The Real World is a Messy Place:

The Challenges of Technology Use in Care Provision

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***Abstract*—This paper reports on the ongoing demonstration project to assess the effectiveness of three distinct eHealth technologies to contain costs, make the provision of care more efficient, and to contribute to the wellbeing of individuals with intellectual and developmental disabilities and severe mental illness by increasing their independence. The challenges of providing care for these populations is discussed, as well as the demographic trends that will, over time, not only result in a threefold increase in the number of individuals in populations, but dramatically impact the cost of their care. Data collected from 14 different locations over the past three years will be discussed in order to determine if the selected technologies resulted in an improvement in living conditions and wellbeing, and to judge the acceptance of the technologies by both staff and customers. Findings indicate that the technologies have largely exceeded expectations resulting in plans to expand the project to other facilities, to build a new residence in which all the tested technologies will be installed and to begin to move beyond company owned facilities into residences within the community.**

***Keywords*—real world; intellectual and developmental disabilities; severe and persistent mental illness; eHealth; demonstration project; multiple technologies; financial impact; business decisions**

I. INTRODUCTION

The impetus behind the inception of this Project was the recognition that the only way to provide cost effective care to individuals with disabilities and severe mental illness, is to incorporate appropriate technologies into existing care models which is the driving force for a multi-year, multi-site demonstration project being undertaken in the eastern United States. Findings from the first Stage of the Project [1] were so encouraging that a second Stage is underway and a third being planned.

The urgency to contain the cost of delivering care to a wide range of populations has seen the development of new technologies, as well as the innovative use of existing technologies, in an ever enlarging number of care models. Thus, it is not surprising that new and reconfigured eHealth technologies are increasingly being used to provide care and services to individuals with Intellectual and Developmental Disabilities (IDD) and those with Severe and Persistent Mental Illness (SMI) [2][3]. As in the use of new technologies, in each and every care model there are challenges to using innovative technologies in addressing the needs of these two populations, but the necessity to contain, and if possible, reduce the cost of providing care to these populations, makes the use of technology, in some form, inevitable. However, three different trends intersect in such a way that result in the urgency to develop more efficient care models for the IDD and SMI populations: the cost of care; the aging of the two populations, and a reduction in the number of qualified staff providing care to the IDD and SMI populations.

First, because of a wide-spread belief that very large state-run institutions resulted in dehumanizing individuals with disabilities, deinstitutionalization, in both the United States and Europe took place from the mid-1960's through the 1970's. This process of deinstitutionalization had a dramatic impact on the care models employed [4][5]. Between 1967 and 2008, the population of individuals with disabilities in large state-run institutions declined from a peak of 194,650 to 32,909 in 2009 [6]. The impact of this massive deinstitutionalization on the cost of care varied significantly, but the impact on the care model was significant as most individuals with IDD and SMI moved into the community, many living in some form of group home. The number of individuals living in any particular group home varies based upon the needs of the individuals. The most common number of residents is four with some group homes having as many as eight to ten residents. In the most severe cases, an individual lives alone in a residence with 24 hour supervision. Although costs of providing care to the residents in group homes vary based upon the needs and location, the average cost is between $40-50,000 per year per resident and if an individual needs to live alone, the cost can top $150,000 per year [5][7].

Second, the rapidly increasing number of such individuals brought about by the same demographic factors as for the general population is adding even greater cost to the care of IDD and SMI populations [8]. In particular, it is estimated that the number of adults with disabilities will almost double between 2000 and 2030 to over 1.2 million [9]. As individuals with IDD or SMI age, they are as susceptible to chronic illnesses as the general population, but the cost of caring for them is much greater. For example, care for an individual with IDD who has congestive heart failure costs approximately eight times more than for a person without IDD [5]. The ratios for other chronic diseases and individuals with IDD versus SMI vary somewhat, but the reasons are consistent. Many individuals with IDD and SMI make poor lifestyle decisions—use tobacco products and abuse alcohol and drugs. In addition, many are unable to self-manage disease, e.g., adhere to

complicated medication regimes and follow complex health care instructions. Thus, greater cost of care for individuals with IDD and SMI when combined with the cost of residential care in general, results in a compelling reason for attempting to use technology to contain costs.

A third reason is that there is an increasing imbalance between the growing needs of the IDD and SMI populations and the number of qualified staff available to provide care. Projections from the federal government suggest that the need for trained staff will increase by over 30% in the next decade, while the supply of individuals who traditionally have filled these jobs is expected to increase only by 7% [10]. In addition, the high turnover rate for individuals caring for these populations adds another dimension to the staffing challenges. It is estimated that turnover for direct support professionals (DSPs) ranges between 50-70% depending on the specific jobs undertaken, e.g., residential care versus in-home care. This high turnover rate adds at least $2,500 in direct expenses plus a minimum of an additional $1,000 of indirect expenditures for an organization to replace a single DSP, thus adding to the ever increasing cost of providing care to these populations [11].

In the next section, a brief discussion of attempts at using technology to provide care for these populations is accompanied by a short description of the the overall goals and objectives to be achieved by the introduction of the new technologies. In Section III, the different Projects undertaken are described along with the care models employed and the technologies introduced. The next section discusses the methodologies employed in gathering data on the individuals with disabilities and mental illness and staff in order to assess the effectiveness of the technologies in care delivery, while Section V offers a discussion of findings for the first two Stages. What has been learned from the analysis is summarized in the Discussion Section, while plans for the roll-out of the technologies to other facilities and the financial model to pay for this expansion comprise the concluding section.

II. THE PROJECT

Even though NHS Human Services, through its subsidiaries, is one of the United States' leading non-profit providing education and human services to individuals with special needs., it was clear by 2012 that to be able to continue to provide cost-effective and high quality care to individuals with disabilities and severe mental illness, it was essential to introduce new and innovative technologies into existing care models. As a result, in the spring of that year, the organization created an Assistive Technology Executive Steering Committee to plan a demonstration project. One of the first tasks of this Committee was to assess the state of related work.

A. Related Work

It was quickly apparent that there had been few other attempts to utilize technologies in a similar manner. From its inception, the Project was viewed as a demonstration project to assess both the benefit that could be gained by incorporating specific technologies into existing care models, and the ability of the company to pay for the use of the technologies. As such, the Project was neither a pilot study of the use of a specific technology within a controlled environment [12], nor a short-term, funded research project [13], nor a study relying on a small number of volunteers to evaluate the effectiveness of a given approach to the use of a selected technology [14]. Thus, previous studies were of only limited help in the planning and implementation of the project.

Certainly, the fact that the selected technologies had all been tested and were all commercially available was a definite advantage for the Project and saved much time and money. However, the downside was that many of the technologies had been tested by a relatively small number of individuals, usually 20-50, and in controlled environments [15][12][13][14]. Given that the goal of the Project was for the selected technologies to be used in the provision of care for hundreds and, eventually, for thousands of individuals within the normal care model and not in a laboratory or controlled environment proved challenging. It is one thing for a technology to be effective in a controlled environment being used by carefully selected individuals, and another to be incorporating the technology into existing care models within the community.

Another limitation on the usefulness of related works was that the majority of studies of individuals with disabilities that exist focus on children within the context of school [16][17][18], rather than adults living in the community. Some studies of younger populations did prove to be of limited utility because of the convergence of similar technologies, i.e., iPad, but most were too focused on educational issues to be that helpful. A final limitation of the literature, even if the populations were similar, was that the rapid advances in technology made many of the studies, even if conducted less than a decade ago, out of date [19][20][21].

Nevertheless, the related work did confirm one of the basic premises that motivated the Project in the first place, that the utilization of technologies in the provision of care to individuals with disabilities and severe mental illness is limited [22]. Given the trends outlined in the Introduction, this underutilization of technology must be rectified. Consequently, the effort to use a series of technologies within the NHS care system should be viewed as more than just a localized demonstration project; it is, in reality, a test of the resolve to make these technologies widely available within the larger IDD and mental health communities [23].

B. The Strategic Plan

The planning process was inclusive and there was a recognition that in order to "do it right" it would take time to put everything in place. The first step was to encourage employees to propose sites at which new technologies could be used. During the remainder of 2012, proposals were received and evaluated based upon specific criteria: administrative and staff buy-in; existence of suitable

technology; evidence that technology would enhance care provision; evidence that, if successful, the technology could be used at a large number of other care facilities within the organization; and a financial model showing that the technology was sustainable—the organization would be reimbursed for its use. Finally, there was an attempt to achieve a rough balance among the different care models employed throughout the organization. This process took over a year which afforded a thorough evaluation of the resources available at each of the selected sites. The final decision was confirmed at an all-day meeting of administrators and representatives from each of the chosen sites in the fall of 2013.

C. The Project Goals

As planning progressed, three main goals emerged: 1) to determine which, if any, of the technologies being tested can allow for an improvement in living conditions and the care being delivered in the selected facilities; 2) to judge the acceptance of the technologies by both the staff and individuals with disabilities and mental illness; and 3) to assess whether the technologies should be rolled out to other facilities with similar care models. In order for any of the Projects to be deemed successful, it was necessary to determine if the new technologies allowed for an improvement in living conditions and the care being delivered in that the individuals with disabilities and mental illness express that their lives are better after the introduction of the technologies than before. It was also necessary to determine if care delivered is more timely, efficient and cost effective than the care delivered without the technologies.

It was also essential to ascertain if staff could properly use the new technology, that they believed in its effectiveness, and accepted that the technology would require that they did their jobs differently. Likewise, it was necessary to determine if the individuals with disabilities and mental illness accepted the use of the new technologies in the care that they received, if they were intimidated or not by the technologies and if they would willingly comply with requirements for the use of the technologies. Finally, even if it was determined that the new technologies provided improved care, were accepted by staff and individuals with disabilities and mental illness, it was still vital to find out if the care provided with the new technology was reimbursable as a billable expense.

D. Project Timeline

Given the challenges of incorporating multiple technologies into existing care models, the Assistive Technology Executive Steering Committee decided that it was best to start slowly with a gradual roll-out, rather than trying to introduce multiple technologies simultaneously. Although this gradual approach meant that some components of the Project would begin before others, thus risking the loss of initial enthusiasm, the ability to focus on getting one technology up-and-running, instead of having to deal with potential problems with three technologies, appeared prudent.

In addition, a preliminary plan was developed for the roll-out of the technologies to other locations, if, of course, they proved successful in providing care and were cost effective. Once again, a measured approach was taken and a two-step roll-out envisioned. The first expansion would be to a small number of locations that mirrored the initial test sites in care model, size and staffing.

Rather than create a formal timeline for the Project, a three-stage timeline that relied on measured success, rather than arbitrary dates was formulated. This flexibility was possible because the Project was largely self-funded and because long-term success in incorporating the selected technologies into the organization's care models far outweighed any short-term success brought about by reaching arbitrary benchmarks.

III. THE TECHNOLOGIES AND LOCATIONS

After reviewing the submitted proposals, the Assistive Technology Executive Steering narrowed the proposals to three that were to be part of the first phase of the Project: 1) the Communication Technologies Project (CTP); 2) the Smarthome Project (SHP); and 3) the Biometrics Project (BMP). Based upon the desire to stagger the start dates of the three Projects, it was decided to begin the SHP early in the summer of 2014, followed by the CTP in late summer and the BMP later in the fall. Although the SHP began slightly before the CTP, the CTP has advanced at a faster rate than the other two Projects which were delayed by unanticipated problems in the renovation of facilities and the equipment to be used to monitor vital signs.

A. The Communication Technologies Project (CTP)

The CTP began in the late summer of 2014 with the selection of sites and upgrading of wireless routers. Work continued during that summer with the focus of training staff in the use of AbleLink software [24] that had been selected for use and during the fall of 2014, staff and individuals with disabilities were surveyed and the Glasgow Depression Scale (GDS) administered to all individuals with disabilities participating in the Project [25][26]. The main goals of the CTP was fourfold: to enable individuals with disabilities to stay in touch with family and friends; to allow a greater ability for them to communicate with members of the support services team; to encourage them to acquire basic computer skills; and to permit safe and secure access to the internet in order for them to pursue their particular interests. Seven sites were selected for inclusion in the first phase of the CTP. Five of the sites are group homes and two program centers, all in Western Pennsylvania. The group homes are single sex residences for between three and six individuals. In contrast, the two program centers serve between 90 and 130 individuals on any given day.

The hardware introduced into the five group homes were iPads and laptops while at the day programs, all-in-one desktop computers, laptops, tablets and iPads were made available. The hardware was customized to meet the needs of

the IDD population, e.g., large keyboards, headphones. After much research, a software package designed specially for individuals with cognitive disabilities—AbleLink—was purchased and installed. AbleLink allowed individuals to experience a more self-determined and fulfilled life through an empowering technology characterized by a person-centered design philosophy. Several AbleLink applications were installed that allowed individuals to use email (voice activated), Skype and webcam broadcasts, along with providing prompts for tasks that increased independence.

In 2015, the CTP was expanded to include three additional locations in Pennsylvania and Virginia: a large congregate intermediate care facility (ICF) and two adult training facilities (ATF). The ICF has 103 residents, of whom 30 are included in the project while the Pennsylvania ATF has 29 individuals receiving services of whom 16 individuals are participating in the Project and the Virginia ATF has twenty-two individuals receiving services with 10 participants in the Project. The ATFs are non-residential centers which provide services in functional activities, assistance in meeting personal needs and assistance in performing basic daily activities to individuals who are 59 years of age or younger and who do not have a dementia-related disease as a primary diagnosis. Unlike the first Stage, rather than laptops, tablets and iPads being made available to the participants, AbleLink applications were enabled on all-in-one computers. This configuration was deemed to be the most useful equipment for their client base and size within these facilities.

Three additional sites have been selected for inclusion in the third Stage of the CTP: a large congregate intermediate care facility with an estimated 30 participants; a large adult training facility with an estimated 60 participants and a smaller adult training facility with an estimated 29 participants. Currently, funding is being secured to enhance the internet capabilities in the three facilities, and training of the identified staff has begun with the goal of all three facilities being up-and-running in the fall of 2016.

B. Smarthome Project (SHP)

The SHP required a remodeling of a residential unit which faced construction problems delaying the start of the Project several months. However, by the summer of 2014, the four residents were able to move into the remodeled facility and be administered surveys and the GDS. The main objectives of the SHP were to increase the independence of the four IDD residents and to conserve energy through the use of "green" appliances and more efficient heating and air conditioning systems (HVAC). To achieve the goal of increasing the independence of residents, a Smart TV was installed, iPads and remote controls for lighting and window blinds were made available to them. Additionally, motorized cabinetry and cook tops and sinks were installed in a lowered position to allow wheelchair access. Finally, to reduce the amount of energy consumed, remote control HVAC systems and smaller and more easily accessible dishwashers and refrigerators were installed.

NHS' second Smarthome Project is currently in the planning phase. Over $650,000 in funding has been secured to build a brand new facility, as opposed to retrofitting an existing residence. The building plans include a six bedroom residence to support the six individuals who will live in the wheelchair accessible home. The home will be designed to include: a fully accessible kitchen; home automation system; tintable window technology/moveable blinds; green components; more accessible bathroom components; and the CTP technology and biometrics system used in the other two projects.

Given the cost of building new Smarthome facilities, there are no concrete plans to expand the SHP beyond the currently planned location. However, the goal is to gradually include smart technology in renovations of existing homes and build new facilities incorporating all previously used smart technologies that have proven to be sustainable and useful in the everyday lives of the residents, as well as additional technologies that can increase independence.

C Biometric Project (BMP)

The BMP began in the summer of 2014 with the development of protocols, the installation of the technology, training of staff, retrospective data collection, the creation of event and error forms and administering surveys to residents and staff and the GDS to the residents. The main goal of the Project was to use technology to reduce the number of emergency room visits and hospitalizations and thus, by doing so, curtail costs by delivering care in a more timely manner and at a lower level of care [27]. Two group homes with four residents each were selected for inclusion along with a Long Term Structured Residence (LTSR), a locked facility that served eight male individuals with serious and persistent mental illness. The technology installed was a basic vital signs monitoring system including a digital scale, blood pressure cuff and pulse oximeters. The software included with the system allowed data to be sent to an external location and was configured to send alerts when the data collected went outside preconfigured parameters.

Planning for Stage 2 of the BMP began in 2015, but the project has yet to get underway because of the complexity of the facility selected. The location is a large adult behavioral health outpatient clinic serving over 400 individuals. The goal is to use a vital signs kiosk for the purpose of capturing basic biometric measures, initially blood pressure and weight, during the intake procedure. The plan is to electronically transfer the collected data to both the individual's psychiatrist and general practitioner in real time and be available in the individual electronic record. In addition, the goal is to be able to display a longitudinal record on the vital signs and have a warning system that indicates when any one of the vital signs is outside the normal range.

Preliminary plans for a Third Stage for the BMP are under way, in which a vital signs monitoring system is installed in the residences of individuals living in the community. The goal of the Stage is to have the data collected sent for review and evaluation by a clinical professional who could consult

with the individual by phone or video for the purpose of providing reassurance and/or guidance for the next step in receiving additional care. It is anticipated that the initial systems will be installed by the first quarter of 2017.

IV. METHODS

There were several challenges to the selection of the methods to use to collect data on the three Projects. First, the Projects were not a test of the technologies themselves, as it was already known that they worked. Instead, the objective of the Projects was to determine how the selected technologies could be used to enhance the provision of care, while at the same time curtailing the cost of that care. Thus, the methods had to capture specific data on various components of care delivery. This entailed collecting data on the staff at each of the sites, both the way they used the technologies, and their level of acceptance and willingness to change how they did their jobs. Data also had to be collected on the level of acceptance of the technologies by individuals at each of the sites. If individuals were uncomfortable with the use of the new technologies it would not be possible to roll out the technologies to other facilities. Secondly, although ideally the same methods of data collection would be used at each of the sites, this proved impossible because of the differences in the nature of the sites and the care models employed.

A. Communication Technologies Project

The main challenge was to develop questions that could be answered by individuals with disabilities and would, at the same time, provide the data necessary on which to make future decisions [28][29]. Achieving these twin goals necessitated the development of a Project-specific questionnaire for the CTP, which included simple straightforward questions and took no more than 15 minutes to administer. The questions asked included:

- Which of the following electronic devices do you use to communicate with friends, family or other people?
- How much help do you need to use these devices?
- When you want to communicate with friends, family or other people, how often is the device available?
- What devices do you use to play games or watch movies?
- How much help do you need to use these devices to play games or watch movies?
- When you want to play games or watch movies, how often is the device available?

The questions were to determine the amount of change that took place in both device use and amount of help needed by individuals with disabilities during the length of the Project. Staff were trained to administer the questionnaire to individuals with disabilities at each of the sites with the goal being that the same staff member at each of the sites would administer the questionnaire at initiation of the Project and at three, six and 12 month intervals. However, this proved to be difficult because of the high rate of staff turnover. Thus, in order to minimize the impact of staff turnover for the CTP and the SHP, specific staff at the program centers and the individuals' case workers were designated to conduct the surveys.

The staff questionnaire was self-administered and, similar to the questionnaire for individuals with disabilities, was repeated at three, six and 12 month intervals. The GDS was administered by staff members at the inception of the Project and six and 12 month intervals.

For reasons that are discussed below in Section E, the GDS was not administered to individuals in the second Stage of the CTP. All other instruments were used to collect data in the three facilities in Stage 2 and it is anticipated that they will be used in the locations in Stage 3.

B. Smarthome Project

The methods used for the SHP were closely matched to those used for the CTP: Project-specific questionnaires were given to the residents at the initiation of the Project and three, six and 12 month intervals; likewise the GDS was administered at the initiation of the Project and six and 12 month intervals. Questions focused on the ability of the residents to undertake basic tasks within the home, e.g., meal preparation, putting away groceries, controlling the lighting and blinds in their rooms, using computers and other electronic devices, using email to communicate with family and friends. Thus, it was possible to determine changes in both the residents' ability to use the new technologies and the impact on the technology of residents' well-being.

C. Biometric Project

The methods employed for the BMP, to a large extent, mirrored those for the other two Projects with a couple of exceptions. Staff were surveyed at the beginning of the Project and after six and 12 months. Questions for the staff focused on:

- The comfort level of staff members in the use of the biometric devices;
- The reliability of the devices;
- The acceptance of the devices by individuals with disabilities; and
- The perceived change in the quality of care with the use of the biometric devices.

Similarly residents at the three facilities were administered questionnaires and the GDS at the inception of the Project and at six and 12 month intervals. In addition to these instruments, event and error forms were developed for use. The event forms were used to record each event triggered by a biomedical alert, the actions taken by staff in response to the event and the outcome, e.g., a visit by a nurse, emergency room visit or hospitalization. The error forms were used to record problems with the various devices comprising the vital signs array, steps taken to correct the problem, the potential

risk to the health/safety of the residents and how the problem was resolved.

D. Limitations of the Methods

There were several factors which limited the effectiveness of the data collection and the quality of the data. First, the fact that individuals at all the sites had either developmental and intellectual disabilities or were diagnosed with severe mental illness limited the type of questions that could be asked and often required prompting by the staff member administering the instrument. Secondly, although not optimal from a research perspective, given the scope of the three Projects, it was necessary for staff to administer the questionnaires and GDS. These staff members were para-professionals whose main responsibility was not research, but instead, the delivery of care. Staff turnover also impacted the ability of the questionnaires and scales being administered at the designated intervals. Finally, and perhaps most importantly, the Projects were not research per se, but a real world evaluation of the effectiveness of technology within challenging care models. In other words, the information collected was that which could help NHS determine whether the technology installed in the sites should be rolled out to other facilities, rather than what would necessarily be collected in a controlled research project.

E. Modifications in Methodology

The limitations outlined above have resulted in modifications in the methods used during the second and third Stages of the Project. The most significant was the discontinuing of the use of the Glasgow Depression Scale for three reasons: 1) no significant differences were obtained when the results from the pre-Project and the six and the 12 month intervals were compared, primarily, it is believed, because of the small sample size; 2) in the vast majority of cases, the GDS was not filled out by individuals receiving services, but instead by a caseworker, which violated the GDS protocol; and 3) the close contact between individuals and case workers provided a better guide to the psychological state of participants than the use of the GDS.

The inclusion of the outpatient clinic in Stage 2 of the BMP will also require significant changes in the methods employed. Brief questionnaires will be used to ascertain both the acceptance of the kiosk by individuals receiving services and the acceptance by staff. An event form, similar to that used during Stage 1 of the Project, will be used to track the care delivered when one or more of the vital signs for an individual are outside the normal range. The goal is through tracking body mass index and blood pressure to assist in the identification of two comorbid conditions most associated with mental illness—obesity and hypertension—so that appropriate care can be provided. Finally, the kiosk software should be able to create omission reports for missing data and an error form, modeled after the one used in Stage 1, will be used in order to track any problems that may arise with the recording and transfer of the vital signs data.

V. FINDINGS

In an ongoing, multi-year, multi-stage, multi-site, multi-technology Project, in some ways, all findings are preliminary, since data are continuously being generated and will continue to do so for the foreseeable future. However, there are sufficient findings available from the first Stage of each of the three Projects to draw conclusions on the success of the use of the selected technologies. There is also adequate data from Stage 2 of the CTP to present some preliminary findings, but since the second Stages of the SHP and the BMP are still in the planning phase, no data are available for analysis. However, with the completion of the second Smarthome facility in 2017, and the anticipated roll-out of the outpatient clinic in the fourth quarter of 2016, and the home vital signs systems later that year, data will be available for on-going analysis.

A. Community Technology Project

The findings from a comparison of the data collected from the four sets of questionnaires are, from an organization perspective, very encouraging. Questions were asked about the use of electronic devices, both the number of devices used and the purpose for the use of the device. Answers to these questions showed a distinct pattern of the increase in both device use and the number and type of applications used. Sixteen of the 35 individuals (44%) for which data on all four sets of questionnaires are available were using more devices after 12 months than at the initiation of the Project, while fifteen (43%) were using more applications than in the prior 12 months. For the majority of individuals, the added device was a laptop that was made available in their residences. The pattern that emerged was quite clear. Individuals learned to use new applications on the desk-top computers at the day programs and then used the applications on the laptop when they returned to their residences.

The findings for the amount of help that individuals required to use the new devices and applications are a bit more complicated to interpret. The raw findings are: 2 (6%) of the individuals did not need help throughout the twelve months; 11 (31%) of them had no change in the level of help needed to access the devices and applications; 12 (34%) increased the level of help needed to access the devices and applications; and 10 (29%) decreased the level of help needed to access the devices and applications. These data are confusing enough, but in addition, there is no distinct relationship between the individuals who increased their use of devices and applications and the need for help. The amount of staff time required to train staff in the use of the technologies and to help individuals with new devices and applications is a key factor in the decision to expand this Project to other facilities and therefore, having more usable findings is extremely important.

Similarly, the findings from the GDS are ambivalent. Although there is a slight overall decrease in the number of answers that reflect a depressive state for over one-third of the individuals with disabilities, there is no apparent relationship

between an increase in the use of devices and applications and a decrease in a depressive state.

Although the main conclusion that can be drawn from the staff surveys is that the staff believes strongly that the introduced technologies have been greatly beneficial, the findings did expose some problems. A full quarter of staff believed that the technology was not useful for all individuals with disabilities. In particular, those individuals who had problems with reading grew frustrated when attempting to use the various applications. Secondly, almost half of staff reported that there were problems with the applications periodically crashing and/or having difficulty in getting the applications to work properly. However, the data did indicate that over time, the technological problems decreased significantly. Finally, the data confirmed the high rate of staff turnover, as only 12 of the 50 staff who completed at least one survey completed all three. In fact, an equal number—12—of staff completed only the last survey as those who had completed all three.

Findings from the three locations in Stage 2 of the CTP confirm the findings from the analysis of data from Stage 1. Since the findings from administering the questionnaire during Stage 1 at three and six month intervals contributed little if anything to the analysis, it was decided to only survey individuals receiving services and staff at the initiation of the Project and after 12 months. Questions were, once again, asked about the use of electronic devices, both the number of devices used and the purpose for the use of the device and, once again, the answers followed the same pattern: thirty-one of the 38 individuals (82%) reported that their use of electronic devices had increased over the twelve months and likewise, the same number reported that their use of applications had increased. There were two differences between the findings for Stages 1 and 2. The first was that fewer than 25% of the individuals included in the surveys reported that they used no electronic devices at the beginning of the Project, whereas approximately 50% of individuals in Stage 1 reported that they used no devices at the beginning of the project. The second difference between the findings for the two Stages is that a full 23% of individuals in Stage 2 were using no electronic devices at the end of the 12 months. In other words, their behavior had not changed, even though a direct effort had been made to encourage these individuals to engage in the project and utilize the readily available devices.

Another major difference in the findings from the two Stages is the amount of help from staff needed by individuals using the devices. Unlike the findings in Stage 1, the findings from Stage 2 indicate that the individuals who had increased the electronic device and application use needed “a lot of help”; from 29% to almost 90%. This dramatic increase in the help needed appears to be the result of the fact that such a small number of individuals in Stage 2 indicated that they used no devices at the beginning of the Project. Thus, the vast majority of individuals in Stage 2 were starting from ground zero resulting in the help of staff members to get them “up to speed”. It will be interesting to see if the amount of help needed declines during the second year of the Project.

As was the case in the findings from Stage 1, the vast majority, 18 of 20 (90%) of staff at all three locations in Stage 2 viewed the Project as successful and they believed that the individuals who used the electronic devices benefited. Also, similarly to the results of the staff surveys in Stage 1, some staff in Stage 2 expressed a level of frustration with the amount and type of training they received in the use of the technology and various applications. However, the number of staff who expressed this frustration declined from almost 50% in Stage 1 to only 20% in Stage 2, thus indicating that the change in the type of training had been, to a certain degree, successful.

B. Smarthome Project

There were no problems with data collection for the SHP. All four individuals with disabilities completed the three questionnaires and GDS administered upon initiation and three, six and 12 months into the Project. Nevertheless, the simple fact that there were only four residents in the study does limit the ability to generalize and reach firm conclusions about the wisdom of expanding the Project to other facilities.

The findings are largely positive, as three out of the four residents expressed that over the twelve months of the Project, their level of independence had increased: three out of the four residents expressed an increase in the ability to operate blinds and lights without help; two out of the four residents expressed an increase in the ability to undertake chores in the kitchen without help; and one out of the four residents recorded a greater ability to communicate with family. Answers on the GDS indicated that two of the four residents experienced a slight decrease in their level of depression. Staff also filled out the GDS for the residents and once again, it appeared that the same two residents experienced a decline in their level of depression.

In addition to the quantitative data collected, more informal interviews with both residents and staff revealed a very high level of satisfaction with the modifications made in the residence and the addition of the Smart TV, iPads and remote controls for blinds and lights. In particular, staff indicated that the mood of the residents had become more positive and that residents are much more active in the kitchen and taking pride in their increased independence.

C. Biometric Project

The findings for the BMP are the most problematic of the three Projects, primarily because of equipment issues that delayed its start and continued during the entire data gathering period. Nevertheless, there are sufficient data to draw some conclusions that can be used as the Project is expanded to other facilities. For this analysis the two residential facilities serving IDD residents will be lumped together, while the findings for the LTSR are presented separately.

Staff surveys at the two IDD facilities showed that at the beginning of the Project over one-half of the staff did not know how to use at least one of the devices that was being installed. However, by the 12 month mark, all but one staff

member, not only could use all of the devices, but were comfortable using them. The 12 month survey also indicated that, overall, staff were very positive about the use of the biometric equipment: a clear majority believed that care had improved with the use of the equipment; and all staff believed that residents had accepted the use of the equipment and were comfortable with its use. Over the 12 months of the Project, there were 10 instances when one or more vital sign reading was beyond the safe range. In seven cases, a physician was contacted and in three cases, a nurse was contacted. Although in none of these cases was hospitalization necessary, four residents were put on outpatient observation in order to more carefully track their vital signs.

The only negative finding was the number of problems with the equipment recorded in 32 error logs. Just over 50% of the errors were a failure of the data to upload from the device to the iPad, which was used to record and forward the data to the nursing staff. In one-third of the error logs, the problem was that the devices were not actually recording any data, e.g., the blood pressure cuff not indicating a reading. These findings have led to a reevaluation of the vital signs system being used.

All staff at the LTSR, when surveyed, expressed a high level of familiarity with all equipment used in the Project, both at the inception and twelve months later. Eight of the nine staff reported that the residents were comfortable with the use of the vital signs array, but one-third reported that the equipment was not as reliable as they would have liked. This unreliability was reflected in the nine error reports that indicated both problems with uploading data, and the blood pressure and oximeter cuffs not generating a reading. Finally, there were eight events when one or more vital sign reading was beyond the safe range. In four of the cases, the nurse was contacted and the resident more closely monitored for the next 24 hours.

VI. Discussion

As stated in the previous section, not only have the three Projects in Stage 1 been on different timelines, but Stage 2 of the CTP has produced findings from three additional sites with the result being that the discussion of the findings from the 14 different sites is complicated by this variation in timeline and amount of data available for analysis. However, there are sufficient findings for the steering Committee to make crucial decisions as to the success of the technologies in providing cost effective care to the different locations. In particular, it is possible to determine what has exceeded expectations, what has worked as hoped and what has not worked as well as hoped. Additionally, valuable lessons have been learned that can be used to move the SHP and BMP to Stage 2 and the CTP to Stage 3.

A. Successful Implementation

Findings from both Stages clearly indicate that the CTP has been a tremendous success and has far exceeded expectations. The vast majority of individuals in all ten locations embraced the new technology and the applications made available through the Project. These individuals were able, in a relatively short period of time, to use the technology to communicate with family and friends, safely surf the internet in order to pursue their individual interests and to play games and watch movies—none of which they could do on their own before the Project. Although not all individuals at the ten facilities were able to utilize the technology, the majority could and they were able, over time, to do so with less staff help. Staff were equally pleased with the introduction of the technology and consistently reported that individuals were happy with their increased independence.

Perhaps the most positive finding is that the technology and applications employed in the CTP proved equally effective in quite different types of facilities with dissimilar care models. Five of the locations were small single sex group homes, with between three and six individuals; two were Adult Training Facilities serving between 80 and 130 individuals who varied in level of ability and had been brought to the facility from their group homes; one was a large congregate ICF in which over 100 people lived of whom 30 participated in the CTP; while the final two locations were small adult training facilities to which individuals with disabilities were transported for skills training. The success of the CTP in these varied locations has allowed the Steering Committee to, not only plan for Stage 3 of the Project, but to begin planning for a much larger roll-out in the near future. This is exactly the success that was hoped for, in that a single technology and application (AbleLink) can be used throughout the organization without having to find, test and use a variety of different applications in facilities with varied care models.

The SHP also exceeded expectations. Even though the number of residents impacted by the introduction was small, four, the findings clearly show that they benefited from having the new technologies. Their independence increased over the duration of the Project because they were able to undertake tasks that they could not accomplish prior to the introduction of the new technology. The simple ability to control the lights and blinds in their own rooms, not only increased their level of independence, but staff reported that the residents' mood became increasingly positive over time.

This does not mean that everything went smoothly, even though the assistive technologies installed in the Smarthome were all well tested and appeared appropriate for the residents. One example of a technology not working as intended was an adjustable sink that could be lowered to a height that made it usable for an individual in a wheelchair. The original bowl of the sink was much shallower than normal kitchen sinks to allow for the space underneath for wheelchair accessibility. Unfortunately, this design made it much more likely that water was splashed during usage resulting in the individual using the sink frequently being soaked by the splash of water from the faucet. This led, not only to the necessity for the DSP to change the resident's clothes, but often the resident becoming agitated, thus disrupting the home's routine. Also, several of the individuals living in the residence have motor skill and spasticity issues which made it even more difficult for them to operate the water controls placed at the rear of the sink. The

solution was to reconfigure the sink with more sensitive controls placed at the front of the sink, rather than at the back. This reconfigured sink will be installed in future Smarthomes.

B. Meeting Implementation Objectives

Although the BMP did not exceed expectations, it certainly succeeded in meeting the objectives set out at the beginning of the Project. The vital signs system is able to record, upload and send data to an external location as was hoped. In addition, the system was able to determine when readings are outside established norms and this information was used at all locations to take action, e.g., notify nurses, inform physicians. It is too early to determine if the use of the technology has reduced emergency room visits and hospitalizations, but staff believe that the system is able to allow more timely care and, as a result, the well-being of individuals has increased. However, even this degree of success was sufficient to begin planning for the use of a vital signs monitoring system in an outpatient clinic, as well as an even more ambitious plans to use such a system in the residence of selected individuals.

C. Hardware and Software Problems

Even though the CTP far exceeded expectations, there have been some issues surrounding the reliability of both the hardware and applications used and staff concerns. Most of the technology problems were resolved during Stage 1 of the Project, but the need for better and more continuous staff training lingered as Stage 2 commenced. Many staff expressed the need for better hands-on training at the beginning of the Project and for on-going training, once individuals receiving services began to explore additional capabilities of the AbleLink applications. The high rate of staff turnover indicated that a more thorough on-going training program than was anticipated at the inception of the Project was necessary. In response to these findings, members of the Steering Committee periodically conducted Skype sessions during the year with all staff responsible for Stage 1 and Stage 2. These sessions reinforced the goals of the Project, allowed the sharing of resources/ideas and encouraged on-going peer led discussions at each of the Project locations. In addition, newly identified staff for Stage 3 have been included in these Skype sessions during the spring and summer of 2016.

The biggest issue with the technology occurred in the BMP. The number of error reports filed at the three facilities, confirms the overall impression that a different vital signs system needed to be used as the Project moved forward. This has resulted in several vital signs monitoring systems being evaluated and a much more robust and flexible system being selected for use at the outpatient clinic. The encouraging conclusion is that, even with the problems with the technology, the results were sufficiently encouraging to plan for the Project's expansion.

D. What Has Been Learned

In the last three and one-half years, many lessons have been learned about the process of incorporating new technologies into NHS's various care models Among the most important are: 1) detailed planning is indispensable; 2) there must be buy-in at all levels—board, C.E.O, upper administration, management and line personnel; 3) one technology must be working before the next one is introduced; and 4) everything takes longer than originally thought.

In the early stages of the Project, many individuals at NHS believed that things were moving too slowly; they were anxious to "get-on-with-it". This urge to move quickly is natural, especially from individuals who have been recruited because they are enthusiastic about the introduction of new technologies. Nevertheless, taking the time to plan every step of the Project was vital to success. Even with careful planning, mistakes were made and problems encountered. Likewise, there must be buy-in at every level of the organization and this also takes time. Without buy-in and commitment, there is the tendency to "cut the losses" when problems arise. The buy-in of the NHS Board, C.E.O. and upper administrators was key to the continuation of the Project when things went wrong.

The incremental approach to the introduction of the technologies also proved to be a wise decision. Once again, there was a push to introduce "everything" at once, but the plan to make sure that one technology worked before installing a second, allowed staff and individuals with disabilities and severe mental illness to adjust to the first change before a second was introduced. Finally, although initially people involved with the Project were confident that the timeline for their slow and cautious approach was realistic, as the three Projects got under way there was a realization that the amount of time necessary to get 14 different sites up-and-running was going to take longer than anyone had anticipated. Fortunately, the fact that there was agreement among all individuals in the Project that the long-term goal of the implementation of the selected technologies throughout the organization, rather than success in one or two locations, allowed the Projects to progress at the slower pace required.

VII. CONCLUSION AND FUTURE WORK

When the Assistive Technology Project was being planned in 2012 there were doubts whether, because of its scale and complexity, it could achieve its objectives. Even as the technologies were being installed in the first Stage and problems emerged, there were concerns that trying to evaluate three distinct technologies in 11 locations was just too ambitious. However, the Project leadership persevered and with the commencing of the second Stage and planning for a third, it is impossible to conclude otherwise than that the Project has been a success.

A. Improvements for Next Stage

Based on an analysis of the results from the three Projects in Stage 1, several adjustments have been made to both the

technologies employed and the implementation protocols for the next two Stages. First, problems with the biometric instruments used in the BMP have led to a switch to more robust products from companies that offer greater technical support. In addition, the needs inherent in collecting vital signs at an outpatient clinic have led to the decision to employ a kiosk that collects a series of vital signs. The advantage of the kiosk is threefold: first, it is a self-contained unit that can be easily placed in a small room at the clinic; second, it allows for as few as one vital sign to be collected and up to six, thus allowing the ability to start off slowly by collecting two vital signs—blood pressure and weight—and adding more as individuals receiving services and staff become comfortable; and third, it allows the information collected to be sent electronically to psychiatrists and physicians, prior to face-to-face meetings. The switch to a more robust system has also enabled concrete plans to collect vital signs in the residences of individuals receiving services from NHS and to send this data to care providers at a remote site in Stage 3 of the BMP.

Similarly, dissatisfaction on the part of staff and individuals with disabilities with several products in the SHP has resulted in the selection of more sophisticated equipment that incorporates more sensor technology. In addition, the positive results from the CTP and BMP will allow for these technologies to be incorporated into the Smarthome currently being constructed.

An unexpected finding from the CTP has led the Steering Committee to dramatically alter the selection of facilities for Stage 2. It was thought that expansion would be to small group homes, but the overwhelming success of the AbleLink technology in the larger day facilities has resulted in the technology being installed in a large congregate ICF and two adult training centers and plans for further installations in Stage 3 in similar facilities. Longer term plans include the installation of AbleLink in group homes, but the use of the technology in larger facilities has proven to be more cost effective because of the more efficient use of staff.

B. Expansion

The best measure of this success is that NHS has made the decision to extend all three technologies to additional locations. The CTP has already been expanded to three new locations bringing the total number of participants to approximately 200 and there are plans to include three additional facilities before the end of 2016. NHS is also working with AbleLink to develop new applications specifically targeting individuals with disabilities, as well as working to refine and enhance existing applications.

The Delaware County Adult Behavioral Health Outpatient Clinic will be added to the BMP by the end of 2016, and vital sign monitoring systems will be installed in the residences of selected individuals with disabilities during 2017. The complexity of incorporating vital signs monitoring into an outpatient clinic is, from NHS's perspective, outweighed by the opportunity to effectively offer psychiatric services, primary care physicians and pharmacy services in one location along with an integrated medical record. Likewise, the difficulty of recruiting participants, installing systems and establishing a remote monitoring location is balanced by the benefits of being able to track vital signs and respond to alerts.

Perhaps the most significant indication of the success of the overall Project is that there are plans to build, ground up, a new facility in Western Pennsylvania which will include technologies from all three Projects.

C. Financial Model

From the inception, one of the key components of the Project was to construct a financial model that would allow NHS to be reimbursed for the care delivered by the use of the new technologies. The Project itself, costing over $200,000 in real money and much more when the amount of staff time expended is included, has been financed by grants. Although grant funding is satisfactory for a project whose goal is to evaluate the appropriateness of new technologies in the delivery of care, it is not a satisfactory means for developing a sustainable financial model. A sustainable financial model can only exist if the care delivered with the use of the new technologies is reimbursable by Medicare (the health insurance program for people in the United States who are 65 or older. Medicare Part B covers certain doctors' services, outpatient care, medical supplies, and preventive services) and, especially, Medicaid (the U.S. government program, financed by federal, state, and local funds, of hospitalization and medical insurance for low income persons of all ages) as billable services that can be reimbursed to NHS. Without the ability to be reimbursed for the services provided through the use of the technologies, a hoped for roll-out to a large number of locations will be impossible.

The problem is that, currently, most of the care delivered in the three Projects is not billable and thus, not reimbursable, but this situation is changing. A number of states have granted Medicaid waivers that can now allow reimbursement for care delivered with some of the selected technologies, but not all of the services delivered through the use of the selected technologies are reimbursable. For example, one of the challenges faced by the Steering Committee in using a kiosk to collect vital signs at the out-patient clinic is how to pay the staff member who will help customers in using the system. It is anticipated that this staff member will need to be available to help with the kiosk all day, five days a week. If NHS is unable to bill Medicare/Medicaid for her time, the organization will be unable to continue providing this service and expanding to other facilities. If the three Projects have done nothing else, they have confirmed that the use of technology to aid in the delivery of care to individuals with disabilities and severe mental illness is inevitable. The increasing numbers, along with the aging of both populations, is increasing the cost of care exponentially, at the same time as the number of people available to deliver the care is stagnating. The only way to maintain, let alone enhance, the level of care to these populations is through the innovative use of technology and the only way to make this happen is to develop a means of reimbursing this care. This must and will occur; the only question remaining is when?

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