cannot do less and states cannot leave it to insurers to define habilitative services themselves. The rule goes on to require states to achieve parity between habilitative and rehabilitative services and in the 2017 plans, any limit set on these benefits cannot be combined and must be kept separate.

The second example is related to the prescription drug benefit requirements. Under current rules, an insurer’s drug list must cover the greater of at least one drug from each United States Pharmacopoeia (USP) class or category or the same number of drugs for each USP class as is covered by the state’s benchmark plan. Beginning in 2017, plans will also be required to establish pharmacy and therapeutics (P&T) committees, similar to those required under Medicare Part D, that will develop drug formularies. These committees have a prescribed membership by profession, rules about conflict of interest, meetings quarterly, requirement to document decisions and base inclusion or exclusion decisions on scientific evidence. It is the committee’s charge to review newly approved drugs and new uses of existing drugs within a set time limit to ensure availability of a broad range of drugs and to not discourage enrollment by any group of enrollees.
Conclusion

If there was a diagram of how and where changes could be made to the EHB packages in states, it would be fraught with colors, arrows and explanations. If there is anything to be taken away from this discussion, it may be that the EHB package is a piece of the health reform structure that has options for tweaking, at regulatory and business market levels, but that the package also provides the core that defines what having health insurance coverage means to the individual.

Advocacy organizations such as Easterseals will have a wide range of opportunities to work to modify the package to function better for individuals. In each state, in each plan, in each bucket of benefits there will be numerous actions that can be taken to improve or change the way the benefits work as more is learned about actual day-to-day experiences.

Promoting and providing information for people who are seeking to choose an insurance plan, or are trying to make a plan work for their family, will be integral to the success of improving the health of the larger population. The passage of this law is not enough and the information in this survey suggests that people could use more specifics of what is covered, what it will cost and what they should do if they are not getting what they need. The potential for better health care coverage is in the language of the ACA and all the strings that are tied to it to make it stand, but the way to judge a positive outcome will be if individuals who purchase insurance plans get what they need at a cost they can afford. Easily accessible, clear, concise and accurate information is one of the keys to fulfilling that potential.
Questionnaire—Essential Health Benefits Packages Purchased in Exchanges

**General Questions**

1. Have you purchased an insurance plan through either the federal or state exchange/marketplace in your state that was established through the Affordable Care Act?
   - Yes
   - No

2. In which state exchange did you purchase the insurance plan?
   - Connecticut
   - Iowa
   - Florida
   - Michigan
   - Indiana
   - Texas

3. Do you qualify for federal tax credits/subsidies to help cover the cost of the premiums for this plan?
   - Yes
   - No

4. Overall, how satisfied are you with the care and services available through this insurance product? (scale of 1-5, least—most)
   - 1
   - 2
   - 3
   - 4
   - 5

**Pharmacy Benefit/Formulary:** list of drugs covered by plan

5. Have adults in your family utilized the pharmacy benefit through this plan?
   - Yes
   - No

6. Have your children utilized the pharmacy benefit through this plan?
   - Yes
   - No

7. Was there information available about the formulary list, prior authorization process, estimated costs and tiering information before the health plan was purchased?
   - Yes
   - No

8. Was there information available about the formulary list, prior authorization process, estimated costs and tiering information after enrollment?
   - Yes
   - No

9. Has your health care provider suggested/prescribed specific drugs/medicine that were not in the formulary for the insurance plan?
   - Yes
   - No

10. Are you aware of an exceptions and appeals process for formulary concerns?
    - Yes
    - No

11. Was there copayment/coinsurance required to be able to get a prescription?
    - Yes
    - No

12. Was there copayment/coinsurance that was prohibitively high such that the cost prevented getting the prescription filled?
    - Yes
    - No
### Mental Health Benefits: covered access to mental health professionals, substance use disorder treatment

13. **Has an adult in your family utilized mental health benefits through this plan?**
   - Yes  
   - No  

14. **Have your children utilized mental health benefits through this plan?**
   - Yes  
   - No  

15. **Did your mental health provider suggest/prescribe more visits for you than the insurance plan covered?**
   - Yes  
   - No  

16. **Did your mental health provider suggest/prescribe more visits for your child than the insurance plan covered?**
   - Yes  
   - No  

17. **Has your mental health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?**
   - Yes  
   - No  

18. **Was there copayment/coinsurance required for you to access this benefit under the plan?**
   - Yes  
   - No  

19. **Was there copayment/coinsurance that was required to be paid to access this benefit for your child under the plan?**
   - Yes  
   - No  

### Behavioral Health Benefits: access to professionals with a goal of changing behavior, example, treatment of autism, psychotherapy

20. **Have adults in your family utilized behavioral health benefits through this plan?**
   - Yes  
   - No  

21. **Have your children utilized behavioral health benefits through this plan?**
   - Yes  
   - No  

22. **Did your behavioral health provider suggest/prescribe more visits for you than the insurance plan covered?**
   - Yes  
   - No  

23. **Did your behavioral health provider suggest/prescribe more visit for your child than the insurance plan covered?**
   - Yes  
   - No  

24. **Has your behavioral health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?**
   - Yes  
   - No  

25. **Was there copayment/coinsurance required for you to access this benefit under the plan?**
   - Yes  
   - No  

26. **Was there copayments/coinsurance required to access this benefit for your child under the plan?**
   - Yes  
   - No
Rehabilitative (1) and Habilitative (2) Services: (1) services to restore functional capacity, minimize limitations on physical and cognitive functions and maintain or prevent deterioration of functioning or (2) help a person keep, learn or improve skills and functioning for daily living; example, physical therapy with a child that isn't walking, speech therapy. Such services also include training of individuals with mental and physical disabilities to enhance functional development.

27. Have adults in your family utilized rehabilitative or habilitative services through this plan?
   - Rehabilitative  □
   - Habilitative  □
   - No  □

28. Have your children utilized rehabilitative or habilitative services through this plan?
   - Rehabilitative  □
   - Habilitative  □
   - No  □

29. Did your health care provider suggest/prescribe more visits for you than the insurance plan covered?
   - Yes  □
   - No  □

30. Did your health care provider suggest/prescribe more visits for your child than the insurance plan covered?
   - Yes  □
   - No  □

31. Has your health care provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?
   - Yes  □
   - No  □

32. Was there copayment/coinsurance required for you to access this benefit under the plan?
   - Yes  □
   - No  □

33. Was there copayments/coinsurance required to access this benefit for your child under the plan?
   - Yes  □
   - No  □

Learning of your first hand experiences will help us to be able to improve the way this process works. Please provide any comments you may have about your experience with the exchange/marketplace in your state. Include your full name and email if you would be willing to share this story beyond this questionnaire.
## Survey Comments

<table>
<thead>
<tr>
<th>State</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Connecticut</td>
<td>Documentation about coverage or dis-enrollment are not clear enough to understand.</td>
</tr>
<tr>
<td>Florida</td>
<td>For children with special needs including Autism the plans stink. Deductibles were too high or coverage not provided for services such as ABA. We had to put him on Florida Kids Care, CMS. Through CMS, there are not adequate providers such as a certified AA therapist in our area. It has been quite a strenuous journey.</td>
</tr>
<tr>
<td>Florida</td>
<td>Florida does not run a state exchange so I used the federal marketplace and it worked well after the initial website issues were resolved. To me the best feature of the ACA is pre-existing conditions elimination and mental health coverage for my autistic son. Florida, like many states must eliminate the age cap for ABA coverage for adults with autism.</td>
</tr>
<tr>
<td>Florida</td>
<td>We were able to find providers in our area to meet our needs. The amount of the deductible makes some services cost prohibitive, such as a colonoscopy prior to the age of 50 needed because of family history. This year, we must meet the deductible in order to have lab visits covered which significantly increased our out of pocket cost over the plan we had last year. With our subsidized monthly premium cost, copays for doctor visits and prescriptions, co-insurance, deductibles up to the maximum out of pocket expense, if we were to need a significant amount of care it would exceed 20 percent of our bring home pay. The affordable care plan is not really affordable.</td>
</tr>
<tr>
<td>Florida</td>
<td>The cost is way too high!</td>
</tr>
<tr>
<td>Florida</td>
<td>The plan that I purchased from United Health Care does NOTHING MORE than get me an appointment with a doctor—I am on the hook for EVERYTHING else! Needed an EPI PEN for a peanut allergy and even with the coupon provided by the doctor, the pharmacy said I still would be required to pay $300.00—not pick up the script. My PCP ordered a CT Scan for my sinuses and the company would not approve the test—said that I had to be on an antibiotic for at least a week—can’t get an appointment with an ENT and have spent literally HOURS on hold. I give up.</td>
</tr>
<tr>
<td>Florida</td>
<td>Excellent and worthy</td>
</tr>
<tr>
<td>Florida</td>
<td>Lack of decent options from different companies. We have three in our family and have three different plans and the one through the Marketplace is the most expensive.</td>
</tr>
<tr>
<td>Florida</td>
<td>There are not enough doctors close to me that take my Insurance. That is my main complaint.</td>
</tr>
<tr>
<td>Florida</td>
<td>I need Lymphatic treatment but cannot afford it. Too high co-pays and only one choice of place to get treatment</td>
</tr>
</tbody>
</table>
Florida  The payments are so expensive I cannot afford the insurance. It was $450.00 a month and I lost my job and couldn’t afford these types of monthly payments as I no longer had an income besides unemployment.

Florida  The premiums are way too expensive for an average person. We are not happy that prescriptions that the doctor has prescribed for my husband have been denied by the insurance company. They shouldn’t be telling the doctors what they can prescribe to their patients. I also don’t like the fact that they will only pay for generic prescriptions. This is also a big problem.

Florida  My experience with this plan has been satisfactory. Your questions however, should have on most questions, especially if you don’t have children or does not apply.

Florida  The number of doctors who will take this insurance is minimal. It took 2-3 months to find a local doctor who treats sleep apnea & accepts my plan. Then it took 6-8 weeks to get an appointment. His request for a sleep study in a lab has been denied twice after reviews (I think the review process is mostly fair) but the doctor has not responded to my calls about our next appt. which was to discuss the sleep study results (which I can’t have). He initially told me he’d do a home study but he keeps asking for a lab study & in the meantime I’m not getting any sleep! So my point is, the ONLY doctor I can see, is trying to get more money from the insurance (his own sleep lab vs. home study) and is not responding to my calls & I am being UNTREATED. I HAVE NO OTHER OPTIONS. Also my insurance REFUSES to fill a non-generic prescription even though my doctor has stated that I need the brand medication. My alternative is to pay over $300/month for the pills. The generic, I have tried several times over the years, DOES NOT work the same way, and is useless to me. MOSTLY THE LACK OF DOCTORS WHO WILL ACCEPT THE INSURANCE IS AN ISSUE. The ones who do are over-booked and have less concern about their patients. I am over 50. I have seen a lot of doctors and have had many different insurance plans. THIS IS NOT PATIENT-FRIENDLY.

Florida  I cannot find doctors that will take this insurance.

Florida  We have experienced increases in generic drug prices that were unanticipated. Also, drug prices varied according the form of the drug (tablet or capsule) that made little sense to me. I have learned to shop for prescription drugs using web sites like Good Rx. In one case, I got a much better price using a coupon than I could get for a drug through my insurance. We are now using three or four different pharmacies because prices vary so much from one pharmacy to another, or some take coupons while others don’t. We have also run into a problem getting more than one month's supply of a drug when my daughter was traveling out of the country for the summer. She went ahead and paid out of pocket and, even though we got a travel authorization approved in a timely fashion before her travel, we were unable to get reimbursed. We had no idea there was prior authorization required.

Florida  I hate Obamacare and I’m very upset that I have to pay such a high premium for an insurance that is crap! Give me my choice back to not have health insurance and not get fined! Get rid of Obamacare.
<table>
<thead>
<tr>
<th>Florida</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rate increase of 19 percent and no claims. This is not working as advertised!</td>
<td></td>
</tr>
<tr>
<td>I feel very lucky to have the affordable care act available to me. I am 51 years old and was able to retire much earlier than I anticipated because of the availability of health insurance!</td>
<td></td>
</tr>
<tr>
<td>Not happy with the drug portion, as I went to get a certain prescription filled for my fibromyalgia, the plan would not cover it unless I tried a different medication first. So I just went to GoodRX and had this filled at Walmart. So basically I have not used the drug/prescription portion as with GoodRX I can get script cheaper. Should not be this way!</td>
<td></td>
</tr>
<tr>
<td>We’ve been self-insured for many years and we feel the marketplace has made comparing plans across companies much easier. Our marketplace plan is also less expensive than plans we purchased prior to the marketplace’s existence.</td>
<td></td>
</tr>
<tr>
<td>Still very expensive. My husband is a full time student at a local university and I make $38000 per year at a non-profit. Insurance through work is prohibitively expensive for my spouse so we bought his on the exchange. For a 27 year old healthy man with no pre-existing health condition we have to pay $150 per month. That is nearly $2000 a year. That is extremely straining on our income as I am a paraplegic who has had serious health problems this year. I believe the Affordable Care Act to be a helpful step in the right direction, but I hope for universal coverage through a single payer system. Health Care is a human right that should not be limited by income or prosperity!</td>
<td></td>
</tr>
<tr>
<td>Still difficult to understand &amp; I ended up selecting wrong plan. My existing PCP was listed but then when I went for a scheduled visit, I was told the insurance I had was not accepted. I am very, very dissatisfied with being forced to have this insurance, pay over $500 a month and it doesn't help me.</td>
<td></td>
</tr>
<tr>
<td>Since we are not eligible for a subsidy, my family was forced to buy the cheapest plan—a plan with a family deductible of $12,200. This plan offers no benefits except for one preventive care exam (free) until we meet the deductible. We may as well not have insurance. The cost of this horrible plan is $1090 per month. My experience with the Marketplace was terrible—the answers they gave were sometimes different depending on who I spoke with (for example, one person told me a change in income gave me a special enrollment period—it does not—I could not sign up or change plans because of a change in income). They have no understanding of the various plan available—I imagine that is because they are not licensed to sell insurance. My experience with Navigators was just as bad—although they clearly had no knowledge of the dozens of plans available—and evidently are not insurance licensed, they made recommendations. The recommendations were for one particular insurance company and made me wonder if they were getting a finder’s fee to direct people to that company. I got a referral to an insurance agent from a friend—the agent spent a lot of time explaining the options available and looked up my doctors to see if they were in network and to look up my meds to see how much they would cost. Although I was not able to buy a better plan because of the expense, at least my doctors and local hospital take the plan (which I discovered was not the case with the plans recommended by the navigator).</td>
<td></td>
</tr>
</tbody>
</table>
Florida 

Having dealt with the exchange both in Florida and in Minnesota, the difference in cost is astounding. In Florida, in order to even remotely afford the premiums, I had an extremely high deductible. I shouldn't have bothered considering I paid far more for the insurance than I did for any medical services during the time period. Also, Minnesota offers short-term plans as an alternative to COBRA for people who are starting new jobs and have a gap in coverage. This should be available everywhere since it's a common situation.

Florida 

I am 50. I was denied coverage after missing one payment based on a 10 year old ankle sprain. Bogus. I went 5 years with no insurance. With ACA, had a routine X-ray. After multiple tests I was determined to have a very rare autoimmune disease that was attacking my lungs. It could have (and still might) kill me. But ACA literally saved my life. Treatment early doesn't always help, but it's better than silently suffering.

Florida 

Cost are extremely high for our income level which means that even with the amount that is subsidized it is more than we can afford and we have a high deductible plan. My family only uses the preventive services but pay far more than a family with no health issues should pay.

Florida 

I have had a terrible time with my marketplace. I purchased and paid online through the marketplace. I received a welcome letter, but never received my insurance cards. Apparently there were problems within the system if a payment is made online at the time of enrolling for the plan. I called four times in one month, each phone call resulted in someone attempting to “rush” the processing, at this point it has been almost 6 weeks, and I still do not officially have any coverage although the payment was fully process and posted 6 weeks ago. I have been told that any health care costs incurred during those 6 weeks will eventually be reimbursed, but I don't feel like I can trust the system. It has been a terribly negative experience. When a person receives health insurance through their employer, they have one person that can help solve problems. When a person goes through the exchange, every phone call results in a different representative attempting to solve a problem, but no continued follow-up.

Indiana 

I was very happy with the service.

Iowa 

Allow doctors to work together regardless of provider affiliation.

Michigan 

The plan was purchased to supplement Medicare. Because I have a chronic health condition that has disabled. Unfortunately the services I require are considered habilitative PT, chiropractic and massage therapy and are considered habilitative because of my condition. There for aren’t covered and I have to pay which averages 200-500 a month. Not affordable for this benefit.

Michigan 

I think the instructions need to be much clearer at the start of each enrollment season. If you are happy with your current insurance do nothing, not even logging into the healthcare.gov and policy automatically resets, or something to that effect. I did it last December thinking I was logging in to like my current insurance and lo and behold it changed the plan and a lot more paper requests which I could have avoided if it had been categorically clear that I can do absolutely nothing and my insurance will continue. Just a thought.
<table>
<thead>
<tr>
<th>Texas</th>
<th>I've had no problem. As a small business owner with a pre-existing condition, I'm very thankful for it.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Texas</td>
<td>Overall having insurance helped me obtain the medical attention I needed. I'm not exactly sure what would've happened had I not seen a doctor, but the costs didn't appear to offer much benefits as the initial claims stated. I did not receive any mental health/behavioral services through this insurance ad no longer use the insurance through the Affordable Care Act.</td>
</tr>
<tr>
<td>Texas</td>
<td>I had to cancel the policy and ended up just paying the fine to IRS on my taxes. The health insurance plan I could afford had a $6000 deductible, which I could not afford to pay and could not afford the monthly fee PLUS have to pay a co-payment for medicines, Dr. visits, etc...It is less cost just to pay the fine. It was easy to sign up for, but the (for me) “affordable” coverage plans had such high co-payments and then there was no mention of mental health benefits anywhere online, but there was just one single page in the booklet that arrived a couple weeks later. I had to call BC/BS to ask about mental health benefits and they told me what page it was in the booklet. I am better off using our County's indigent care mental health insurance which covers better and is less cost for me. As for other medical health insurance, I am a fairly healthy young man, so I can chance it and be seen at a clinic for most things. I work two jobs that are minimum wage and cannot afford this “affordable” insurance and survive on my own.</td>
</tr>
<tr>
<td>Texas</td>
<td>I am self-employed so I do not know exactly how much I will make each year, but I have to estimate my upcoming annual income during the enrollment period. My income is right around the bottom threshold between qualifying for a subsidy and not. I know that If I underestimate my income during the enrollment period I may have to pay back some of my subsidy and at my low income level that is a huge burden. But what if I overestimate it and then make TOO LITTLE to qualify for the subsidy that I receive? (I am in Texas with no expanded Medicaid) Will I have to pay it all back? The website does not address this. I have called the 800 # and some reps say yes and some say no. The IRS cannot answer this. So every year I am scared to death that if my income falls too low (through no fault of my own) to qualify for my subsidy I may have to pay it all back. This program is not set up for people who are self-employed and whose income varies from month to month.</td>
</tr>
<tr>
<td>Texas</td>
<td>The process for applying online was convoluted, unnecessarily complicated and confusing—and I have a Master's degree. It was unclear when coverage started, when we needed to make payment, if and when proof of insurance would be issued.</td>
</tr>
<tr>
<td>Texas</td>
<td>It was nice to have the option though for me it costs more than I can afford to have both drug coverage and be able to keep my physician of 20 years.</td>
</tr>
<tr>
<td>Texas</td>
<td>The rates for even high deductible plans are not affordable for me personally, as I am unable to work due to chronic illness. A relative is paying for my coverage this year. I was denied Texas Medicaid, and don't qualify for the federal subsidy. So the exchange/marketplace still doesn't really provide me with “affordable care.”</td>
</tr>
</tbody>
</table>
Texas

Very expensive insurance plans even with HMO. Not fair at all.

Texas

The response to your question about pharmaceuticals should not be a simple yes or no as it's more complicated than that. There are plan specific limitations that are not clearly explained prior to enrollment, and it is often very difficult to tell what is covered and not covered. A major issue I have is that although the legal name listed on an application can be changed (it's not an easy process, but can be done), the name on a Marketplace profile cannot be changed after a legal name change. For transgender persons, this is not only disturbing and discourages access, it can also out a person as trans to navigators, so discourages persons getting assistance. Further, such oversights convey social stigma that even after a legal name change a trans person's identity is “false,” increase minority/marginalization stress and even suicidal ideation (the trans community has a 41 percent lifetime attempted suicide rate due to such discrimination), and due to the impact on seeking navigator access disproportionately affects persons with less technology literacy and greater instability in their lives. I believe plan complexities with more confusing deductibles, co-pays, co-insurance, what is and is not covered under wellness care are all becoming more complex to allow insurers more leeway to load costs into plans that people don’t understand. This is intentional and unethical, and greater attention needs to be paid to simplifying these patient responsibilities because these provide a significant barrier to healthcare insurance literacy. I’ve even had to explain to navigators I was speaking with about partnering with for my organization about the difference between co-pays and co-insurance because they didn’t know the difference.

Texas

Marketplace insurance helps the people that make more money pay for the insurance, but those of us who have lower incomes and need the insurance the most, no one helps pay for anything. Seems like everything else, insurance is for the rich and not the poor.
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- Easterseals of Greater Houston
  Elise Hough, CEO
  www.eastersealshouston.org/ | 713-838-9050
Supportive Organizations

The following groups provided insight and support to the building of the questionnaire and the evaluation of the responses. The use of varying outside organizations was to assure that differing perspectives provided the broadest view of the questions as possible.

- The AIDS Institute;
- American Association on Health and Disability;
- The Arc of the United States;
- The Brain Injury Coalition;
- Christopher & Dana Reeve Foundation;
- Consortium for Citizens with Disabilities (CCD);
- Epilepsy Foundation of America;
- Family Voices;
- Habilitation Coalition;
- Independence through Enhancement of Medicare/Medicaid (ITEM) Coalition;
- Lupus Foundation of America;
- National Association of Councils on Developmental Disabilities;
- National Alliance on Mental Illness (NAMI);
- National Consumers League;
- National Multiple Sclerosis Society; and
- Partnership for Medicaid.
Survey Questions and Responses

Have you purchased health insurance through either the federal or state exchange/marketplace in your state that was established through the Affordable Care Act?

- Yes: 127
- No: 177

In which state exchange did you purchase the insurance?

- Connecticut: 15
- Florida: 56
- Indiana: 10
- Iowa: 4
- Michigan: 9
- Texas: 25
- None of the Above: 8
Do you qualify for federal tax credits/subsidies to help cover the cost of the premiums for this plan?

- Yes: 65
- No: 48

Overall, how satisfied are you with the care and services available through this insurance product?

- Very Satisfied: 10
- Satisfied: 22
- Neutral: 27
- Dissatisfied: 22
- Very Dissatisfied: 26
Have adults in your family used the pharmacy benefit through this plan?

- Yes: 61
- No: 22

Have your children used the pharmacy benefit through this plan?

- Yes: 19
- No: 62
Were you able to access information about specific pharmaceuticals, including the prior authorization process, estimated costs and tiering information before the health insurance was purchased?

- Yes: 37
- No: 44

Was this information available after enrollment?

- Yes: 65
- No: 18
Has your health care provider suggested/prescribed specific drugs/medicine that are not covered in your health plan?

- Yes: 37
- No: 44

Are you aware of an exceptions and appeals process to get a specific drug?

- Yes: 25
- No: 56
Was there copayment/coinsurance required to be able to get a prescription?

- Yes: 74
- No: 5

Was there copayments/coinsurance that were so high that you could not fill the prescription?

- Yes: 34
- No: 44
Has an adult in your family used mental health benefits through this plan?

- Yes: 11
- No: 67

Have your children used mental health benefits through this plan?

- Yes: 8
- No: 70
Did your mental health provider suggest/prescribe more visits for you than the insurance plan covered?

Yes: 9
No: 57

Did your mental health provider suggest/prescribe more visits for your child than the insurance plan covered?

Yes: 7
No: 59
Has your mental health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?

- Yes: 11
- No: 57

Was there copayment/coinsurance required for you to access the [mental health] benefit under the plan?

- Yes: 32
- No: 35
Was there copayment/coinsurance that was required to be paid to access the [mental health] benefit for your child under the plan?

- Yes: 17
- No: 50

Have adults in your family used behavioral health benefits through this plan?

- Yes: 9
- No: 65
Have your children used behavioral health benefits through this plan?

- Yes: 6
- No: 66

Did your behavioral health provider suggest/prescribe more visits for you than the insurance plan covered?

- Yes: 6
- No: 53
Did your behavioral health provider suggest/prescribe more visit for your child than the insurance plan covered?

Yes: 5
No: 55

Has your behavioral health provider suggested/prescribed specific therapies/services that were not covered by the insurance plan?

Yes: 8
No: 53
Was there copayment/coinsurance required for you to access the [behavioral health] benefit under the plan?

- Yes: 18
- No: 43

Was there copayments/coinsurance required to access the [behavioral health] benefit for your child under the plan?

- Yes: 9
- No: 51
Have adults in your family used rehabilitative or habilitative services through this plan?

- Habilitative: 0
- Rehabilitative: 5
- No: 61

Have your children used rehabilitative or habilitative services through this plan?

- Rehabilitative: 1
- Habilitative: 2
- No: 62
Did your health care provider suggest/prescribe more visits for you than the insurance plan covered?

- Yes: 5
- No: 50

Did your health care provider suggest/prescribe more visits for your child than the insurance plan covered?

- Yes: 1
- No: 52
Has your health care provider suggested/ prescribed specific therapies/services that were not covered by the insurance plan?

Yes: 6
No: 48

Was there copayment/coinsurance required for you to access the [rehabilitative and habilitative services] benefit under the plan?

Yes: 17
No: 37
Was there copayments/coinsurance required to access the [rehabilitative and habilitative services] benefit for your child under the plan?

- Yes: 6
- No: 47
Acknowledgements

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Health care reform is dynamic and changes that take place may supersede the information in this report.
Endnotes


6 http://www.SSA.gov/history/tally65.html.


18 Weiner and Colameco, (October 2014).


21 Centers for Disease Control and Prevention (CDC), Health, United States, 2014, Trend Tables—Table 85, 271.


