**The Importance of Electronic Health Records In the Field of Developmental Disability**

Gidden Fellowship

ELECTRONIC HEALTH RECORDS

According to the Centers for Disease Control and Prevention (CDC), a developmental disability is a diverse group of long-lasting conditions due to intellectual, physical impairments, and/or behavior issues (Centers for Disease Control and Prevention, 2020). Living with developmental disabilities is associated with multiple challenges in certain areas of life like speech, learning, and independent living (Kripke, 2018). When living with a disability, many individuals will reside in a community-based setting that supports people with intellectual and developmental disabilities (Rubin et al., 2016). Community-based settings help ensure persons with disabilities (PWDs) have similar rights and opportunities as other community members (National Academies of Sciences, Engineering, and Medicine, 2017). These rights may include, equal healthcare access, education, employment, skills training, social mobility, family life, and political empowerment (NASEM, 2017). Persons with intellectual developmental disabilities (IDD), as noted by The Arc (2021), often require community-based long-term supports and services (LTSS). Such services are critical in supporting the PWDs' independent living activities., with the most critical ones being those supporting them in their activities of daily living (ADLs) (The Arc, 2021). These activities include but are not limited to dressing, taking medication, meal preparation, job coaching, residential supports, and financial management.

Evidence suggests community based settings produce positive outcomes for PWDs. For instance, in their study, Mauro et al. (2014) evaluated a community-based rehabilitation (CBR) program on different subgroups of PWDs disadvantaged on the dimensions of interest. These dimensions included pensions access, aid appliances use, access to paid employment, and improvements in autonomy (personal-practical). after between four and seven years of joining the program (Mauro et al., 2014). Data collection was done in Karnataka state, India, specifically the Mandya and Ramanagar districts from 2009 December to 2010 May (Mauro et al., 2014). Interviews were conducted on 2540 PwDs using stratified random sampling (Mauro et al., 2014). The intervention group comprised 1919 program beneficiaries, while the control group comprised 621 persons who lived in villages but had not been part of the program (Mauro et al., 2014).

After controlling for systematic differences between persons joining and not joining the CBR, they established a significant positive impact of the CBR in relation to services access, rights, and opportunities for PWDs (Mauro et al., 2014). The researchers’ findings further established that improvements in pensions and allowances access (29.7%), aid appliances (9.4%), access to paid employment (12.3%), and personal-practical autonomy (36.2%) after seven years (Mauro et al., 2014). Positive outcomes were established in a study by Bongo et al. (2018), which investigated the efficacy of a CBR program in Zimbabwe’s Chipinge Ward 20. The study also aimed at ascertaining the positive changes in the quality of life (QoL) and resilience amidst disaster among children with disabilities (Bongo et al., 2018). The researchers used key informant interviews, document analysis, and focus group discussions for data collection.

Multiple organizations provide such community settings as part of their CBR programs. Among the organizations that provide these services is the Long Island Developmental Disability Service Office (LIDDSO). LIDDSO is part of the Office for People with Developmental Disabilities (OPWDD) of New York (N.Y.) (Kalevas, n.d.). OPWDD offers access to services for people with developmental disabilities (D.D.s) via a regional system that divides N.Y. into different sections, which are overseen by Developmental Disabilities Services Offices (DDSOs) (Kalevas, n.d.). The DDSOs offer multiple services comprising “family support, case management, respite, housing, supported employment, recreation, skills development, training, long term habilitative services, and nursing” (Kalevas, n.d.). LIDDSO is among the DDSOs and covers Long Island. LIDDSO offers multiple services and among those provided for persons with PWDs in a rehabilitative community setting is a group home for the physically and mentally disabled. Here, the PWDs receive support in different areas, which promotes improvements in their QoL.

LIDDSO has several units that I am responsible for overseeing. Within these units, the individuals have multiple,physical, developmental, intellectual, and mental health matters. For instance, Down syndrome, fetal alcohol syndrome, fragile X syndrome, Prader-Willi Syndrome (PWS), and cerebral palsy and autoimmune diseases. These conditions cause these individuals to be in and out of the hospitals. Because they are PWDs, a lot of errors and miscommunication often happens. As noted by Boardman et al. (2014), persons with PWDs have speech communication issues often due to disordered speech production and/or impaired hearing tied to their disease. For instance, Al-Biltagi (2015) highlights that persons with Down syndrome experience grammatical challenges, including tenses and word ending challenges. Hence, they find it challenging to express themselves fully as they utilize shorter sentences in their communication. For example, there have been times that the patient has received the wrong medication and wrong consistency in feeding, because we hand write our information about the patient on what we call ready-to-go packets the hospital nurse may misread what it states. A mistake like this causes a great strain on the individual and, in some instances, violates their rights.

When a patient is in the hospital, the policy at LIDDSO is that a nurse should do an initial visit within 48hrs. The nurse must call the hospital every day to see how the individual is doing; this can be very time-consuming and challenging on both sides (Group home/Hospital). When a patient is being discharged from the hospital, the agency must do a 24hr discharge meeting with the hospital staff and the group home staff to see if there are any new changes in the person's status. If the person is stable, they may return to the group home.

A solution to LIDDSO’s problem would be the introduction of an electronic medical record (EMR). Therefore, the current project seeks to determine, in individuals with a developmental disability who are admitted to the hospital, does nurses' use of an electronic health record compared to verbal and written communication improve the quality of care for the individual? An EMR allows access to a patient’s information that would promote proactivity along with the doctor and already have discharge instructions in place. Nurses would have access to labs, new medication if ~~any here~~ prescribed, and any new recommendations.

An interconnected medical health system providing direct access to a patient's past medical history, lab work, blood type, allergies, etc., can improve quality care, decrease medical errors, and improve safety (Topol, Erick J., 2012). There is scientific evidence that suggests that electronic health records systems improve the quality of care through better access to information for health care providers (Blackford et el., 2013). LIDDSO is currently using computers; however, it is not interconnected with the other institutions (i.e., Hospitals) that also participate in providing care to our patients. The absence of an electronic health system in our environment limits our efficiencies and increases our workload and increases the potential for medical errors. Using an EHR may advance productivity by limiting the time it to takes the nurse to complete admission paperwork. Errors may be decreased by making readily available information from previous admissions, health history, medication regimen, and current practitioners. Being at the front line of our health institution places us in a great position to contribute to the creation and implementation of electronic health records along with our physicians and an information technology (I.T.) specialist.

The short-term goal is to provide extensive training to all staff who will be using the new system prior to implementation. Project implementation will be done using the IOWA model of evidence-based practice (EBP) as it provides an evidence-based approach to quality improvement. Pre-and-post testing will be used to determine performance improvements in decreasing re-admission to the hospital, reduce infections, tracking test results, obtaining prescriptions, improve services, and staff satisfaction. The Q.I. project should be fully implemented within the next six months. The project will be deemed successful if there is an 80% improvement in the performance of services provision of services and reported patient and staff satisfaction with the EMR within the six months. The project's key stakeholders will include N.Y.'s OPWDD, the PWDs, nurses, and the hospital management.

Further, the project will be tested by the I.T. specialist’s team to identify and correct our potential obstacles. The assumption of this project is that electronic health records will create better health by improving information access. The long-term goal is to improve the accuracy of diagnoses and health outcomes, improve care coordination, track tests results, obtain electronic prescriptions, drug allergies/interaction, and better manage patient care through secure use and sharing of patient's health information. The project will consider a gradual implementation to facilitate the transition from paper charts to electronic health records and give the institution a chance to correct mistakes from different departments (i.e., Hospitals) as the EHR is being implemented. Having access to personal health records (PHR) will enhance patient-provider collaboration and communication (Davis et al., 2017). Electronic PHRs are easily accessible to the healthcare team. The hospital will have access to the patient EHR, which will cut down tremendously on errors and give the nurse more time with the patient. When a patient is hospitalized, it would be the responsibility of a nurse to call the hospital every day to find out the patient's status. However, where there is an EHR system at the facility, any patient information can be accessed via the intranet, saving time.

**Abbreviated Literature Review**

Studies conducted in the past have revealed the benefits of EHRs among PWDs within different care facilities. This section analyzes previous literature regarding the benefits of EHR compared to written/paper records and the benefits of EHRs for PWDs in hospitals.

**Tsai, J., & Bond, G. R. (2008). A comparison of electronic records to paper records in mental health centers.**

In this study, the researchers aimed to examine whether electronic medical records (EMRs) are more complete and readily retrieved medication documentation compared to traditional paper records. Tsai and Bond compared the archived paper record and current EMRs via a chart review using a convenient sample of three large community mental health centers drawn from Indiana (Tsai & Bond, 2008). Medical charts for one hundred and eighty schizophrenic patients whose rating was done using a checklist comprising sixteen items adapted from a national project (Tsai & Bond, 2008). Comparisons were made between documentation prior to and after the EMR system implementation. The completeness of the documentation and retrieval time were the primary outcome measures, and the researchers established that the EMR provided more complete and faster documentation retrieval than paper records across and within the centers (Tsai & Bond, 2008). Forty percent of EMRs were complete, with twenty percent retrieved faster. EMRs were found to potentially improve medication management for patients in mental health facilities compared to paper records (Tsai & Bond, 2008). Regardless, the documentation for diagnosed schizophrenics was deficient in multiple areas, whether paper records or EMRs.

**Mudrick, N. R., Breslin, M. L., Nielsen, K. A., & Swager, L. C. (2020). Can disability accommodation needs stored in electronic health records help providers prepare for patient visits? A qualitative study.**

In another recent study that focused on persons with disabilities, Mudrick et al. (2020) examined whether and how information regarding the accommodation needs of PWDs should be inpatient records is used within a primary healthcare center for care planning. The researcher employed an exploratory-descriptive study approach and collected data using focus group discussion among a sample of 35 participants drawn from the staff of a Federally Qualified Health Center that asked four accommodation questions during intake for EHR (Mudrick et al., 2020). Respondents were questioned on how they learned of the patient accommodation needs, if and how they used such information in the EHR, use barriers, and recommendations on where such information should be stored (Mudrick et al., 2020). A brief semi-structured interview was also conducted among a sample of 12 patients to establish their experience based on their recent appointment (Mudrick et al., 2020). Using structural coding and theme extraction, the focus group identified several themes: staff often lack knowledge on the patient’s accommodation needs prior to the patient’s arrival; accommodations are developed during the time of visit: provider knowledge on the regularity of patient visit is the basis of accommodation preparation; staff recognizes the importance of advanced knowledge which is similar to the findings by Tsai & Bond (2008) which recognized the importance of EHRs in retrieving information. Just like EHRs help ensure complete and fast medical records retrieval (Tsai & Bond, 2008), it is also useful in visitation planning (Mudrick et al., 2020). Similar to the challenges noted by Tsai & Bond (2008) in relation to documents for schizophrenics, Mudrick et al. (2020) established challenges in the structuring of information regarding scheduling and direct care and making need-based changes. Other challenges noted by Mudrick et al. (2020), flexibility in recording the various needs and differentiating accommodation needs from other alters hence the need for staff education.

**Kersten, M. C., Taminiau, E. F., Schuurman, M. I., Weggeman, M. C., & Embregts, P. J. (2018). How to improve sharing and application of knowledge in care and support for people with intellectual disabilities?**

The study by Kersten et al. (2018) was based on the fact that there is minimal knowledge regarding the degree of the barriers and facilitators of sharing and applying knowledge for the care and support of persons with intellectual disabilities (I.D.s) based on the attributes of longterm care. Different from the studies by Mudrick et al. (2020) and Tsai & Bond (2008), Kersten et al. (2018) employed a systematic review of literature design that identified the enabling and/or disabling organizational factors in the stimulation of knowledge sharing and application in caring and supporting persons with I.D.s. The review was done on five electronic databases for studies published over 15 years (2000-2015) published in English (Kersten et al., 2018). Of the retrieved articles (n = 2,256), 19 met the inclusion criteria, and the organizational factors derived from the articles were categorized into three primary themes: interventional characteristics – tied to tools and processes of implementing the method; people-related issues – individual and group; and organizational factors – connected to office arrangements, information and communication technology (ICT) systems, resources, time, and organization and immaterial factors – tied to training, staffing, and team size (Kersten et al., 2018). The systems, resources, time, and organization here comprised the use of EHRs. These were established as critical in sharing and sharing and applying knowledge relevant to caring and supporting persons with I.D.s. Therefore, in addition to allowing complete and fast retrieval of medical records as identified by (Tsai & Bond, 2008) and visitation planning as established by (Mudrick et al., 2020), Kersten et al. (2018) confirmed that EHRs were vital in information sharing and application for promoting care and support. The challenge identified by Kersten et al. (2018) was the lack of staff knowledge and the need to train the staff on using the ICT systems.

**Kraal, B., van Dooren, K., Popovic, V., Lennox, N., & Livingstone, A. (2018). The role of electronic records in disability support.**

The study explored how support organizations for PWDs and employees within these organizations comprehend electronic records in the context of their daily tasks. Kraal et al. (2018), just like Mudrick et al. (2020), used interviews for data collection. The interviews were done on front-line support management staff (n = 16) drawn from organizations that had introduced shared electronic records. The participants comprised a representative from a software firm and a project manager (Kraal et al., 2018). A thematic analysis (T.A.) was conducted on the interview responses, with the results indicating a lack of consistency in their description and anticipation of the electronic record (Kraal et al., 2018). They also lacked clarity on those required to use and benefit from the record and the role of third parties; for instance, medical professionals lacked clarity (Kraal et al., 2018). Similar to Tsai & Bond (2008), Kraal et al. (2018) established inherent challenges in EHR implementation. Specifically, the similar challenge of lack of staff understanding of the use of EHRs as identified by Kersten et al. (2018) is also identified by Kraal et al. (2018). The recommendation is similar to that by Mudrick et al. (2020) is the need to provide staff education on the use of EHRs without which there is a risk of failure in the future implementation of EHRs to provide disability support.

**Lin, H.-L., Wu, , D.-C., Cheng, S.-M., Chen, C.-J., Wang, M.-C., & Cheng, C.-A. (2020). Association between electronic medical records and healthcare quality.**

Finally, different from the other studies discussed above, Lin et al. (2020) took a generalist approach in their assessment of the correlation between the extent of adopting EMRs and patients outcomes for patients with all conditions, including PWDs. The researchers used ab observational approach of discharge data for five years (2013-2018) from a Tri-service General Hospital (Lin et al., 2020). The levels of use of EMRs were categorized into: no EMRs, partial EMRs, and full EMRs, with the primary quality measures being inpatient mortality, readmission within 14 days, and 48-hour mortality postoperatively (Lin et al., 2020). They conducted a Cox proportional hazards regression analysis for evaluating the correlation between the level of EMR use and care quality. The study comprised a sample of 262,569 patients and established that full implementation reduce inpatient mortality and readmission risk: [adjusted hazard ratio (HR) 0.947, 95% confidence interval (CI): 0.897–0.999, P = ..049] and [adjusted HR 0.627, 95% CI: 0.577–0.681, P < .001), respectively (Lin et al., 2020). It also reduced the mortality risk [adjusted HR 0.372, 95% CI: 0.208–0.665, P = .001] compared to no EMRs. Partial implementation was tied increased readmission risk compared to no EMRs [HR 1.387, 95% CI: 1.298–1.485, P < .001] (Lin et al., 2020). Therefore, overall, the quality of care improved.

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