# A Model Assessment for Surveillance of Disease Prevalence and Monitoring Cost Utility and Health Outcomes of Individuals with Physical Disabilities Served by HCBS Waivers

Amanda Reichard, PhD[1], Martha Hodgesmith, JD[1], & Michael Fox, ScD[2]

[1]University of Kansas Research and Training Center on Independent Living

[2]University of Kansas Medical Center-Kansas City and University of Kansas Research and Training Center on Independent Living

## Background

- Individuals with physical or intellectual and developmental disabilities experience health disparities for adverse health outcomes:
  - Diabetes, obesity, heart disease, and high blood pressure
- Individuals with physical or intellectual and developmental disabilities are also less likely to receive appropriate preventive health services (e.g., breast and cervical cancer screening), and appropriate counseling and education regarding disease management for chronic conditions.
- Medicaid-funded Home and Community Based Services (HCBS) waivers provide coverage for community services that help minimize loss of function in areas of daily living (e.g., Activities of Daily Living/Instrumental Activities of Daily Living) that directly affect health status and, by association, an individual's ability to fully participate in the community.
- By providing these services, HCBS waivers enable people with various disabilities and substantial long-term care needs to remain in the community.
- In order to monitor, improve, and build a case for continuing their programs, Medicaid and HCBS program managers must have a clear understanding of health care utilization and expenditures for this population.

## Objective

To create a model assessment using Medicaid claims data that state Medicaid programs can employ to monitor cost utility and health outcomes of individuals with disabilities served by HCBS waivers (or other Medicaid programs).

## Using the Assessment Model to Inform Policies

### As an Assessment Tool

Medicaid programs can use the information they gather from the Assessment Model to address health inequalities among individuals with disabilities and to assess what new program and funding policies are needed and where to establish these policy provisions. Ideally, in addition to using the information to inform Medicaid policies, program staff should work with state health department staff to ensure that appropriate and sufficient public health programs exist and are implemented to address any shortcomings in meeting the specific needs of people with disabilities.

### As a Surveillance Tool

Medicaid programs can use the model assessment as a population-based surveillance tool to track the health and service utilization patterns of each segment of the disability population they support with health insurance. This will allow them to have greater access to more timely and more relevant information to guide health policies and strategies. The assessment model provides step-by-step instructions for using the tool for both cross-sectional analysis and longitudinal analysis so that they can monitor population trends over time.

### As an Evaluation Tool

The Assessment Model also provides Medicaid programs with the means to evaluate program and funding policies they implement and further assess the utility and impact that the policies have on intended outcomes. If the Medicaid programs routinely use the Assessment Model as a surveillance tool, they may in many instances be able to have the analysis serve dually for surveillance *and* evaluation.

### Acknowledgement

The contents of this poster were developed under a grant from the Department of Education, NIDRR grant number H133B060018. However, those contents do not necessarily represent the policy of the Department of Education, and you should not assume endorsement by the Federal Government.

For more information contact:
Amanda Reichard, PhD, RTC/IL,
University of Kansas, 1000 Sunnyside Ave., Suite 4089
Lawrence, KS 66045
Reichard@ku.edu

## Why Create a Model Assessment for Medicaid Programs?

- Medicaid Program staff can be strapped for time addressing the demands of a very challenging agency, especially when national and state funding is limited.
- In addition, Medicaid programs in states like Kansas may not have the means to employ enough staff with the knowledge of how to effectively use available data.
- Having a model with detailed, step-by-step instructions provides them with a user-friendly tool that simplifies the process and saves time.
- The Model Assessment pulls together and applies all currently available resources into one assessment system. It eliminates the need for Medicaid staff members to "reinvent the wheel" by developing their own way to analyze available data.

## What Does the Model Assessment Add to Existing Tools?

1. The Model Assessment explains what questions can be asked/answered with the data and provides a detailed description of how to do it as well as why the questions are important to ask.
2. The Model Assessment explains how to complete the analyses using SPSS, SAS, or both.
3. The Model Assessment provides detailed instructions on how to incorporate available and relevant software tools in evidence-based policy analysis.
4. The Model Assessment provides a list of other possible software tools available for incorporating into further analysis.

## The Model Assessment (and Guide)

- Provides detailed, step-by-step instructions, including SPSS and/or SAS code, for use in conducting analysis of in patient care, out patient care, pharmacy, home health, HCBS services, and transportation.
- Provides a comprehensive list of suggested analyses to routinely implement for surveillance.
- Provides numerous examples of more in-depth analyses to consider in assessing the needs of each HCBS waiver population.
- Provides numerous examples of more in-depth analyses to consider in evaluating the effectiveness and utility of programs/policies implemented by the Medicaid program.
- Provides links and instructions for how to incorporate the following software tools from the ***Healthcare Cost and Utilization Project*** (HCUP):
  - Clinical Classifications Software (CCS)
  - Chronic Condition Indicator (CCI)
  - Comorbidity Software
  - Prevention Quality Indicators (PQI)
- Provides a codebook to help interpret data analyses.

## The Process Involved in Creating the Model

### Step 1: Obtaining the Data

We began by requesting data from the Medicaid program. However, we experienced multiple problems in getting a clean and accurate data set. In particular, Medicaid staff limitations and demands caused multiple and lengthy delays in data acquisition.

### Step 2: Data Analysis

After spending time analyzing the claims, we discovered they were not accurate; why and how they were inaccurate was unclear. To investigate the flaws, we compared notes with a colleague who had access to similar data and had discussions with multiple experienced colleagues about the problem of inaccurate data. The main reasons the MSIS data were inaccurate were (a) the time-consuming work of ensuring its accuracy was prohibitive, (b) *programming* rather than *data analysis* Medicaid staff, and (c) the need for staff to complete other, more imminent and complex demands for the Medicaid program. As a result, we had to find another way to obtain accurate data.

### Step 3: Obtaining the Data…again

We also learned that the most accurate method for obtaining Medicaid claims data in Kansas (without buying them from ResDAC) was to make a request for the data through the Medicaid claims adjuster. By necessity the claims adjuster has to maintain accurate claims in order to ensure accurate payment. However, their primary responsibility is to the Medicaid agency and, thus, data pulls for outside analysis are very low priority. In addition, you can only access them through the Medicaid agency. We were not able, then, to receive timely access and had to seek another solution.

We resolved the problem of no data through our collaboration with a colleague who has established a business associates agreement (BAA) with the agency that houses our state Medicaid program. This contract is to maintain, through the Medicaid claims adjuster (EDS) an active and up-to-date database of all claims for individuals with disabilities supported by the Kansas Medicaid. The BAA allows her to approve and provide data pulls to others for analysis. Under this BAA she was willing to provide us with the data we needed for our project.

### Step 4: Gathering a National Context and Relevant Tools

While waiting to receive these data, we worked to better understand the national context of health disparities for individuals with disabilities. To do so, we analyzed Medical Expenditures Panel Survey (MEPS) data, and identified available relevant tools that could assist Medicaid programs in assessment, surveillance and evaluation of their services.

### Step 5: Completing the Development of the Model Assessment

To finalize the development of the Model Assessment, we included (a) annotated syntax, with step-by-step instructions, (b) analyses using real state Medicaid claims, (c) the results of our analysis to share with Medicaid and HCBS agencies, along with recommendations for policy change based on this information, and (d) recommendations for how our state Medicaid program can use the Model Assessment to evaluate policies and to partner more regularly with our state public health agency.

## What Difficulties Were Involved in Creating the Model Assessment?

**Difficulty:**
In working to create the Model Assessment, we experienced difficulty obtaining data; we had to rely on our network connections. Initially, we relied on our professional relationships with staff at the Medicaid agency to obtain the data. When we learned that the data through this avenue were inaccurate, we had to rely on a relationship with a colleague outside of the Medicaid agency.

**Why this matters:**
- Most analysts do not have existing relationships with staff from Medicaid programs that would allow them access to the data. Buying data from ResDAC can be cost prohibitive.
- Even where relationships exist, getting a Data Use Agreement in place to protect both interested parties can be extremely time consuming and delay project analysis.

**Difficulty:**
We also experienced difficulty in ensuring that the data we obtained were accurate and reliable.

**Why this matters:**
- From what we learned, typically the data available through the company responsible for claims adjustments are much more reliable and accurate. This means that whenever Medicaid staff members do not have anyone responsible for cleaning the data and ensuring the accuracy and reliability of the data pulls, they should rely on the programmers at the claims adjustment contractor to pull data for them.
- However, this can raise further difficulties during times when there is a transition from one contractor to another for claims adjustment. These transitions can result in a time lag for available data or in some cases incomplete or inconsistent data transfer.
- For analysts outside of the Medicaid agency, it can be very difficult to know if the data they receive is accurate and reliable.

**Difficulty:**
During the duration of our project, our state Medicaid agency has been in a transition period both administratively and economically.

**Why this matters:**
- Medicaid program staff members were especially strapped for time and even less available than usual to give attention to this project. The staff members most well suited to make the data pull for us were not asked to do it because they were needed on other projects.
- Administrators may not be supportive of non-agency analysts, thus they might also refrain from supporting any policy recommendations that may come from the analysts' research studies.
- Changes in high level state agency personnel can complicate the process of obtaining data.

## Potential Barriers to Using the Model Assessment

1. Lack of sufficiently trained staff; or, a lack of established relationships with outside analysts to contract out the work.
2. Lack of emphasis on the need for ongoing funding for policy analysis work.
3. Limited value (by some) placed on implementation of such evidence-based policy making.
4. Addressing the day to day business of Medicaid program management, eligibility determination and claims processing gets in the way of implementing new practices and policy analysis.
5. Overall, there remains a lack of focus on medical management and prevention rather than eligibility and claims processing.