Integrated Care Through Education: Improving Care for Those With Serious Mental Illness and/or Intellectual Disability and Diabetes in Rural Indiana

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Diabetes is becoming an epidemic within the general population. The risk of developing diabetes is estimated to be twice that for people with serious mental illness (SMI) or intellectual disability (ID). Simultaneously, persons with SMI or ID typically receive fewer primary care services for chronic disease management. This situation is more challenging for those populations living in rural areas with reduced access to care. This project was designed to address these concerns by providing training on the mental health and medical aspects of diabetes to providers in both primary care and behavioral health to increase competency, treatment coordination, and outcome effectiveness for both disciplines. Results included increased primary care visits, attention to the whole person, and use of monitored HEDIS assessments for diabetes.

Keywords: diabetes, mental illness, intellectual disability, integration, education, rural

Diabetes, Serious Mental Illness, and Intellectual Disability

Diabetes presents a tremendous health challenge in Indiana and the United States as a whole. The World Health Organization (2012) estimates that the number of adults in the United States with diabetes will double by the year 2030. In the United States, the diabetes epidemic has been growing rapidly. From 1963 to 1975, there was a sharp increase in diabetes, during which prevalence went from 13.6 to 25.8 per 1,000 Americans (Centers for Disease Control [CDC], 2010). Diabetes prevalence leveled off in 1975 but more than doubled by 1990 (26.4 to 54.5 per 100,000; CDC, 2010). Its prevalence continues to grow, increasing by almost 5% each year (CDC, 2010). It is estimated that almost one third of all diabetes cases are undiagnosed (CDC, 2010). The estimated rate for diabetes was 9.3% for the adult population in Indiana, which means more than 447,000 individuals in Indiana reported that they had been diagnosed with diabetes (Thomaskutty & Dwivedi, 2011). This rate exceeded the diabetes prevalence of the United States, which was 8.3% (Thomaskutty & Dwivedi, 2011). Additionally, rural areas of the country experience, on average, approximately 17% higher diabetes prevalence rate than urban areas (Massey et al., 2011). Currently, every county in Indiana has estimated diabetes prevalence higher than the national rate of 8.3% (Thomaskutty & Dwivedi, 2011).

Diabetes is costly, financially and socially. The average annual health care cost for a person with diabetes in the United States is $11,744, compared with $2,935 for a person without diabetes. The total annual economic cost of diabetes in the United States was estimated at $218 billion per year, including diagnosed and pre-diabetes and direct and indirect costs (Dall et al., 2010). This number does not include social costs, such as pain and suffering and loss of quality of life from complications (amputations, blindness, cardiovascular and kidney disease, neuropathy, and many others) for those living with diabetes. It also does not include the pain and suffering of those diagnosed or care provided by nonpaid caregivers.
Mental disorders are common in the United States and internationally. An estimated 26.2% of Americans ages 18 and older—about one in four adults—suffer from a diagnosable mental disorder in a given year (Kessler et al., 2005). When applied to the 2004 U.S. Census residential population estimate for ages 18 and older, this figure translates to 57.7 million people. Even though mental disorders are widespread in the population, the main burden of illness is concentrated in a much smaller proportion—about six percent, or 1 in 17—who suffer from a serious mental illness (NIMH, 2008). In addition, mental disorders are the leading cause of disability in the United States and Canada for ages 15–44. Nearly half (45%) of those with any mental disorder meet criteria for two or more disorders, with severity strongly related to comorbidity (NIMH, 2008). People with serious mental illness (SMI) experience various chronic disease at rates from one to 10 times that of the general population depending upon the disease (Gold & Kilbourne, 2008). For people with serious mental illness (SMI), the risk for developing diabetes is estimated to be twice that of the general population (Gold & Kilbourne, 2008).

The President’s Commission on Persons with Intellectual estimates that between seven and eight million Americans of all ages, or three percent of the general population, experience intellectual disabilities (ID). Nearly 30 million, or one in 10 families in the United States, are directly affected by a person with ID at some point in their lifetime. Van Schrojenstien et al. (2000) estimated that people with ID generally have chronic disease at rates around twice that of the general population. The exact prevalence of diabetes mellitus in people with ID is unknown, as little research has addressed this issue, but it is likely to be higher than in the general population for various reasons. For instance, type 1 diabetes is up to 35 times as common in people with Down’s syndrome (Anwar et al., 1998). Type 2 diabetes is also common, but there is no reliable estimate of its prevalence.

Both of the ID and SMI populations face increased risk of developing diabetes and other chronic diseases for multiple and diverse reasons. Both populations have high rates of health-related behaviors that increase risk including poor nutrition, inadequate physical activity, and tobacco use (less so for people with ID). Both populations are prescribed psychotropic medications that affect blood sugar regulation and weight management. These individuals tend to belong to demographic groups that also have an increased risk of developing diabetes—minimal education and low income. People with less than a high school diploma and those with income less than $15,000/year have twice the incidence of diabetes as those with a college degree or an income greater than $50,000/year (Thomaskutty & Dwivedi, 2011). Additionally, on average, they die earlier, are seen less often by primary care physicians, receive fewer referrals for preventative care, and less frequently receive recommended standard of care less frequently than the general population (Evenhuis et al., 1997; Jones & Kerr, 1997; Nasrallah et al., 2006). Those living in rural areas even have greater challenges given reduced access to health care providers.

Needs Assessment

Before developing this program, Affiliated Service Providers of Indiana, Inc (dba ASPIN) conducted a needs assessment in the state. The need for coordinated, integrated care to encourage compliance and provide appropriate access to primary care was established through five processes: 1) a statewide electronic survey of over 900 human service providers, primary care providers, educators, and community leaders; 2) 10 focus groups conducted in the 10 public health districts of the state; 3) a survey of care support personnel for persons with chronic mental illness or intellectual disabilities; 4) qualitative interviews of key administrators in relevant organizations, and 5) a review of demographic data which highlighted rural counties with the highest concentrations of persons with diagnosed diabetes or mortality rates from diabetes.

The electronic survey, circulated in June of 2008, identified the top special populations in Indiana in terms of prevalence. Persons with mental illness and/or intellectual disabilities were among the top five populations named. In addition, respondents requested training to work with persons with these diagnoses.

These data were subsequently corroborated in the 10 focus groups in July of 2008. ASPIN staff went to all regions of the state to find out,
from regional perspectives, what the training needs were for working with various special populations. These focus groups were open to consumers and their families, and advocate representatives were encouraged to attend. Again, in nine of the 10 focus groups, persons with mental illness and/or intellectual disabilities were prioritized in terms of prevalence and in terms of the need for training to work effectively with the populations.

In August and September of 2008, interviews were conducted by phone and in person to understand the need and potential for a multidisciplinary approach to care integration. Interviews were conducted with upper level administrators of seven key service provider groups. These groups included a private, not-for-profit, multistate provider of services to persons with intellectual disabilities; the state agency responsible for services to those with disabilities, the elderly, and rehabilitative services; the state agency serving care providers for persons with intellectual disabilities; the state agency responsible for Medicaid policing and planning in rural areas; two managed care organizations; a consortium of all community mental health centers in Indiana; and the ASPIN Board of Directors. Through these interviews, the topic of improved compliance in the management of diabetes in these populations surfaced as a need.

In September of 2008, a needs assessment instrument was disseminated among direct care workers for the target populations including managed care workers, mental health case managers, and waiver case managers to identify issues in diabetes management within the population. The top responses related to diet/nutrition, activity/exercise, glucose monitoring, sufficient medical supervision and preventive care, inconsistent supervision in the home environment, and medication compliance. These issues served as the genesis for the chosen curriculum to be developed through Project ICE. Survey responses also identified training needs focusing on strategies for working with the population and greater general knowledge about diabetes.

Lastly all the counties in Indiana were examined based upon the demographics of counties with highest rates of diagnosed diabetes and/or diabetes mortality rates, cross-referenced with rurality and levels of available health care professionals to serve the populations (CDC, 2010; ISDH, 2006). This analysis generated a list of 36 rural Indiana counties as most in need of diabetes intervention (see Figure 1).

Project Overview

Focus

ASPIN is a 501(c) 3, nonprofit behavioral health provider and education network. Incorporated in November of 1995, ASPIN offers access to clinical providers in more than 50 locations throughout the state of Indiana. This project was funded under a three-year Rural Health Care Services Outreach grant by the Health Resources and Services Administration (HRSA), Department of Health and Human Services. The population targeted for training under Project ICE included mental health professionals, intellectual disabilities professionals, managed care managers, physicians, nurses, and other medical office personnel who work in the 36 counties of focus. It was projected that, within those 36 counties, more than 5,000 consumers with mental illness and/or intellectual disability diagnosed with diabetes or at-risk for developing it could be touched by those who were trained under this grant.

To impact the management of three chronic illnesses in this population, care providers need an understanding of the complexities of the three possibly co-occurring issues and be able to coordinate nutrition, exercise, medical care, and diabetes self-management for these individuals. Therefore, a specialized curriculum was developed that cross-trained care workers in mental health, intellectual disability, and diabetes management concepts including tools for in-the-field communication with clients and their caregivers. Providing a uniform curriculum enhanced cross-discipline knowledge and created a shared foundation for communication which empowered the care support providers and established a coordinated and consistent way of talking about, supervising, reminding, and supporting diabetes management.

Program Activities

The Project Director, an LCSW with a Certificate in Diabetes Management, and a consortium of partners supervised the coordination, logistics, and development of materials for proj-
ect activities. This consortium consisted of ASPIN; two Indiana Medicaid Managed Care Organizations, MDWise and Advantage Care Select; a multistate provider of intellectual disability services, Anthony Wayne Services; and an evaluator. The consortium also had an advisory member from the Indiana State Office of Medicaid Policy and Planning (OMPP). This member helped to guide the project and was responsible for the provision of outcome data reports.

The overarching goal of increasing the baseline knowledge and skill level of care support persons working with individuals who have a SMI and/or an ID and who have or are at risk for developing diabetes was accomplished using a complement of

Figure 1. Grant-targeted counties.
educational formats. These activities included a series of trainings that were disseminated over a three-year period, a list-serv, and a website.

In the first year, a day-long, three-part, in-person training was developed which included fundamental information about the genesis, identification, and management/treatment of mental illness, intellectual disability, and diabetes. The training also included information about the interrelatedness of these conditions and ways to improve work with clients and coordinate care. This training was presented in seven regions of the state to accommodate all 36 targeted rural counties. It was also provided to the care managers of the two Managed Care Organizations that partnered on this project as they work throughout the entire state with members and providers. After the face-to-face trainings were completed, the training was converted to an online format and archived on the ASPIN Educational Network’s learning management system (LMS). This format allowed for continuous, asynchronous availability to others.

In the second year, three 2-hr webinars were developed and broadcast live across the state. The content of the three webinars included medication management, proper nutrition, and physical activity needed to properly manage diabetes. These trainings presented evidence-based and best practices in these three areas, including interventions such as the plate method for proper nutrition, the Diabetes Prevention Program, and federal guidelines for physical activity, weight loss, and diabetes risk reduction, and motivational interviewing, cognitive-behavioral interventions, and other methods for promoting treatment compliance in these two populations. These webinars were also recorded and archived on the ASPIN learning management system (LMS) and offered at no charge as online courses.

In the third year, an hour-long, online training was developed for staff working within primary care offices. This training provided information on the health disparities experienced by people with mental illness and intellectual disabilities, the importance of primary care to these patients’ health, and concrete strategies to manage problematic behaviors and disabilities to optimize the content and value of office visits. This training was placed on the ASPIN LMS with two previous years’ training.

One-shot training experiences often have a halo effect, with limited transfer of skills, philosophy, or carry over momentum to the work environment. Therefore, this project also developed a list-serv and website to extend the impact of the trainings, to support continued intervention with clients, and to serve as a conduit for further professional development. The Web site provided statistics, information resources, and links to information and tools on diabetes, mental illness, and intellectual disabilities. Web site content changed regularly as new studies, resources, and information became available. The list-serv was used to disseminate updated information about these topics to participants once or twice each month to enhance knowledge and skills and keep these issues on mind in their daily work.

As the project progressed, customized trainings were requested. The two MCO’s sponsored two training sessions at their annual provider conference. Other venues included the annual conferences of a local university for National Public Health Week and the Indiana Rural Health Association. Presentations and occasional updates were also provided to OMPP’s Behavioral Health Quality Improvement committee and the Indiana State Department of Health’s Diabetes Council.

Evaluation

Project outcomes were evaluated in a number of ways. OMPP provided a quarterly report with specific measures from their database on Medicaid members in both Traditional Medicaid and Care Select who were receiving Comprehensive Diabetes Care and had an ID and/or MI diagnoses. These measures included demographic, services utilization, and HEDIS measures. Demographic measures included number of members in program along with age, gender, racial, and ethnic make-up. Service utilization measures included percent of members using emergency room visits, average number of emergency room visits per member using the emergency room, percent of members using psychiatric inpatient services, average number of days for psychiatric inpatient services, percent of members using other inpatient services, average number of days of other inpatient services, percent of members receiving primary care visits, and average number of primary care visits received. HEDIS measures included HbA1c testing, LDL-C screening, retinal eye exam, and medical attention for
nephropathy. Figure 2 gives examples of the baseline data for a number of these measures over the three-year grant period and reinforced the need for this project as they are well below Medicaid benchmarks for each.

**Results**

The following results were realized during this project. The project performed outreach to and created awareness in more than 7000 providers and formally trained over 565 in mental health and primary care arenas. During this project, the number of members on the Medicaid programs surged from 5029 in 2008 baseline data to 10,710 in the third quarter, third year data. The Project ICE website received an average 96.3 unique visitors each month in the first year, 153 in second year, and 202 in the third year. The list-serv maintained an average membership of around 200 individuals for the course of the three-year grant.

![Chart of LDL-C Screening, HbA1c Testing, and Medical Attention for Nephropathy](chart.png)

Figure 2. Indiana baseline HEDIS measures for comprehensive diabetes care. Data provided by the Indiana Office of Medicaid Policy and Planning, 2008.
The only statistically significant change in Medicaid indices occurred in utilization numbers for primary care visits which increased significantly among the targeted members and counties. This result is important given the historically low level of care experienced by these populations. Although other changes had not reached statistical significance, there were continual and gradual increases each quarter in a few other measures. These measures included HbA1c, LDL, and nephropathy screenings.

During the final year of the grant, an online survey of training participants was conducted. Through this process, it was found that participants were actively implementing information gained through Project ICE. Participants reported increasing referrals to primary care physicians, dieticians, and MCO care managers. Some identified increases in medical screenings/assessments and improved coordination with primary care providers. Others identified some success in healthier meal planning, increased exercise, stabilization of blood sugar, reduction in diabetic complications, and prevention of developing Type 2 diabetes in some clients. Two survey participants indicated that they were contemplating substantial system changes as a result of the training. One was compiling data to make a case to providers to change treatment planning strategies, and another was creating a business plan for a new department in their hospital.

**Discussion**

**Implications**

The more than doubling of Medicaid members who were receiving treatment for SMI or ID and diabetes during the tenure of this grant was probably a result of many factors occurring in the state but represents an important confirmation of the need for an integrated approach to treatment. Not improving clinical outcomes has serious social implications for the state and nation including reduced quality of life and disability for these members and increased expense for the state from increased utilization of medical services, utilization of more costly treatments, and loss of productivity.

This project represents a potentially useful model for a number of reasons. Access to primary care was increased significantly and important assessments and screenings, including HbA1c, LDL, and assessment for nephropathy, were continuously increasing and held for the duration of the project. Perhaps, these changes would have reached statistical significance given more time and opportunity to reach more providers. Because trainings are provided online, we can track this possibility. The survey of participants demonstrated that some had taken the information to heart and were implementing it into their daily practice.

This project presents a model for disseminating a vast amount of information in a cost-effective and time-efficient manner to multiple providers in a broad, rural geographic area. Although many studies have shown that education alone does not produce behavior change, it is the foundation for all change. Trainings that are made available in live and archived formats allow providers to participate in a training that suits their time constraints, financial considerations, and learning style. This model also reduces costs to both the training facilitators and the participants. The information is given in digestible dosages in short periods of time, which decrease time away from work and loss of productivity. Rural providers receive additional cost savings from live webinar or online formats in the form of decreased travel time and expense. Archived trainings and even webinars are less expensive for the facilitating organization to deliver because they can be given to more individuals simultaneously and in shorter formats. A reduction in the cost of production can translate to a reduction in cost to the consumer of training. Also, archived trainings can provide continuous access and are more cost-effective to sustain given reduced staff time needed to maintain and deliver them.

These types of training formats also facilitate mixing, discussion, and dialogue among multiple providers from different professions and different locations throughout the state. Such interaction can improve understanding of each other’s system, limitations, barriers, and challenges and encourage better coordination and communication. It also encourages the silos of behavioral health and primary care to see these issues as connected and to address them more holistic. This is particularly important in rural setting where providers can be scarce.

Using a consortium was beneficial as well. Collectively, consortium members were able to
facilitate access to multiple provider systems. They also helped by marketing trainings to their own staffs, network of providers, and contacts. Both MCOs offered additional Project ICE training internally and at provider meetings. Consortium members had different expertise and audiences, which made the trainings more comprehensive, accurate, and applicable when developed by the team. Developing a Consortium of stakeholders motivated to improve the outcomes in their constituents supported investment and cohesion. Additionally, the partners we chose were programmatically responsible to the entire state so they were invested in any area we targeted and themselves had contacts in those regions.

This model is very flexible and could be replicated in or adapted to most rural settings. However, providing the variety of training modalities would require appropriate technology and staff competency. Organizations would have to have equipment (computer, recording ability), software (LMS, conferencing software), and connectivity (Internet with sufficient bandwidth). However, given the technology, the provider of the training would not necessarily need to be located in the rural area, and most agencies have computer access these days.

New questions and needs arose in the process of program delivery. For instance, at almost all trainings, participants requested more training on the evidence-based methods recommended such as motivational interviewing, particularly as it pertained to chronic disease self-management behaviors. Also, most participants discussed the difficulty experienced in finding affordable healthy foods and exercise outlets for the clients. A lack of partners and referral linkages to meet community needs was identified. Workforce gaps were also expressed, leading to a desired role for community health workers and/or recovery specialists to engage clients and encourage whole-health behavior change.

Challenges

During the three-year grant period, there were many challenges to implementing activities and achieving the goals. The largest disruption occurred in the second year of the grant. Indiana was revising its Medicaid Rehabilitation Option rules and regulations. These changes posed significant logistical and financial challenges for the Community Mental Health Centers which were a large audience for trainings. Facilities began to cut expenses including staff and cost associated with staff development, making it difficult to attract significant numbers of providers to attend trainings. For example, we had approximately 75 people registered for each webinar, but only 18–25 people actually participated when broadcast. This reduction was largely attributable to staff turnover, staff choosing not to attend to meet increased productivity demands, and staff being reassigned tasks on the day of the webinars. Recording and archiving trainings and placing them on the ASPIN LMS were key to recouping much of this loss over the duration of the grant.

Another challenge arose within the consortium. One of our MCO members received a reduction in a contract from the state and the staff originally assigned to the consortium was released from employment. Staff from this MCO had to be reassigned twice over the next year, which broke some continuity as these staff did not have the institutional memory and had significantly more responsibilities due to staff reductions. Also the State Office of Medicaid Policy and Planning was experiencing significant staff turnover; however, the agency maintained its commitment and the project continued to receive data uninterrupted. Despite this turnover, the consortium continued to function as planned, and its existence did make a difference to the project. Again, we believe that choosing parties with existing, internal interests and investment in the project goals was the key consortium cohesiveness and dedication. Individual meetings with new consortium staff members to explain the project, having regular contact with members, and making overtures to participate in significant ways contributed to cohesiveness and investment.

A third challenge was that the outcome measures chosen were not sensitive enough to overcome the scope of the large outreach area to measure appreciable results within three years using a training intervention. We could not ensure that we could train enough providers in 36 targeted counties to obtain a large enough change in provider behavior, client treatment processes, and client behavior to significantly shift our outcome measures at the statewide level. In future projects, we would recommend...
targeting a smaller area and partnering with agencies that may be able to provide clinical outcome data that is more responsive, sensitive, and directly related to the intervention.

References


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