

# **SURVEY TO DETERMINE OUTCOMES OF SERVICES CLOSER TO HOME – PRELIMINARY RESULTS**

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## **ABSTRACT**

Specialty medical and assistive technology services are provided to children with disabilities and their families in 14 unserved and underserved areas of a large Midwestern State. Through 29 years of service, surveys have evolved from program satisfaction to program outcome measurement and now to patient outcome measurement. Preliminary results of the latest version of our outcomes survey will be shared and discussed.

## **BACKGROUND**

The goal of the clinic is to bring specialty services to children with disabilities and their families in 14 unserved and underserved areas of a large Midwestern State. The main purposes are specialty medical care, assistive technology fitting and repair services, and consultation and training with state-of-the-art equipment. Through 29 years of service, surveys have evolved from program satisfaction to program outcome measurement and, in 2013, to patient outcome measurement.

Satisfaction, outcomes, and, more recently, value are measurements that many use in service delivery. Assistive technology service satisfaction surveys used in early years of the project told us that we were doing a great job – nearly 100% of the time, but these results told us nothing about how our client lives were changed as a result of the service. In the 1990s, we learned about outcomes (Bell, Ostroske, et. al 1996), and instead of asking about satisfaction, we asked clients if services made any measurable change in their lives. Results were used to improve the services and as justification for funding the program.

## **METHOD/APPROACH**

As we learned more about outcomes, the term value came into our vocabulary. “Value (is) defined as the health outcomes achieved per dollar spent . . . Outcomes, the numerator of the value equation, are inherently condition-specific and multidimensional . . . Cost, the equation’s denominator, refers to the total costs of the full cycle of care for the patient’s medical condition, not the cost of individual services.”(Porter, 2010)

In an effort to measure value, we expanded our survey to include medical services, and will look at cost in the

broader scope as well. This paper focuses on the outcome measurement in the value equation.

The outcomes survey was developed to provide program and patient outcomes. The questions relating to program focus on access to care, including travel distance and expenses. This section of the survey was developed to help our efforts to improve and fund the program (Hatry, H.P., Cowan, C., Hendricks, M. 2004). The patient outcome questions focus on sustained health and include questions about activities and effects on life. Activity questions ask the following. Compared to other alternative, how has the availability of the Outreach Clinic affected: work or school attendance for the patient; ability to keep appointments; family stress level; and family ability to take vacation time. Effects of service on life questions ask patients to rate better, same, or worse: comfort; general well-being or health; function or access to other assistive technology; mobility or movement; posture or alignment of body or part of body; endurance/stamina; independence; safety; patient ability to communicate; nutrition or weight; hygiene or elimination; timely medical care; participation in social/community activities; participation in recreational/fitness activities; involvement of local professionals in the evaluation; understanding of use and care of equipment; ability of local providers to maintain ongoing care; and ability to obtain and use assistive technology devices.

We will ask patients to complete the survey yearly, so that we can eventually compare responses to determine long term outcomes for each patient using single subject design (Smith 2004).

## **EVALUATION/RESULTS**

The survey instrument has been in use since July 1, 2013. We will provide program results, and if IRB approval is granted, preliminary patient results.

From July 1 to December 31, 2013, 194 surveys have been completed. For those surveyed, access to medical specialty services has improved for 84%, and not changed for 16%. Access to assistive technology services has improved for 78%, and not changed for 22 %. Distance patients would travel for services if the Outreach Clinic was not available is reported as follows: 69% would travel more than 100 miles, 24% would travel between 50 and 100

miles, and 7% would travel less than 50 miles. Patients report expenses that would be incurred if services were provided elsewhere as: mileage (88%), meals (70%), lost wages (47%), lodging (40%), care provider expenses (25%), lost vacation time (24%), and sibling care expenses (21%). Compared to other alternatives, the availability of the Outreach Clinic has improved ability to keep appointments (62%), family stress level (59%), work or school attendance for the patient (46%), and family ability to take a vacation (32%).

## DISCUSSION

Porter describes a three-tiered hierarchy of outcome measurement. Tier 1 outcomes focus on the health status achieved or retained and includes measure of survival or degree of health or recovery. Tier 2 outcomes focus on the process of recovery and measure time to recovery, time to return to normal activities, or disutility of care or treatment process. Tier 3 outcomes focus on sustainability of health and measure sustainability of health or recovery and recurrences of illness or long-term consequences of therapy. (Porter 2010)

For the population served, it is the Tier 3 outcomes that are of most interest. The preliminary survey results begin to tell us that services closer to home do affect home life. The ability to keep appointments, family stress, work or school attendance, and family ability to take vacation are all tier 3 type outcomes and improve with services closer to home. Expenses that would be incurred if services were not available are especially important for this population where poverty and unemployment are high.

Individual patient outcomes will be paired with costs will allow us to evaluate the value of services when IRB approval is obtained.

## CONCLUSIONS

Services in rural, underserved areas are essential to providing positive patient outcomes. The data is important for practitioners interested in how the service model increases quality of life for individuals with disabilities and their families. Outcome measurement can also provide data to measure value of the program, but further analysis of data, paired with cost is needed. As competition for funding of programs constricts, analysis of data will determine program worth.

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