

RUNNING HEAD: Technology and Surveillance

Technology Tools: Increasing our Reach in
National Surveillance of Intellectual and Developmental Disabilities

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Abstract

Challenges in collecting comprehensive health surveillance data on people with intellectual and developmental disabilities are numerous. A number of important issues and strategies are discussed in papers contained in this special issue of *Intellectual and Developmental Disabilities*. In this manuscript, we focused on the advances and tools available in the area of technology. We explored a number of possible sources including accessing big data such as analyzing health information contained in Medicaid and Medicare health databases. We also discuss some of the possibilities afforded to us by complementing Medicaid/Medicare database information with health information available in the myriad of electronic health records. Lastly, we explore other technologies available that might yield valuable health supports and information, including wearable devices, remote supports and other smart home technologies, telehealth and telepsychiatry, as well as looking at ways to access other technologies that collect health information (e.g., glucometer, health apps, connected exercise devices, etc.).

Keywords: health, surveillance, technology, digital health technologies, intellectual disability, developmental disabilities, well-being

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Collecting information about the health status of a population is essential to gaining critical information and understanding of issues, impacts, and trends about specific disability and disease groups. Conducting national and international surveillance of groups of interest may be further challenged by the members of that group's willingness or ability to self-identify and report on their own health status. People with intellectual disability, because of the social stigma often associated with that condition (BLINDED, in press; Scior, 2011; Scior et al., 2016) even when reached may often deny having the disability. This was first reported by Edgerton (1967) in a study of people with intellectual and developmental disabilities who were discharged into the community from having lived in a large institution for people with intellectual and developmental disabilities. In his study of these individuals, Edgerton found that many of them, in their efforts to integrate into the community, refused to identify themselves as disabled and fewer identified themselves as having an intellectual disability, a term coined Edgerton used to describe this observation was "cloak of competence."

Because of the functional deficits that are associated with intellectual disability (i.e., deficits in intellectual functioning and adaptive behavior) as well as the often-associated stigma to the condition itself, it may be challenging to find and survey people with intellectual disability (Altman, 2014; Krahn et al., 2010). A number of the more traditionally used surveys in large population health surveillance studies may prove particularly challenging because few contains items that can help identify people with intellectual and developmental disabilities (Hatton et al., 2015). The articles in this special issue address a number of these challenges and present

potential solutions and alternatives to enhance our ability to nationally surveil people with intellectual and developmental disabilities.

Krahn and colleagues (2010) identified a number of datasets that might provide additional information on the effort to improve our reach and understanding of the health of people with intellectual and developmental disabilities (IDD). Representativeness aside, select datasets (such as the Special Olympics Healthy Athletes) should be mined more fully to explore potentially important health indicators and associated factors (Morad & Merrick, 2006; Weiss & Bebko, 2008). Other existing longitudinal tracking programs such as the Wisconsin Longitudinal Study (Taylor et al., 2008) or standardized outcome surveys such as the National Core Indicators (Gettings & Bradley, 1997) should also be considered when trying to study the health status, access to health care services, and important predictors of health status change over time for people with IDD. Some efforts have started aggregating Medicaid data from different states to conduct health surveillance of people with IDD (e.g., McDermott et al., 2018); however, these data remain limited to those who are receiving Medicaid services.

“Big data” has garnered increased interest in the field of health care research, yet its definition remains ambiguous to most. Bates, Saria, Ohno-Machado, Shah, & Escobar (2014) defined big data as consisting of the three “Vs”, high volume, variety, and velocity of accumulated data that can be analyzed to permit the discovery and communication of patterns in the data. Administrative data, which are generally compiled by public sector systems (e.g., Medicare, Social Security Administration), are one type of big data. An important characteristic of big data is that they were not constructed by researchers nor intended to be used for research purposes (Connelly, Playford, Gayle, & Dibben, 2016). Although population-based healthcare research on people without IDD using big data shows promise (Hansen, Miron-Shatz, Lau, &

Paton, 2014; Huang, Lan, Fang, An, Min, & Wang, 2015; Senthilkumar, Rai, Meshram, Gunasekaran, & Chandrakumarmangalam, 2018), we still have a ways to go to ensure these large data systems are inclusive of, and/or can identify, people with IDD.

In this paper, we examined how technologies, electronic health records, and big data can be used to increase the reach and data gathering ability of national surveillance studies examining the health status and utilization of healthcare services of people with IDD. Despite not having a national health database in the United States, as is found in other countries (e.g., England, Norway, South Korea), there exist numerous technologies that, if harnessed, can potentially increase reach and ability to study the health status and healthcare utilization of people with IDD (see also Haile & Reichard in this special issue). We also presented briefly on the use of smart technologies and wearable devices that can used to collect health data on people with IDD.

Electronic Health Record Systems

Hospitals and healthcare professionals use software called electronic health records (EHR) to help document and track the health of their patients. Signed into law by President Obama, the American Recovery and Reinvestment Act (2009) mandated that all public and private healthcare providers and other healthcare professionals adopt the use of electronic health records by January 1, 2014, in order to maintain their existing Medicaid and Medicare reimbursement levels. As a result, the U.S. has become a leader in promulgating the global dissemination of EHR systems. Several companies have developed EHR software, offering different functionalities and features. At the most basic collection of functions, an EHR will likely contain the following features: patient demographics,

patient problem lists, lists of medications taken by patients, clinical notes, prescription orders, laboratory results, and imaging results (DesRoches et al., 2008).

EHR programs augment care for patients by creating an easy way to track health progress throughout one's lifespan, including tracking health from one healthcare professional to another. Records created decades earlier may inform a healthcare professional about important questions to ask their patients, medications to suggest or exclude, or which vaccines have been received, even if the record originated with a different member of one's care team. However, this interoperability from one caregiver to another is only made possible when software applications are capable of communicating with one another. Without the ability to connect between applications, healthcare providers are left uninformed about healthcare visits to providers using EHR systems that are incompatible with their own.

EHR systems, while used by healthcare professionals to track their patients' health status and healthcare utilization, are not intended to be used for national surveillance. One barrier to using EHR systems for national surveillance, including the collection of national prevalence data, is that the software is not designed to easily accommodate this purpose. Another barrier is the incompatibility within EHR software to communicate between EHR programs. The issue of interoperability has been recognized by many organizations that call for change across the healthcare system. A 2018 electronic health record white paper written by Stanford Medicine stated:

“Perhaps the biggest disappointment of EHRs is that they are still to a large degree static. Although they store data electronically, that data is still trapped within the institutions that gather it. The next step in the digitization

of health care, symposium participants agreed, is to free up this information in ways that enhance patient health while protecting privacy.”

Stanford Medicine (2018) recommended that analytics data be made available to healthcare professionals and that the information is presented in an intuitive way, starting at the point of care. Most concerns voiced in this article and others involved the frustration healthcare professionals had when they were unable to know valuable health information about their patients such as previous medicines prescribed or whether a prescription was filled.

The U.S. Department of Health & Human Services encouraged all health care providers to transition to the use of EHR systems. While many care providers were using EHR systems, a survey distributed and analyzed by the American Hospital Association (AHA) showed that between 2008 and 2015, only 52% of all EHR users collected data from outside providers (AHA, 2016). By 2017, approximately 86% of office-based physicians had adopted EHR systems (Office of the National Coordinator, 2019a).

When EHR systems are able to talk to one another, patient records are presented in a less fragmented manner, enabling healthcare professionals to more effectively recognize and meet the needs of their patients. A universal collaboration between EHR programs, however, would not only be valuable for rendering care, but also for aggregating data for research purposes, enabling researchers and research funders to draw conclusions about how to prioritize research initiatives. If EHR systems were designed with a function to meet this need, the data would identify patterns of health across the population. By identifying common comorbidities from any category, healthcare agencies can be better prepared and know what to look for when caring for their patients, including those with disabilities.

The ability to aggregate health information across EHR platforms would enable healthcare professionals to draw conclusions from those who allow their de-identified health information to be made available for research based on large samples. This means that researchers could review a national sample to identify comorbidities with any documented diagnosis; healthcare professionals could use artificial intelligence (AI) to predict health needs and identify them in the early stages; and people and organizations could better recognize the national prevalence of specific medical needs and prioritize time and spending in response to those medical needs. Potentially, these data could help identify the national prevalence of IDD and identify trends that occur alongside the diagnoses.

EHRs are in a position to make these data available and understandable for various audiences. Having recognized this, the EHR at The Ohio State University Wexner Medical Center (i.e., Epic) has been working on the development of software that would enable this service. Termed *Epic Cosmos*, the system gathers data from organizations that choose to participate in the database. These organizations then contribute a HIPAA-defined limited data set for each patient. The uploaded data includes birth information (such as one's weight and head circumference), demographics (age, gender, race, location), immunization and medication history, problem list, diagnoses, and more. Though some of the patients served through these EHR systems may reside outside of the U.S., Epic reported serving a patient population of almost 200 million in 2016, which represented almost 57% of the U.S. population (Epic, 2016). While this does cover a large portion of those who use EHRs, it still only includes a handful of EHR systems that are interoperable with Epic. It does not cover the *entire* population, those whose information is included in incompatible EHR systems.

The U.S. Department of Health and Human Service (HHS) has recognized that EHRs contain datasets that would be valuable for promoting patient care. HHS has also recognized the issues that incompatible EHRs present both with improving health care and with aggregating national data. In response, HHS created the Office of the National Coordinator (ONC) in 2004. According to the description at HealthIT.gov, ONC is “a resource to the entire health system to support the adoption of health information technology (Health IT) and the promotion of nationwide health information exchange to improve health care.” Goals for this government organization include: Advance person-centered and Self-Managed Health; Foster Research, scientific knowledge, and innovation; Enhance Nation’s Health IT infrastructure; and Transform health care delivery and community health (ONC, 2019b).

ONC promotes sharing data that patients desire to be shared. While it may be a commonly held belief that healthcare professionals can provide better care with more information, there may be personal information that a patient does not want to be shared from one healthcare professional to another. Researchers are among the first to see the potential benefits of having access to these large troves of de-identified medical information. Secondary use of health information contained in EHR systems can play a crucial role in expanding our research and understanding around important health issues (Safran and colleagues (2007). Research collected in this way can only be as strong as the trust that patients place in the healthcare professionals in their lives. Even when EHRs and similar programs are constructed for the intention of collecting national prevalence data, it is still, nonetheless, the individual’s right to decline to share their information.

Right Care Now Project

The notion of interoperable EHR systems brings promising projections in health surveillance for the IDD population. Additionally, EHR-based technology may be leveraged to *increase health outcomes and reduce barriers to accessing healthcare* for people with IDD (Kruse & Beane, 2018; Mishuris, Linder, Bates, & Bitton, 2014). The Right Care Now Project (RCNP) is endeavoring to accomplish this goal by translating health data in a static, electronic health record system to alerts and prompts about specific health needs and medical follow-ups needed by individuals with IDD.

Research has identified difficulties in communication between individuals with IDD and their health care staff. A review of the literature on barriers to health care access for adults with IDD found that expressive and receptive communication skills was a barrier to accessing health care for many individuals with IDD (Williamson, Contreras, Rodriguez, Smith, & Perkins, 2017). Therefore, additional support is often helpful when transferring information about a patient with IDD to their healthcare professional and vice versa. If the individual with IDD has a caregiver, this can sometimes result in said caregiver helping the individual with IDD communicate with their healthcare professional. These supports are provided often by direct support professionals (DSP) or other caregivers who answer questions using their own experience with the patient. Despite these supports, difficulty in delivering information about patients' health status has been identified as a barrier to ensuring healthcare quality in DD population (Krahn, Hammond, & Turner, 2006; Ward, Nichols, & Freedman, 2010; Williamson et al., 2017).

To address this issue, RCNP uses software constructed with an EHR as its basis to aid in the communication of health or medical history with one's care team and to notify caregivers proactively when identifying situations that may require a response. RCNP tracks patients'

health status and changes by having the DSP or caregiver complete a standard health questionnaire on a quarterly basis. The standard interview questions contained on the health questionnaire collect updated health information on the individuals with DD, including data on specific physical health conditions (e.g., falls, seizures, pain, etc.), mental health conditions (e.g., depression, anxiety, thought problems, etc.), challenging behaviors, quality of life, and other health observations from caregivers. Then, the RCNP system can summarize the collected health information in the form of a “health passport.” The system uses assessment algorithms to detect elevated risk for over 40 common conditions (e.g., pneumonia, poorly-controlled seizures, thyroid deregulation, constipation, dental problem, dementia, etc.) and changes in function or quality of life. When a risk is detected, the system is designed to notify caregivers, leading to scheduling of a consultation with a health care provider and further clinical evaluation. Preliminary data from RCNP reported that nearly 35% of the participants with IDD who used RCNP were able to receive appropriate interventions from health care providers because of the risk report from the system (Abend & Dharampuriya, 2018). The RCNP model tracks person-level, longitudinal health data and creates opportunities for detecting health risks and changes in function, validating intervention effectiveness.

Technology Use and People with IDD

There is a growing body of research studying the impact of assistive and remote support services technologies such as the use of cell phones, tablets, computers, sensors, and other smart-home technologies on independence. One study reported that less than 30% of the participants with IDD in the community used a cell phone versus 89% used a land line telephone on a regular basis (Bryen, Carey, & Freidman, 2007). There is a need for updated research to address if these rates of technology use among people with IDD have changed. In the same vein, little published

data are available on the use of health-related sensors and wearable technologies for people with IDD. Tassé (2019) reported that less than 2% of all eligible adults with IDD receiving Home and Community Based Services took advantage of remote support and other assistive technologies (e.g., heat sensors, motion sensors, two-way communication devices, personal assistance, automated medication dispensers) in their home in Ohio. This is particularly notable given Ohio was reported as the largest in-home technology provider in the U.S. A number of barriers exist that prevent people with IDD from accessing technologies, including financial, awareness of technologies, and education/training (Boot, Owuor, Dinsmore, & MacLachlan, 2018). It is important to consider different types of technologies in this discussion, including, but not limited to, digital health technologies, activity monitors, parameter-specific wearable biosensors, medication technologies, and remote support technologies.

Digital Health Technologies

EHR based models, including RCNP, have recently considered (and some have implemented) the use of digital health technologies (e.g., wearable sensors) in connection with their software. By incorporating autonomously collected health information in-between appointments with the care team, these digital health technologies have the potential to provide an even more complete understanding of a person's health.

Increasingly, technologies are emerging that respond to the consumer's health needs. IQVIA for Human Data Science (2017) reported that over 318,000 health care apps and more than 340 consumer wearable devices are available worldwide. Their study reported that 153,000 of those software applications were introduced through popular application stores within two years prior of the writing their article (IQVIA, 2017). These technologies include hardware and

software, and many of these technologies can be accessed and used from any internet connected-location.

Lupton (2017), in her book *Digital Health Critical and Cross-Disciplinary Perspectives*, defined digital health as “*a wide range of technologies directed at delivering healthcare providing information to lay people and helping them share their experiences of health and illness, training and educating healthcare professionals, helping people with chronic illnesses to engage in self-care and encouraging others to engage in activities to promote their health and wellbeing and avoid illness*” (Lupton, 2017; p. 6). Validic is a company that takes information collected by digital health technologies and aggregates it for health care agencies. They have defined digital health as “*The use of wearables, in-home clinical devices, and applications to remotely generate and collect valuable user data.*” (Validic, 2017; p. 2)

In short, digital health technologies collect data about an individual’s health and use it to improve their wellbeing. This is accomplished through various formats such as monitoring one’s fitness levels, bring proactive about biometric readings, and reactive to health monitoring needs. Those who incorporate this technology into their daily life have the option to use this information to autonomously improve their health (e.g., with recommendations or reminders from the various digital health platforms available to them) or share the health data with others to receive support from their healthcare professional, family members, and/or friends. By sharing these data, a family physician, for example, could be updated about their patient’s exercise habits, heart rhythm, medication adherence, and even sleep quality in real-time or at their next appointment.

The National Cancer Institute's (2017) Health Information Trends reported that more than 8 in 10 individuals surveyed reported owning a tablet or smart phone and over one-third of respondents reported owning an electronic monitoring device (e.g., Fitbit, glucometer, blood pressure monitor, etc.). It was also estimated that 4 in 10 tablet or smartphone users have a health or wellness application on their device (National Cancer Institute, 2017). To this end, the use of wearable technology, such as activity monitors, could serve an important role among disability populations in tracking and potentially improving health.

Activity Monitors

The use of wearable technology that is used to remotely monitor biometrics is not a new concept. Vital signs such as electrocardiogram (ECG) activity (a measurement of heart rate), transthoracic impedance (a measurement of respiration), body temperature, and more were used to monitor real-time biometrics of the Apollo 11 astronauts' mission in 1969 (from as far as 250,000 miles away; Luczkowski, n.d.). Many athletes use wearables during training camps to monitor their conditioning and ensure that they are in the best condition possible for game time. In 2017, the use of wrist-worn biometric readers called Whoop were approved by Major League Baseball and were commonly used by professional baseball players during regular games (Burns, 2017). These wearable health sensors and devices provide real-time health information that can be used to inform health-related decision making of athletes.

Research has shown that commercially available wearable physical health monitors such as Jawbone Up24, various types of Fitbits, and Omron HJ-720ITC, among others, can effect change on one's activity levels (Strath & Rowley, 2018). Strath and Rowley conducted a literature review of 54 peer reviewed journal articles and identified 11 studies that focused on

using these technologies to modify physical activity and impact health outcomes. Wearable physical health monitors included sensors that can measure many different health activities, including the number of steps, body acceleration, heart rate, sweat rate, and skin temperature (Strath & Rowley, 2018).

One study involved 51 inactive women with a mean age of 60 years and a mean BMI of 29.2 (obese range; Cadmus-Bertram et al., 2015). The participants in this study were asked to meet the activity goals of 10,000 steps/day and 150 minutes of exercise per week. The authors reported that participants who used a Fitbit and an associated web-based activity tracking tool (n=25) increased, on average from pre- to post-, their time being moderately to vigorously active by 62 minutes and steps/day by 789 (Cadmus-Bertram et al., 2015).

A study from the University of Tennessee Knoxville tracked the fitness progress of four college students with intellectual and developmental disabilities. Kraiss (2017) used a Fitbit to monitor the daily number of steps taken by their participants. After finding a baseline for the number of daily steps taken for each participant, a goal to increase each participant's number of daily steps by 10% was set. Although the degree of improvement varied across participant, their results suggested that the goal-setting intervention was an effective way to increase the number of daily steps and lead to an increase in consistency in daily activity level across participants (Kraiss, 2017). Goal setting can be an important factor towards increasing physical activity levels. The use of a Fitbit-type of device can provide a concrete way of tracking progress for users. Technologies like the Fitbit device provide information about health habits and can help to monitor progress towards a goal and goal attainment.

Parameter-Specific Wearable Biosensors

Wearable biometric sensors are becoming commonplace. Some wrist-worn devices and other personal fitness trackers can be used to track heart rate with reasonable accuracy (Reddy et al., 2018). These technologies are capable of warning us of potential issues before they occur by recognizing the implications of one's biometric readings. The Apple watch series 4, for example, received clearance from the U.S. Food and Drug Agency (FDA) to market its device for monitoring heart rate. If the wearable device detects an irregular heart rhythm it can alert the wearer of the situation and that further consultation with a healthcare provider may be warranted. Apple also claimed that the series 4 watch has fall detection capabilities which would be of relevance for many with disabilities, including aging adults. If a fall is detected, the watch, if paired with a cell phone, can automatically place a call to a 911 operator, unless the wearer responds to the prompt indicating "I'm OK" on the Apple Watch touch screen. The incorporation of biometric data is a new standard for wearable devices and other technology companies are adding similar features to their products.

The Embrace watch by Empatica is another wrist-worn device that can notify the wearer of possible health concerns. This device received clearance from the FDA and can notify a support person when a wearer is having a seizure episode. It is not designed to preemptively notify the wearer of or prevent a seizure but can alert others of the person's need for assistance when a seizure occurs. Thus, Embrace is reactive instead of proactive to individuals experiencing a seizure episode, and as such, is designed to warn someone who may be able to assist if needed. Seizure activity is tracked by the device and creates a report, which documents the time and date of when a seizure occurs. The report can be printed or shared digitally. Tonic-clonic seizures are identified by detecting specific movement patterns associated with autonomic arousal that last 20

second or more (Empatica, 2019). All these devices have the capability of storing relevant health data to the cloud.

Technologies like Embrace are capable of supporting an individual in ways that historically have been only possible by having the physical presence of a DSP or caregiver. Rather than having someone come to the home to check glucose levels, measuring someone's blood pressure, or administer medication, these functions can be accomplished autonomously with the use of relatively inexpensive technologies. Data from the devices can be shared with caregivers and medical professionals as well as stored for future data analyses.

For example, consider how the treatment of the metabolic disorder diabetes could be supported with technology. To respond to this disorder, those affected track the glucose levels in their blood with the use of a glucometer. The results of these frequent readings can indicate action steps (e.g., consuming more sugar or administering the appropriate amount of insulin). Continuous glucose monitors, like the Dexcom G6 or the Abilify glucometers, can measure a person's glucose level several times per day. By having these devices worn on the body, the need for caregiver involvement can be reduced to two or three times per month from what was previously a daily intervention.

In December of 2018, the FDA cleared a device that can read one's blood pressure from a wearable watch-like device placed on the person's wrist. The device, called HeartGuide, can read a person's blood pressure with the push of a button, track heart rate and sleep patterns, and even monitor physical activity levels. HeartGuide will record the data and provide feedback, including real-time heart health coaching. Use of technologies like HeartGuide survey the current state of

health of the user, while other technologies, such as medication technologies, remind users of their medication routine and subsequently support medication adherence.

Medication Technologies

Automated medication dispensers relieve some of the risk and difficulties that result from autonomous medication adherence. These technologies can provide reminders to an individual and their caregiver, dispense medication at specific times, lock the medication box when a medication has not been removed after a period of time, and send reminders when a prescription needs to be renewed. Some examples of these dispensers can store up to 90 days-worth of doses. Depending on the type of machine purchased, the option to run reports can be selected. These reports can notify a caregiver about what medications were dispensed or not dispensed and provide usage data related to the history of medication dispensed.

Proteus Digital Health makes a medication that uses an ingestible digital sensor. The Sensor Pill includes a small sensor that will dissolve within the body. The pill is currently FDA cleared for the purpose of reporting medication adherence. It has been used for patients who take anti-psychotic medication and is currently being used to help cancer patients with medication adherence. The ingestible sensor sends a signal to a patch worn on the body. The patch then sends the information to another device, such as one's phone, indicating the medication has been taken. If a medication has not been taken as scheduled, the device can send the individual a reminder or beep to call attention to the missed medication. If non-adherence continues, then another caregiver can be notified. A medication report can be automatically accessed by the individual who takes the medication, an authorized caregiver, or treating physician. While the sensor pill currently only records adherence information, in the future, this technology may lead

to ingestible sensors that record biometrics from within one's body, perhaps providing a regular noninvasive window into one's health status.

As noted earlier, as a result of a national database that aggregates EHR data, the same can be true of these digital health technologies: data collected by these technologies that is shared on a national scale can contribute to better surveillance of health information. For example, this might make it easier to compare diabetes medications. With these technologies, one could easily pull the blood pressure levels of several patients over a period of time who take competing blood pressure medications. One would be able to tell the frequency at which this medication regimen is adhered to and, therefore, remove variables that could confound the comparison. Perhaps new side effects would be identified. Ultimately, by having access to consistent health data from large populations that cover multiple healthy living variables, each individual can be better supported while health data of whole populations can be identified based on analyses of big data. Another important service model that approaches diverse health needs of people with IDD is remote support technologies.

Remote Supports Technologies

One representative service platform that uses technology to meet health care outcomes for people with IDD is the remote support technologies model, also known in some states as remote monitoring. In this service model, supports that would otherwise be offered by the physical presence of a direct support professional can be provided remotely using technology. It generally involves using home-based sensors (e.g., motion, smoke, door and window) and telecommunication systems (two-way video displays, cellular phones) to monitor the individual's home environment as well as the individual's activities and communicating with the individual, a

caregiver, or dispatching a backup support staff if needed (Taber-Doughty, Shurr, Brewer, & Kubik, 2010). Currently, the U.S. is in a situation where the gap between available resources (i.e., direct support professionals; DSP) and the demand for care and support for people with DD is steadily increasing (Hewitt & Larson, 2007). The remote support technology model can be a promising alternative to the constant presence of DSP in the home (Niemeijer, Frederiks, Depla, Eefsting, & Hertogh, 2013; Taber-Doughty et al., 2010; Wagner et al., 2018). One strength of the remote support technology model is the increased sense of independence reported by individuals with IDD (BLINDED, under review). The remote support technology model does not require DSP to be constantly present in an individuals' home to provide care, creating opportunities to exercise *greater* independence when compared to care models that involve the physical presence of support staffs (Mckenzie & Macleod, 2012). Another positive aspect of remote support is an increased sense of safety (Brewer, Taber-Doughty, & Kubik, 2010; Niemeijer et al., 2010). The remote support technology model enables caregivers to detect unexpected activity in the house, identify falls, and spot accidents or serious incidents in the home. The use of remote support technologies is not without fault, however, and a concern among some users with IDD is the issue of privacy.

Privacy

A major concern that has been raised by stakeholders regarding the increasing use of technologies in the home centers around privacy. Despite the reported benefits of remote support technology, a number of service providers have reported a reluctance from individuals with disabilities and their members because of privacy concerns (Niemeijer et al., 2010). A number of studies have examined the ethical issues of remote support technologies (Male, El Komy, & Clark, 1991; Niemeijer et al., 2011, 2010; Perry & Beyer, 2012; Zwijsen, Niemeijer, &

Hertogh, 2011). There was, however, a lack of attention placed in these reported studies on the perspective of the individual with a disability or their perception of remote support technology and its benefits (Friedman & Rizzolo, 2017). BLINDED (under review) conducted a series of telephone surveys and focus group discussions with individuals with IDD and their parents and guardians around their experiences with remote support technologies. Although the commonly held belief is that privacy is one of the biggest concerns with remote support technologies, these authors reported slightly different results. In analyzing their data from these telephone interviews and focus groups of users of remote support technology services, they found that only 8.3% of individuals with DD endorsed privacy as a major concern and 29% of parents or guardians reported privacy as a concern of theirs regarding remote support technology services. Thus, it is important to further investigate the perspective of all stakeholders to understand the complete picture regarding the benefits and concerns of remote support technology services (Friedman & Rizzolo, 2017; Niemeijer et al., 2011).

Telehealth

Another rich source of health care information can come from telehealth services. The Telemedicine model links patients with health care providers from a distance, providing real-time high quality video interface. Telemedicine or telehealth can be delivered between two different health care settings or between a health care provider's workplace and a patient's preferred location (e.g., home or work) (Welch et al., 2017). Telehealth based services have the potential to provide increased support to people with DD by bringing health care providers and specialists to them. For example, it can be used to assess a person's mental health and provide valuable health information that can be used by primary mental health professional or a treatment

team (Szeftel et al., 2012). Telehealth has also been reported to be very helpful in managing chronic health conditions such as obesity (Bennet et al., 2017).

Moreover, telehealth can be used to deliver certain interventions directly to the individual with IDD. A review of literature of the usability of telepsychiatry with individuals with IDD yielded a number of effective intervention programs delivered through telepsychiatry (Krysta et al., 2017). Gentile and her colleagues (2018) have been using telepsychiatry to treat individuals with IDD and a range of co-occurring psychiatric disorders. Ohio's Telepsychiatry Project for Intellectual Disability has been in existence since 2012 and has served individuals with IDD who live in rural parts of the state and for whom access to a psychiatric has proven to be a barrier to effective treatment (Gentile, Cowan, Harper, Mast, & Merrill, 2018). After 5 years of data collection on more than 900 patients with IDD receiving telepsychiatry, Gentile and her colleagues compared mental health and overall functioning during the 12 months preceding the start of the study and 12 months following treatment and reported a 96% reduction in emergency room visits and an 85% reduction in hospitalizations (Gentile et al., 2018).

Another telehealth-based care model focused on using immediate access to a health care professional is StationMD. StationMD is a service model that provides on-demand connection between an emergency department (ED) physician and patients with IDD in an urgent situation. According to the preliminary study conducted on group homes for adults with developmental disabilities by StationMD, 86% of the call to StationMD resulted in avoiding ED visits (StationMD, 2019). The "savings calculator" on the StationMD website suggests that the approximate annual cost of ED visits and hospital admissions for an individual with IDD who lives in a group home is approximately \$3,415. StationMD has reported the ability to reduce these costs by approximately 50% using Station MD (StationMD, 2019).

Conclusion

Being able to get representative surveillance data on people with intellectual developmental disability is an ongoing challenge. The traditional methods of population-based surveillance of using mailed or telephone surveys never were effective strategies for reaching people with IDD (Altman, 2014; Krahn et al., 2010). Even if a person with an IDD were to answer the phone or open the door, they often would not self-identify as a person with an IDD (Edgerton, 1967). Trying to reach people with IDD through the schools and publicly funded service delivery system has its own challenges because it is known that less than one in three people with IDD receive paid services (Braddock, Hemp, Tanis, Wu, & Haffer, 2017; Charting the LifeCourse, 2019). Hence, the importance of this special issue is clear in its focus on exploring innovative ways and strategies of reaching this often difficult-to-reach group.

We explored the opportunities offered to us with the advent of big data and through the use of health technologies, including EHR, wearable devices, telehealth, and other smart home technologies that are becoming increasingly important options of support for people with disabilities. We still need to better understand the fears associated with technologies in our homes, schools, healthcare offices, and the community in general. However, as people with IDD become more interconnected through technology, these newer sources of health data need to be considered in the surveillance data. Importantly, these technologies can provide us with a piece of the picture regarding the health, healthy behaviors, and access to healthcare services of people with IDD living in the community. The growing field of smart health technologies is showing promise in increasing the ability of adults with IDD to live more independently in the home of their choice and age in place. These new supportive technologies have tremendous applicability for all aging adults with developmental and acquired disabilities.

Being able to analyze some of our existing healthcare databases, such as Medicaid and Medicare would provide us with rich information, albeit not entirely representative of the entire population of study, regarding their biometrics, health conditions, and healthcare utilization. Accessing health information by accessing and linking one or more of the available EHR systems, while ensuring de-identification of all data, can also provide critical supplemental information to the Medicaid/Medicare health data. Still, being able to tap into the growing universe of wearable devices and digital services (remote supports, connected exercise devices, telehealth/telepsychiatry, etc.) may seem daunting but is undoubtedly a valuable source of complementary information that can add to the available health information, especially regarding exercise and activity levels and certain healthy choices among people with IDD.

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