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Chair Huffman, Vice Chair Gavarone, Ranking Member Antonio and members of the House Health Committee, Retirement and Aging Committee, thank you for the opportunity to offer proponent testimony on House Bill 241, which would create a diabetes registry in Ohio.

The Ohio 2017-2019 State Health Improvement Plan lists reducing diabetes as one of its 10 priority outcomes under the priority topic Chronic Disease. The best way to know if we've met this outcome is to know exactly from where we start. Without a diabetes registry, our information consists of educated guesses – and as a state, we can do better.

The Children with Medical Handicaps program lists diabetes as number one in terms of diagnoses and money spent for the BCMH population. It is likely that the majority of those cases are type 1 diabetes as that is far more frequently diagnosed in children than type 2 – but we need to know for certain. The treatment methods of each type are different enough from each other that it matters how we treat the diagnosis. We need solid information and we don't have it – and as a state, we can do better.

I can give you a lot of the statistics that currently in use:

- The overall prevalence of diabetes in Ohio is higher than the US median prevalence – 11.7% vs. 9.7%.
- The cost of diabetes and its complications in terms of medical care is estimated at \$13,700 a year – for every person with diabetes, whether they have insurance or not. And those without insurance typically don't have the means to afford care, so the possibility of complications increase, sending folks to the hospitals for not only highs and lows but also kidney failure, neuropathy and vision loss to mention a few.
- Based on CDC and ADA statistics 10% of the population has diabetes and another 20% may have pre-diabetes and not know it.
- I have included with my written testimony information about the cost of diabetes care. The cost of insulin, medications and supplies is overwhelming – even for families with insurance. We would be able to make more educated estimates of the cost with more accurate information on the actual incidence of diabetes in Ohio.

Diabetes is too expensive and too impactful for us to continue making decisions about its treatment and care without accurate, community-specific statistics. It is increasing in epidemic proportions and in the same way we use detailed information to combat the current, devastating opioid epidemic, we need to bring the same attention to targeted treatment and care of diabetes. Because as a state, we can do better.

Thank you.



As Childhood Diabetes Rates Rise, So Do Costs — And Families Feel The Pinch: Study

By Carmen Heredia Rodríguez | June 20, 2016

Childhood diabetes rates are on the rise, and a report released Monday pointed to the impact that the cost of their care could have on families — even those who have employer-sponsored health insurance.

The study, conducted by the Health Care Cost Institute (HCCI), found that children as old as 18 with diabetes who were insured through an employer-sponsored plan racked up \$2,173 per capita in out-of-pocket health care costs in 2014. That spending level was nearly five times higher than that of kids without the illness.

The HCCI researchers analyzed data from claims submitted from 2012 to 2014 through group, individual and Medicare Advantage insurance policies to analyze health care spending and utilization trends among people younger than 65 who had diabetes and employer-sponsored coverage plans.

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In terms of use of medical services, children with diabetes visited the emergency room 2.5 times more often than children without it. Acute inpatient services were used nearly five times more often. In all, a year's worth of care cost \$17,380 — the second only to adults aged 55 through 64 with diabetes.

Although more prescriptions and frequent doctor's visits help explain the difference in the health care costs generated by children with and without this illness, researchers were still surprised by the magnitude of the disparity.

Families are "spending more out-of-pocket across the board on all types of services," said Amanda Frost, a senior researcher at HCCI. "And it's just higher use. So when you end up using all of these health care services, you end up with a very personal impact on your wallet, especially if you're a parent with a child with diabetes."

As of 2012, 208,000 children and adolescents younger than 20 years old lived with diabetes, most of whom have Type I diabetes, which is when the body does not produce insulin, according to the latest data from the Centers for Disease Control and Prevention (CDC). And the rates are surging. In the past 30 years, the total number of cases for all age groups has quadrupled. Childhood Type II diabetes, often associated with obesity, is rising, especially among racial minorities.

Prescription drugs accounted for the largest share of the out-of-pocket costs for children with diabetes in each year of the study period, peaking in 2014 at \$751 per child, driven by spending on brand-name prescriptions. For all other age groups studied, these costs decreased by at least 3 percent.



The price of insulin, the drug used to treat Type 1 diabetes has skyrocketed. A study published in JAMA in March found the drug cost an average of \$12.92 per milliliter in 2013. With children with Type 1 diabetes needing daily anywhere from .5 to 1.5 units of insulin per kilogram of their weight, Dr. Fran Cogen, director of the Childhood and Adolescent Diabetes Program at Children's National Health System said, the price and the burden can rack up quickly.

Cogen also said families who struggle with the financial burden of diabetes treatment wrestle with more issues than the bottom line. Mental health and access to other resources is also a concern in assessing the well-being of the child, adding another layer of cost and complexity in treating children.

"Not only do you have to deal with the diabetes, you have to deal with underlying socio-economic conditions and psychological conditions and their need," Cogen said.

Among the researchers' other conclusions:

- Per capita spending for insured people with diabetes increased between 2012 and 2014 by \$1,310 to \$16,021 in 2014, nearly four times higher than spending for people without the illness, which was \$4,396.
- Spending was the highest for adults between the ages of 55 through 64.
- Increases in out-of-pocket spending for people with diabetes corresponded with the overall rise in costs. However, there were drops in spending on prescription drugs — especially among the oldest age group. This decline is attributed to less spending on brand-name prescription medicines.
- The total cost of health care among those with diabetes tended to decrease with age. Expenditures among those without diabetes trended in the opposite direction.

Note: This story was updated to reflect the correct measures for insulin for children with Type 1 diabetes.

CATEGORIES: Cost and Quality, Public Health, Syndicate

TAGS: Children's Health, Diabetes



Rates of new diagnosed cases of type 1 and type 2 diabetes on the rise among children, teens

Fastest rise seen among racial/ethnic minority groups

Press Release

For Immediate Release: Wednesday, April 12, 2017

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Rates of new diagnosed cases of type 1 and type 2 diabetes are increasing among youth in the United States, according to a report published today in the *New England Journal of Medicine* (<http://www.nejm.org/doi/full/10.1056/NEJMoa1610187>), entitled "Incidence Trends of Type 1 and Type 2 Diabetes among Youths, 2002-2012" (<http://www.nejm.org/doi/full/10.1056/NEJMoa1610187>).

In the United States, 29.1 million people are living with diagnosed or undiagnosed diabetes, and about 208,000 people younger than 20 years are living with diagnosed diabetes. This study is the first ever to estimate trends in new diagnosed cases of type 1 and type 2 diabetes in youth (those under the age of 20), from the five major racial/ethnic groups in the U.S.: non-Hispanic whites, non-Hispanic blacks, Hispanics, Asian Americans/Pacific Islanders, and Native Americans.

The SEARCH for Diabetes in Youth study (<https://www.searchfordiabetes.org/dspHome.cfm>), funded by the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), found that from 2002 to 2012, incidence, or the rate of new diagnosed cases of type 1 diabetes in youth increased by about 1.8 percent each year. During the same period, the rate of new diagnosed cases of type 2 diabetes increased even more quickly, at 4.8 percent. The study included 11,244 youth ages 0-19 with type 1 diabetes and 2,846 youth ages 10-19 with type 2.

“Because of the early age of onset and longer diabetes duration, youth are at risk for developing diabetes related complications at a younger age. This profoundly lessens their quality of life, shortens their life expectancy, and increases health care costs,” said Giuseppina Imperatore, M.D., Ph.D., epidemiologist in CDC’s Division of Diabetes Translation, National Center for Chronic Disease Prevention and Health Promotion.

Results of this [study \(http://www.nejm.org/doi/full/10.1056/NEJMoa1610187\)](http://www.nejm.org/doi/full/10.1056/NEJMoa1610187) reflect the nation’s first and only ongoing assessment of trends in type 1 and type 2 diabetes among youth and help identify how the epidemic is changing over time in Americans under the age of 20 years.

Key diabetes findings from the report:

- Across all racial/ethnic groups, the rate of new diagnosed cases of type 1 diabetes increased more annually from 2003-2012 in males (2.2 percent) than in females (1.4 percent) ages 0-19.
- Among youth ages 0-19, the rate of new diagnosed cases of type 1 diabetes increased most sharply in Hispanic youth, a 4.2 percent annual increase. In non-Hispanic blacks, the rate of new diagnosed cases of type 1 diabetes increased by 2.2 percent and in non-Hispanic whites by 1.2 percent per year.
- Among youth ages 10-19, the rate of new diagnosed cases of type 2 diabetes rose most sharply in Native Americans (8.9 percent), Asian Americans/Pacific Islanders (8.5 percent) and non-Hispanic blacks (6.3 percent). However, the Native American youth who participated in the SEARCH study are not representative of all Native American youth in the United States. Thus, these rates cannot be generalized to all Native American youth nationwide.
- Among youth ages 10-19, the rate of new diagnosed cases of type 2 diabetes increased 3.1 percent among Hispanics. The smallest increase was seen in whites (0.6 percent).
- The rate of new diagnosed cases of type 2 diabetes rose much more sharply in females (6.2 percent) than in males (3.7 percent) ages 10-19.

Cause of rising diabetes incidence unclear

“These findings lead to many more questions,” said Barbara Linder, M.D., Ph.D., senior advisor for childhood diabetes research at NIH’s National Institute of Diabetes and Digestive and Kidney Diseases. “The differences among racial and ethnic groups and between genders raise many questions. We need to understand why the increase in rates of diabetes development varies so greatly and is so concentrated in specific racial and ethnic groups.”

Type 1 diabetes, the most common form of diabetes in young people, is a condition in which the body fails to make insulin. Causes of type 1 diabetes are still unknown. However, disease development is suspected to follow exposure of genetically predisposed people to an “environmental trigger,” stimulating an immune attack against the insulin-producing beta cells of the pancreas.

In type 2 diabetes, the body does not make or use insulin well. In the past, type 2 diabetes was extremely rare in youth, but it has become more common in recent years.

Several NIH-funded studies are directly examining how to delay, prevent, and treat diabetes:

- Type 1 Diabetes TrialNet (<https://www.trialnet.org/>) screens thousands of relatives of people with type 1 diabetes annually and conducts prevention studies with those at highest risk for the disease.
- The Environmental Determinants of Diabetes in the Young (TEDDY) study seeks (<https://teddy.epi.usf.edu/>) to uncover factors that may increase development of type 1 diabetes.
- For youth with type 2 diabetes, the ongoing Treatment Options for Type 2 Diabetes in Adolescents and Youth (TODAY) (<https://portal.bsc.gwu.edu/web/today>) study is examining methods to treat the disease and prevent complications.

Additionally, CDC's NEXT-D study (<https://www.cdc.gov/diabetes/programs/research/nextd.html>) aims to understand how population-targeted policies affect preventive behaviors and diabetes outcomes and answer questions about quantity and quality of care used, costs, and unintended consequences. For more information on diabetes, including tips on diabetes management and type 2 diabetes prevention, visit <http://www.cdc.gov/diabetes> (<https://www.cdc.gov/diabetes>).

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State of Ohio Diabetes Registry HB 241 Position Statement

Introduction

Modeled after Ohio's successful cancer registry known as the "Ohio Cancer Incidence Surveillance System (OCISS)," Ohio H.B. 241 establishes a registry for the recording and tracking of all new cases of diabetes in Ohio (regardless of type). The collection and analysis of population-based diabetes incidence data, like that of cancer incidence data, will help determine the burden of diabetes in Ohio's communities, raise awareness about factors that may increase diabetes risk and the benefits of early detection, and improve the survival of persons diagnosed with diabetes. Ohio's diabetes incidence data could be used by public health professionals, medical researchers, educators, and policy makers to develop, implement, and promote many diabetes prevention and control activities in Ohio and support important diabetes-related research.

Need Defined

According to a recent Ohio Department of Health (ODH) report on the Children with Medical Handicaps Program (also known as "BCMh"), diabetes is number one both in terms of diagnoses (2,763 cases) and money spent (\$3,684,364) for the BCMh population. (The BCMh population includes only children). It is likely that the majority of those cases are type 1 diabetes, since that type of diabetes is usually diagnosed in children and young adults (American Diabetes Association, <http://www.diabetes.org/diabetes-basics/type-1/>).

The SEARCH for Diabetes in Youth study, funded by the Centers for Disease Control and Prevention (CDC) and the National Institutes of Health (NIH), found that from 2002 to 2012, incidence, or the rate of new diagnosed cases of type 1 diabetes in youth increased by about 1.8 percent each year. During the same period, the rate of new diagnosed cases of type 2 diabetes increased even more quickly, at 4.8 percent.

Adults with diabetes have even more staggering statistics. According to the ODH report, *The Impact of Chronic Disease in Ohio: 2015*, "the overall prevalence of diabetes among adults in Ohio (11.7%) was higher than the US median prevalence (9.7%) in 2012". Knowing we also have the ranking of 11th highest rate of obesity in the US (WebMD.com, 2012), we can assume that type 2 diabetes diagnoses have increased.

The cost to Ohio is high and growing. In 2010, "diabetes cost more than \$4.6 billion in medical expenses and absenteeism from the workplace" according to the ODH report, *The Impact of Chronic Disease in Ohio: 2015*. Estimated costs of diabetes management in Ohio, depending upon age, ranges from over \$11,000 to over \$21,000 per year (CDC website).

In addition, while we have yet to receive data from the Ohio Department of Medicaid regarding the cost of diabetes to that program, it is extremely likely that diabetes is among the program's top costliest conditions to treat.

Implementation

Again, we would not be breaking new ground with a Diabetes Registry. First we would want it modeled after the successful Cancer Registry already in place in Ohio. Because this Registry has already been built and would only need to be revised for diabetes, the cost of implementation should be less than the original cost of the Cancer Registry. Also, several other states have registries that collect data either on diabetes only or as part of a collection of chronic or autoimmune diseases. This information helps to inform research projects, funding decisions and may identify neighborhood targets for environmental studies.

It must be noted that no one knows what a "normal" rate of diagnosis of diabetes is – because we have never actually tracked the incidence in Ohio. In order to understand more about the increase, and maybe in some places possible decreases, in diagnoses, we need to know the actual numbers from which we begin.

Benefits

Having accurate information on the demographics of diabetes diagnoses can provide the following benefits:

- Reduce cost of healthcare - People with diagnosed diabetes incur average medical expenditures of about \$13,700 per year, of which about \$7,900 is attributed to diabetes. People with diagnosed diabetes, on average, have medical expenditures approximately 2.3 times higher than what expenditures would be in the absence of diabetes. (The Cost of Diabetes: American Diabetes Association® www.diabetes.org/advocacy/news-events/cost-of-diabetes.html)
- Support Meaningful Use of Electronic Health Records – which is estimated nationally to have the potential to save billions nationally (A computer simulation model developed by Bu *et al.* estimated that diabetes registries could save \$14.5 billion in healthcare expenditures over 10 years).
- Support the Ohio Chronic Disease Plan developed by ODH and the Health Policy Institute of Ohio by providing critical data and surveillance of diabetes– a chronic, costly disease that is one of the four focus areas of the plan.
- Indicate areas of higher diabetes incidence – supporting requests to focus resources and efforts in areas where diagnoses are statistically higher than normal.
- This registry would distinguish among various types of diabetes: type 1 diabetes (an autoimmune disease), type 2 diabetes (a metabolic disorder), gestational diabetes (which leads to a more than a 50% higher risk of developing type 2 diabetes post-birth), and other more rare forms of diabetes.
- Mandatory case reporting would permit state research institutions to see the macro and micro variations by community that may prove crucial in unraveling the complex reasons behind the significant increase in type 1 diabetes diagnoses (paraphrased from the book, Diabetes Rising)

Partners

The Diabetes Registry would use existing processes and reporting structure. No new board or commission is required for accurate, timely implementation of this Registry.

The legislation lists several groups, organizations and government entities that will be represented on a continuing counsel.

- Advocacy group – CODA is the only diabetes organization located in Central Ohio advocating on behalf of all people with any form of diabetes
- Epidemiologist – must practice in Ohio
- Two pediatric endocrinologists practicing in Ohio
- Two adult endocrinologist practicing in Ohio
- Obstetrician with patients with gestational diabetes
- Two adults – one with type 1, one with type 2
- A woman with gestational diabetes

This group will expand to include new groups as needed.