Adults with Intellectual Disability and Mental Illness:

Tracking and Improving the Standard of Care

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Abstract

The purpose of this quality improvement project was to re-align the standard of psychiatric care with best practices for nine clients with co-occurring mental illness and intellectual disability (ID) in an Oregon community mental health center. For three months, a Psychiatric-Mental Health Nurse Practitioner who specialized in Developmental Disability Psychiatry sought to decrease same-class polypharmacy, and benzodiazepine use. A standardized tool, the Aberrant Behavior Checklist (ABC), was used to assess impact of medication changes on behavior problems. Caregivers answered a question comparing the attentiveness of the specialized PMHNP compared to the attentiveness of previous psychiatric providers. Data were analyzed using descriptive statistics, Wilcoxon signed-rank tests, and 1-sample t-tests.

Aggressive and irritable behavior, as measured by the ABC, decreased significantly. Same-class polypharmacy and benzodiazepine use did not decrease significantly due to small sample size and short timeframe. Caregivers felt that the specialized PMHNP was significantly more attentive to their client's needs than previous prescribers. An analysis of financial feasibility indicated that it would be cost-effective for the mental health agency to hire an outside specialized PMHNP to take over care for their clients with ID. The overall findings suggest that this 'knowledgeable provider' clinic model may be one way to optimize medications, decrease problem behaviors, and improve caregiver satisfaction.

Introduction

Developmental disabilities (DD) are a group of conditions that are caused by physical or mental impairments, and first appear in childhood (WHO, 2010). It is a diagnostic umbrella term that includes neurodevelopmental disabilities, such as cerebral palsy, as well as general intellectual disabilities. About 1 in 6 children in the United States have a developmental disability (Boyle et al., 2011). Approximately 1 in 10 American families are affected by an intellectual disability (Boyle et al., 2011). Mental illnesses (MI) are more common than developmental disabilities, and occur in 18% of the U.S. population (Center for Behavioral Health Statistics and Quality, 2015). However, the prevalence of psychiatric disorders in individuals with DD is at least double (40%) that of the general population (Cooper & Bailey, 2001). When individuals experience both mental illness and developmental disability, it is referred to as dual diagnosis.

Biological, psychological, and social factors contribute to the increased prevalence of MI in individuals with DD. For example, genetic syndromes are associated with specific MI risks (e.g., obsessive compulsive disorder in Down syndrome) (Department of Developmental Disability Neuropsychiatry [3DN], 2014). Moreover, many individuals with DD have co-occurring physical health problems (e.g. epilepsy) that predispose them to MI (Summers, Boyd, & Morgan, 2004). Psychological risks for MI in DD include: reduced coping skills, increased likelihood of experiencing physical/sexual abuse, and lack of autonomy to make life choices (3DN, 2014). Social risk factors for MI are relevant as well and include an increased likelihood of: negative life events (e.g., bullying), and involvement in the criminal justice system (Summers et al., 2004).

While individuals with DD are more likely to have a mental illness, they are significantly less likely to receive appropriate mental health services across the globe (Ervin et al., 2014). The United Nations, World Health Organization, and National Institute of Health all emphasize the massive health disparity between persons with DD and the general population (Ervin et al., 2014). In fact, fewer than 1 in 10 children on Medicaid with dual diagnosis receive psychiatric care (Munir, 2016). Despite not receiving mental health care, over 50% of Medicaid-enrolled youths with autism are prescribed at least one psychotropic drug, usually by their Primary Care Provider (PCP) (Murray et al., 2014). In contrast to the United Kingdom (where PCPs refer clients with dual diagnosis to specialists in DD psychiatry), American PCPs prescribe significantly more psychotropic drugs to clients with dual diagnosis resulting in inappropriate polypharmacy and an elevated risk of adverse drug events (Werner & Stawski, 2012).

Within Oregon, there are approximately 16,315 adults and 6,143 children with ID enrolled with the Oregon Department of Human Services (ODHS) (2014). Oregon only provides ODHS services to 5% of the individuals living with I/DD in the state, thus ranking Oregon 40th nationally for service provision (Braddock et al., 2015). By extrapolating data from ODHS (2014), Braddock et al. (2015), and national prevalence rates, it appears that 449,160 Oregonians have a developmental disability, 40% of whom (179,664) have a co-occurring mental illness.

Surprisingly, only 86% of Oregonians with DD have access to mental health services, which is 4% below the national average (National Core Indicators [NCI], 2014). Not only do Oregonians with DD have a harder time accessing mental health care, they are also less satisfied with their mental health clinicians (10% below national average) (NCI, 2014). While Oregon is ranked as the 18th best state for individuals with DD, this ranking only looked at the number of people in: competitive employment, living in state run institutions, and on waiting lists for DD

services (United Cerebral Palsy, 2015). Had the ranking system included measures of access to mental health care or satisfaction with health services, then Oregon would certainly rank much lower. It's likely that Oregonians with dual diagnosis experience poorer health outcomes than other Americans with DD given these barriers. This project sought to improve health outcomes in the dual diagnosis population by translating existing best practices into an Oregon community mental health center.

Literature Review

Relevant articles were identified by searching the following databases: OvidMedline, PsychInfo, PubMed, and Google Scholar. The following search terms were used alone and in combination: developmental disability, intellectual disability, community mental health center, low income, Medicaid, psychiatry, advanced practice nursing, mental health, stigma, reimbursement, Oregon, education, and finance. Studies designs were limited to controlled trials with comparison groups, systematic reviews, expert opinions, national policies, insurance databases, and clinical practice guidelines. This literature review first synthesizes why individuals with dual diagnosis experience poor mental health outcomes in the current health care system. Next, the review provides examples of best practices to remediate health outcome disparities in this population. Lastly, the author describes a quality improvement project that translated best practices into a real-life community mental health agency.

Factors Contributing to Poor Health Outcomes

Reimbursement rates. Most Oregonians with DD rely on publicly-funded health insurance (i.e., Medicare and/or Medicaid) (Oregon Health Authority, 2012). Table 1 indicates that insurance reimbursement rates for CPT code 99214, a frequently used code for established patients in outpatient practice, is highest for commercial insurance, followed by Medicare, and

then Medicaid. Because of these lower reimbursement rates, few providers are willing to accept clients with Medicare or Medicaid. Therefore, most clients with dual diagnosis are served within community mental health centers (CMHCs), which must accept clients with public insurance.

Fee-for-service model. Many CMHCs within Oregon use a fee-for-service model, where clinic revenue is dependent upon the volume of clients seen (Oregon Health Authority, 2012). Expert consensus guidelines consistently report that clients with dual diagnosis need longer appointments because they have more complex needs, and information must be obtained from multiple sources (Aman, Crismon, France, King, & Rojahn, 2004; Deb et al., 2009; Singh, 2016). This means that clinicians see fewer clients per day, so the organization's revenue decreases. The fee-for-service model unfairly pits the organization's and clients' interests against each other.

Providers lack knowledge. Psychiatric providers need specialized knowledge to assess individuals with DD for psychiatric disorders, as symptom presentation and assessment are different in this population (Burge et al., 2002; Krahn, Hammond, & Turner, 2006). It can be challenging to diagnose specific psychiatric disorders in clients with impaired cognition and communication, as the DSM-V relies heavily on subjective reports of symptoms (Summers, Boyd & Morgan, 2004). Instead, clinicians must synthesize data from multiple sources including: caregiver's reports, medical records, developmental histories, psychological testing reports, behavioral observations (Summers et al., 2004).

A lack of knowledge about common behaviors in certain developmental disabilities leads to inappropriate diagnosis and treatment. For example, individuals with Down syndrome are particularly prone to engage in self-talk, which can easily be mistaken for psychosis and subsequently inappropriately medicated (Summers et al., 2004). Additionally, clinicians require

specialized education to safely prescribe medications to clients with dual diagnosis, as they often respond atypically to psychotropic medications (e.g., methylphenidate causes paradoxical reactions in children with autism) (Murray et al., 2014).

Studies routinely find that nurses and psychiatric providers are not knowledgeable about the mental health needs of clients with dual diagnosis (Edwards et al., 2007; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996; Melville et al., 2005; Werner & Stawski, 2012). Between 80-90% of psychiatrists report that they do not receive sufficient training to safely treat individuals with co-occurring DD and MI (Edwards et al., 2007; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996; Werner, Stawski, Polakiewicz, & Levav, 2013). The Institute of Medicine (2009) reported that health professionals are poorly prepared to meet the complex psychiatric needs of people with disabilities (as cited in Krahn & Fox, 2014). This lack of attention to the needs of clients with dual diagnosis is reflected in the requirements for medical and nursing schools. American medical schools and the accrediting body for Psychiatric-Mental Health Nurse Practitioners (PMHNP) do not include a core competency in intellectual disabilities (Trollor et al., 2016; Whiteley, Kurtz & Cash, 2016).

Stigmatized population. The prevailing definition of stigma is, "the public's attitude towards a person who possesses an attribute that fails to meet societal expectations and who is subsequently devalued and disregarded," (Ditchman, 2013, p. 207). Individuals with DD and MI are often stigmatized because they both look and act differently (e.g., lip smacking from tardive dyskinesia, repetitive hand waving in autism). Nurses and other health care providers routinely endorse stigmatizing stereotypes of people with DD (Ditchman et al., 2013; Klooster et al., 2009; Lewis & Stenfert-Kroese, 2010). Ditchman et al. (2013) found that health care providers endorse the stereotype that people with DD are, "childlike," and, "happy and loving," and thus immune

to mental illness. This 'diagnostic shadowing' causes clinicians to attribute symptoms of mental illness to the client's intellectual disability, and vice-versa (Raghavan & Patel, 2005 as cited in Adshead, Collier, & Kennedy, 2015). This can result in inappropriate prescription of antipsychotics for aggressive behavior, or suffering caused by untreated mental illness (Havercamp & Scott, 2015).

Within psychiatry, stereotypes and stigma towards people with dual diagnosis are still rampant. While most British and Australian psychiatrists agree that clients with ID receive poor mental health care, 30% of British psychiatrists and 58% of Australian psychiatrists reported that they would prefer not to treat adults with ID (Edwards et al., 2007; Lennox & Chaplin, 1995; Lennox & Chaplin, 1996). Unfortunately, negative attitudes and stigma about people with ID directly impacts the quality of care that psychiatrists provide to this population.

Historical context. Krahn and Fox (2014) argue that caring for individuals with DD in the community is a relatively new phenomenon in the United States. For more than a century, individuals with intellectual disabilities were housed in large institutions and denied psychiatric treatment (Braddock & Parish, 2001 as cited in Krahn & Fox, 2014). When de-institutionalization began in the 1950s, individuals with all levels of impairment slowly transitioned to living in community settings. Some states, like Oregon, did not even begin deinstitutionalization of individuals with DD until the 1990s (National Council on Disability, 2012). The shift from institutional to community-based housing drove the shift from custodial to treatment-based care (Davis, Barnhill, & Saeed, 2008). This policy change placed pressure on community providers to integrate this complex population into their psychiatric practices with little external support (Krahn & Fox, 2014).

Silos of care. Oregonians with co-occurring mental illness and developmental disability receive services from two separate state agencies: the Oregon Health Authority [OHA] (which funds mental health services) and Oregon Department of Human Services [ODHS] (which funds DD-specific services like behavioral specialists, and residential placements). Despite the overlap in the population being served, OHA and ODHS remain distinct entities that do not coordinate care, let alone funding streams (Oregon Health Authority, 2012). This results in several, interrelated problems. First, mental health providers are unable to request that a client with DD receive behavior specialist services (as these are provided by ODHS). Without adequate behavioral support, mental health prescribers often rely on chemical interventions, such as over-sedating clients with antipsychotics to address aggressive behavior (Krahn & Fox, 2014). Not only is this widespread practice unethical, as it constitutes chemical restraint, but it contributes to shorter life expectancy in this population by causing long-term metabolic side effects (Krahn & Fox, 2014). Second, behavior problems often contribute to failed group home/foster care placements, which results in expensive crisis placements using ODHS funds, or an expensive trip to the Emergency Department paid for by OHA (Beasley & DuPree, 2003). The division between OHA and ODHS means that neither agency is empowered with the responsibility, or funding, to fully treat behavior problems.

Best Practices for Improving Mental Health Outcomes

Service delivery components. While a single superior service delivery model has yet to be identified, several promising models share several effective components. Successful programs largely rely on integrated treatment teams of multidisciplinary professionals including: behavior specialists, registered nurses, advanced practice nurses, psychiatrists, primary care providers, social workers, paid caregivers, family members, and care coordinators (Hackerman et al., 2006;

Hassiotis et al., 2009; Weedon et al., 2012). Notably, all successful interventions utilized psychiatric providers who were specially trained in dual diagnosis psychiatry (Hackerman et al., 2006; Hassiotis et al., 2009; Hodapp, 2012; Lehrer & Ott, 2009; Weedon et al., 2012). Care coordination and longer appointments are central components of all delivery models as this population experiences more complex health needs and communication impairment, which necessitates obtaining collateral information from a variety of informants (Hackerman et al., 2006; Hassiotis et al., 2009; Lehrer & Ott, 2009; Weedon et al., 2012). Moreover, some models combined mental health and developmental disability funding streams to share expenses, as well as significant cost savings (Weedon et al., 2012). While ideal models utilize all of these components, they require significant collaboration between stakeholders, are time-consuming, resource-intensive, and often only done as a result of a legal action that forces states to change systems (Hodapp, 2012).

Expert PMHNP within a community mental health center. A less resource-intensive way to improve mental health outcomes is to incorporate a psychiatric provider who specializes in the dual diagnosis population into an existing mental health agency. Russell, Hahn, and Hayward (2011) established an outpatient mental health clinic staffed with psychiatrists who were specially trained in treating clients with dual diagnosis. These expert psychiatrists assessed clients, provided medication management, and then referred clients back to community psychiatric services when possible (Russell et al., 2011). Of the 115 patients taking psychotropic medication upon referral to the clinic, 42.6% took fewer medications by discharge (Russell et al., 2011). Same-class polypharmacy and benzodiazepine use also significantly decreased (Russell et al., 2011). Overall, client medication regimens were significantly more aligned with consensus guidelines upon discharge from the specialty clinic (Russell et al., 2011). While this study took

place in an academic medical center, the concept of creating a subspecialty clinic should be translated to a community mental health center, as this is where most Oregonians with DD are served.

Quality Improvement Project

The author developed processes for a subspecialty clinic serving individuals with dual diagnosis within a CMHC. The intervention was two-fold: 1) implementing best practices, 2) assessing the economic feasibility of contracting with an outside PMHNP to run the subspecialty clinic.

Evidence-based practices.

Longer initial appointments. Clients received 90-minute intake appointments to facilitate interviewing multiple informants and to ensure a thorough assessment.

Improving care coordination. Successful interventions are categorized by a high degree of care coordination between the psychiatric clinician, developmental disability case managers, primary care providers, legal guardians, and paid caregivers. There are two phases of care coordination: 1) collecting the medical, psychological, and psychiatric records prior to the initial appointment, and 2) on-going communication with informants throughout treatment. A thorough review of all records prior to the initial appointment is necessary as clients are often non-verbal and non-contributory for history. Moreover, many clients reside in professional caregiver's homes and are accompanied to appointments by unknowledgeable staff. The author created a flowsheet to collect the necessary records and informants' contact information prior to the initial appointment. Minimal assistance from agency support staff was required with care coordination efforts (e.g., faxing records to PCP). The clinician received two 30-minute blocks per day specifically for on-going care coordination with established clients. Moreover, the clinician

encouraged legal guardians attend at least two appointments with the PMHNP per year, or participate via phone.

Re-aligning prescription practices. While expert consensus guidelines for the use of psychiatric medications in persons with dual diagnosis offer numerous recommendations, this intervention measured outcomes for the following recommendations:

1) Assess the effectiveness of psychotropic medications on target behavior problems utilizing a standardized scale.

2) Eliminate same-class polypharmacy.

3) Decrease long-term benzodiazepine use.

4) Provide patient-centered care that is attentive to the needs of the client and family.

Economic feasibility. The author interviewed stakeholders to assess the economic feasibility of hiring an outside specialized PMHNP to provide care for a community mental health agency's dual diagnosis patients.

Approach to Conducting the Improvement Project

Setting

LifeWorks Northwest. The project took place within LifeWorks Northwest, a community mental health agency based in the Portland, Oregon metro area. It was established in 1961 as a child guidance center, but its role and services changed with the needs of its community (LifeWorks Northwest, 2013). LifeWorks Northwest (2013) provides comprehensive mental health and addiction services across the lifespan to 17,000 clients annually. The agency has 17 service locations spanning Multnomah, Washington, and Clackamas counties (LifeWorks Northwest, 2013). At the Gresham site, the PHMNP primarily serves adults and older adults with chronic mental illness, but a significant minority of patients have co-occurring mental illness and

developmental disability (G. Peake, personal communication, May 12, 2016). One aim of the intervention was to identify the number of dual diagnosis clients that LifeWorks serves.

Purpose. LifeWorks Northwest's stated mission is to, "promote a healthy community by providing quality and culturally responsive mental health and addiction services across the lifespan" (LifeWorks Northwest, 2014).

Processes. LifeWorks NW provides care to individuals with Medicare, Medicaid, private insurance, and no insurance (LifeWorks Northwest, 2013). To obtain services through LifeWorks, clients must first complete a mental health assessment with a master's level therapist. If the client is currently taking psychotropic medications, then the intake therapist sets up an initial appointment with the PMHNP for medication management. The clinic's psychiatric care coordinator (PCC), a baccalaureate-level employee, is notified that a new patient has been added to the PMHNP's schedule, and requests pertinent records from local hospitals and mental health agencies.

The PMHNP usually receives the records on the morning client's initial appointment, scans through them if time allows, and then does a 60-minute intake with the client and caregiver. Given the large volume of clients seen at LifeWorks-Gresham, clients are typically re-scheduled for follow-up appointments 8-12 weeks later. Typically, care coordination is only done if an appointment ends early, or a client no-shows.

Activities. Each clinic provided psychiatric medication management, daily group therapy, individual supportive therapy with master's level clinicians, and case management. The Gresham clinic staff was comprised of: administrative support personnel, at least one psychiatric provider, master's level therapists, housing specialists, and employment coaches.

Notably, clients had to engage in therapy (regardless of their cognitive ability) at least once every 90 days to maintain services at LifeWorks.

Readiness to change. The LifeWorks Northwest leadership expressed interest in having a single psychiatric provider takeover care for their clients with developmental disabilities. While the leadership team was supportive of re-distributing the care for this population, they were hesitant to support a quality improvement project that wasn't already listed in the agency's Quality Improvement Plan.

Anticipated barriers. Most of LifeWorks' clients with DD live in adult foster care or group homes. Paid caregivers attend the appointments with their clients, and vary significantly in their knowledge of the client's history and behavior. Foster care and group homes experience high staff turnover rates in Oregon (49% annually), therefore staff members who attend medical appointments with clients are rarely knowledgeable informants (Oregon Department of Human Services, 2012). The author anticipated that frequent staff turnover would make it difficult to have the same caregiver complete a standardized behavior questionnaire across visits.

The agency's fee-for-service model and high volume of clients causes that the agency to push providers for short appointments (e.g., 60-minute intakes) that are not conducive to this population. The author suspected that the agency would be hesitant to agree to longer appointments, as it would reduce revenue.

Facilitators. LifeWorks Northwest is a well-established CMHC that is experienced in developing and sustaining mental health programs for specific population (e.g., transitional-aged youth, older adults with dementia) (Lifeworks Northwest, 2013).

Challenges. The Gresham clinic did not have a system for obtaining the necessary records prior to initial appointments for clients with dual diagnosis. A cascade of factors

contributed to this problem. First, intake therapists did not document or assess if the client has a developmental disability. As a result, when the initial PMHNP appointment was scheduled, the PCC was unaware that the client had special needs. Next, even if the PCC knew that the client had DD, the PCC did not know that clients with dual diagnosis need to have records requested from different sources than clients without DD. Specifically, every client with DD who lives in a care home had an extensive packet of records that ODHS gives the care home owner prior to the client's move-in date. This packet of records was the best source of historical information about clients, as many clients did not have living or involved family members. The author anticipated that it would be challenging to get buy-in from the clinic's support staff to collect records from care home owners.

The Gresham clinic experienced a high rate of therapist turnover. A common complaint among the therapists was that they struggle to care for their own clients, while covering for the clients of staff who quit. As a result, therapists did not assist with care coordination or provide behavior management/environmental recommendations to dual diagnosis clients. The author expected that Gresham therapists would not buy-in to a quality improvement project that required them to coordinate care with ODHS, even though type of coordination is in their job description.

Like most mental health agencies, LifeWorks NW did not coordinate care with ODHS. This was important as DD Case Managers were the gate-keepers to accessing a behavior specialist, housing, respite, and crisis services. While every client who lived in a group homes or foster care had a designated DD Case Manager, LifeWorks NW did not collect the case manager's contact information, and thus couldn't coordinate care between systems.

The author anticipated that it would be difficult to obtain informed consent for treatment in this population. Even though many clients were nonverbal, or cognitively unable to understand the risks/benefits of psychiatric treatment, they were still their own legal guardians. This was problematic as the clinicians routinely documented that clients consented to treatment, when in fact many were incapable of consent. The clinic did not have a standardized way of identifying clients' legal guardians, obtaining consent to treatment from outside legal guardians, or determining if the client was capable of consenting to treatment as his/her own guardian. To truly implement ethical and legally-compliant mental health care, LifeWorks NW needed a standardized system for obtaining consent, as well as coordinating with ODHS to help clients obtain healthcare guardians.

Participants

The author and the clinic's PMHNP identified clients with DD who were at least 21 years old by reviewing medical records. Inclusion criteria also included: same-class polypharmacy, benzodiazepine use, or escalating behavior problems. Nine clients and their caregivers agreed to participate. The 100% Caucasian sample consisted of six males, and three females. Participant ages ranged from 23 years old to 72 years old ($M = 43.89$, $SD = 15.33$). Eight clients resided in adult foster care homes, and one client lived at home with his parents.

Protection of participants. This project posed minimal risk, as it involved translating well-established practice guidelines into a real-world clinic setting. Participants did not receive compensation for participating, and the quality of care for clients who chose not to participate was unaffected. The author assigned each client a unique alphanumeric ID code, and identifiable information (e.g., client name, date of birth) was not collected on the REDCap survey. Oregon

Health & Science University's Institutional Review Board determined that this project was not research.

Implementation & Outcome Evaluation

Implementation Procedures

The author called the eligible clients and their caregivers to invite them to participate using an agency-approved script. She created a flowsheet and used it to obtain informant contact information, as well as to track the progress of obtaining psychiatric records from caregivers. The goal was to obtain records at least five days ahead of the initial appointment. The author performed 90-minute intake interviews with the clients and their caregivers. During the first 15 minutes of the initial appointment, the author and caregiver completed the standardized behavior questionnaires together on REDCap and then answered a question about provider attentiveness. After each initial appointment, the author entered information from the client's electronic Medication Record into the REDCap online database. The author scheduled follow-up appointments with clients based on individual needs (typically, 2-4 weeks later). The author and caregivers completed the same behavior questionnaire and attentiveness question on REDCap approximately 2-3 months after the initial appointment. After each client's final follow-up appointment, the author entered the client's medications from his/her electronic Medication Record into the REDCap database.

Measures

Aberrant Behavior Checklist (ABC). The ABC is a 58-item informant rating scale that assesses problem behaviors in five domains: aggression/irritability, lethargy/social withdrawal, stereotypic behavior, hyperactivity/non-compliance, and inappropriate speech (Aman, 2012). It has been used to assess treatment effects, particularly pharmacologic, in individuals with

intellectual disability in over 350 studies (Aman, 2012). The ABC is normed on community samples, and can be completed by caregivers, parents, or residential facility staff who know the client well (Aman, 2012). It is a psychometrically valid tool that can usually be completed in 10-15 minutes (Aman, 2012). The author created a REDCap survey form for the ABC, including all original items and instructions from the printed form. Dr. Michael Aman, the author of the ABC, granted permission for the project to utilize the ABC in an online survey form. In accordance with the published ABC manual, the five subscale domains were compared to assess pre-and-post intervention changes in problem behavior. The hypothesis was that client problem behavior would decrease when a subject-expert in dual diagnosis psychiatry took over care.

Same-class polypharmacy. The author entered data from client's Medication Record into REDCap at the initial appointment, and at the final follow-up appointment. If clinically indicated, the author attempted to simplify medication regimens to eliminate same-class polypharmacy.

Long-term benzodiazepine use. The author used the clinic's existing electronic health record to identify clients who were prescribed benzodiazepines for more than six months, and noted this in the REDCap database. One aim of the project was to titrate clients off benzodiazepines.

Provider attentiveness. Anecdotally, caregivers report that mental health providers who specialized in developmental disability psychiatry are more attentive to their clients' needs. Caregivers answered the following question on the REDCap survey at the initial visit: "On a scale of 1-10, "How attentive was the previous medication prescriber to your client's needs? (1 = completely inattentive; 10 = most attentive possible)." At the last follow-up appointment, caregivers answered the following question, "How attentive was [the author] to your client's

needs? (1 = completely inattentive; 10 = most attentive possible)." Two PMHNPs who were

experts in quality improvement initiatives (i.e., DNP chairwoman, and co-chair) vetted the

language in this question.

Demographic information. The author compiled the following information into a secure

REDCap database: client age in years, psychiatric diagnosis, developmental disability diagnosis,

IQ (if available from records), residence location (i.e., group home, adult foster care, family

member's home, independent), client gender, and client ethnicity.

Use of Information Systems and Technology

Project data were collected and managed using HIPPA-compliant REDCap electronic

data capture tools hosted at Oregon Health & Science University. REDCap (Research Electronic

Data Capture) is a secure, web-based application designed to support data capture for research

and quality improvement studies, providing 1) an intuitive interface for validated data entry; 2)

audit trails for tracking data manipulation and export procedures; 3) automated export procedures

for seamless data downloads to common statistical packages; and 4) procedures for importing

data from external sources. In addition, the medication data (i.e., benzodiazepine and same-class

polypharmacy) was transposed from the agency's electronic health record and into the REDCap

database for analysis. At the completion of the project, the author downloaded the data from

REDCap and into IBM SPSS Statistics, Version 24.0 for analysis. The author consulted with a

biostatistician to confirm that she used the appropriate statistical tests.

Implementation

Evolution of the Project

Despite the author and support staff's best efforts to obtain psychiatric records from paid

caregivers, this component of the project failed. None of the paid caregivers located the requested records. Clinicians face this same situation so often that the American Association of Developmental Medicine and Dentist (n.d.) developed case-study webinars on how to conduct assessments with non-verbal clients who don't have records available. The author used these webinars to evolve her assessment practices to include more first-hand data collection (e.g., physical exams) and referrals to specialists for medical rule-outs.

Unintended Consequences

While all clients were supposed to transition back to the clinic's PMHNP upon completion of the study, three of the nine clients requested to continue seeing the author. Russell et al. (2011) encountered a similar problem when they were unable to discharge about 25% of their clients back to community providers. In Russell et al. (2011), clients who failed to discharge had significantly higher rates of polypharmacy at the time of referral. The author found that clients who requested to remain in her care all experienced high-levels of polypharmacy (i.e., 100% taking 4+ psychotropic medications), and were in the process of titrating off at least one atypical antipsychotic. These results suggest that there is a subset of more complex patients who may require continued treatment by a specialized provider.

Missing Data

100% of caregivers completed all measures. The project did not have missing data or clients lost to follow-up.

Key Findings

Psychiatric and neurodevelopmental diagnoses. The entire sample (100%) had a psychiatric diagnosis prior to the initial appointment. Most clients (55.56 %) had at least two psychiatric diagnoses at intake, and 44.44% had at least two psychiatric diagnoses at follow-up.

Table 2 shows how psychiatric diagnoses changed throughout the project. It was not possible to provide information about the level of intellectual impairment present in the sample given that caregivers did not provide psychological testing records.

Behavior problems. Most informants (66.6%) who completed the ABC knew their client for at least three years. All informants knew their client for at least six months. The author utilized non-parametric statistics to be more conservative given the small sample size. Wilcoxon match pair sign tests compared the medians of each of the five behavior subscales before and after the project. Then, mean change scores and confidence intervals were calculated to show directionality (i.e., behavior problems increasing or decreasing). Irritability/aggression significantly decreased (W = -2.21 , p = .027; M = -7.78, 95% CI [-13.1,-2.46]). Lethargy/social withdrawal (W = -1.27, p = .205; M = -2.44, 95% CI [-6.44, 1.55]), stereotypic behavior (W = -.948, p = .343; M = -1.11, 95% CI [-3.40, 1.18]), hyperactivity (W = -1.69, p = .092; M = -3.22, 95% CI [-6.61, 0.17]), and inappropriate speech (W = .106, p = .916; M = -.44, CI 95% [-2.45, 1.56]) did not significantly differ. All mean change scores trended down.

Same-class polypharmacy. The author used non-parametric statistics given the small sample size. McNemar's test revealed that clients were equally likely to be taking two drugs from the same-class at the initial and follow-up visits (p = .50), thus indicating that same-class polypharmacy did not decrease.

Benzodiazepine use. The author calculated the percent change in benzodiazepine dose for each client. Then, she performed a 1-sample t-test to compare the mean percent change at the initial and follow-up visits $t(5)$ = -2.409 (p = 0.061). While the p-value approaches statistical significance, the benzodiazepine doses did not significantly differ from initial to follow-up appointments.

Provider attentiveness. The author used a Wilcoxon signed rank test as normality could not be assumed given the sample size. Caregivers felt that the author was significantly more attentive to their client's needs than previous prescribers ($W = 2.38$, $p = 0.017$). The median improvement was 34 points (range = 83) on the 0-100 scale.

Financial feasibility. The author interviewed stakeholders at LifeWorks to determine the financial feasibility of hiring an outside PMHNP to take over care for the agency's 269 adults and 81 children with DD (S. Griffin, personal communication, May 15, 2017). The author began by determining how many days a week the PMHNP would need to work to see all 350 clients once every three months for a 30-minute appointment. Given a rate of 12 clients per day, it would require 29.17 work days to see each client one time. On average, there are 20.17 work days per month in 2017 (University of California-Berkeley, n.d.). The PMHNP would need to work 2.42 days per week for LifeWorks to take over care for the agency's clients with dual diagnosis.

Next, the author investigated if this model of care would be cost-effective for the agency. LifeWorks typically receives $104 per encounter billed under CPT code 99214 (i.e., moderate complexity client) (S. Griffin, personal communication, May 15, 2017). On average, a PMHNP costs the agency about $187,988 per year (including salary, benefits, and support staff) (S. Griffin, personal communication, May 15, 2017). This works out to be $776.68 per work day. If the PMHNP works 2.42 days per week, then she would cost the agency $1879.57 per week and would bring in $3020.16 in revenue. If benefits are 20% of the PMHNP's total cost to the agency, then a contracted PMHNP working 2.42 days per week would only cost the agency $2114.11, but will still bring in $3020.16 in revenue.

Outcomes

Discussion of Results

Psychiatric and neurodevelopmental diagnoses. All clients in the sample had a psychiatric diagnosis prior to the initial appointment. In the literature, however, about 1/3rd of adults with ID that are prescribed psychotropic medication never receive a psychiatric diagnosis (Havercamp & Scott, 2015). This difference is likely attributed to program eligibility requirements at LifeWorks, where clients must have a psychiatric diagnosis to obtain services. One unintended outcome of changing psychiatric diagnoses is that some clients may have to switch programs within LifeWorks, or be discharged to Primary Care.

Changes in diagnostic categories (e.g., from psychotic disorder to PTSD) may be attributed to differences in diagnostic criteria. Specifically, the previous prescriber used DSM-V criteria, whereas the author used the adapted criteria in the Diagnostic Manual-Intellectual Disability (DM-ID) (Fletcher, Loschen, Stavrakaki, & First, 2007). Clients with ID often fail to meet criteria using ICD-10 or DSM-V criteria (AADMD, n.d.), but still have a psychiatric disorder that interferes with their functioning. Cooper et al. (2007) found that applying adapted criteria, instead of DSM-IV-TR criteria, doubled the hit rate for psychiatric disorders in clients with ID. In this project, the adapted criteria facilitated a more accurate diagnostic process, as psychotic disorders are nearly impossible to validate in clients who are non-verbal.

Interestingly, none of the clients had autism diagnoses prior to the project. At follow-up, the clinician diagnosed three clients with Autism Spectrum Disorder. The remaining six clients had Intellectual Disability of Unknown Origin. Four of these six clients presented with dysmorphic facial features, and were successfully referred to Oregon Health & Science University's Genetics Department for further evaluation. While the author was not able to

identify neurodevelopmental diagnoses for all clients, she made considerable progress towards

identifying the underlying reasons for each clients' intellectual disability.

Behavior problems. Of the five behavior problem subscales, only one subscale (i.e.,

Irritability/Aggression) significantly decreased. Usually, antipsychotics and benzodiazepines are

prescribed to decrease aggressive behavior in this population through chemical sedation (Aman

et al., 2004). However, in this project, the author attempted to decrease medications and behavior

improved. There are several possible explanations for this interesting finding. First, clients

experienced disinhibition when on benzodiazepines, so decreasing these medications improved

clients' ability to self-regulate emotions (Aman et al., 2004). Two, the author fully assessed

clients for medical causes of behavior problems (e.g., un-treated dental pain, headaches, thyroid

disorders) and frequently identified un-treated medical conditions (AADMD, n.d.). Three, the

author provided psychoeducation and behavior management strategies during the appointments,

which may have provided caregivers with better tools to manage aggressive behavior (Aman et

al., 2004).

Same-class polypharmacy. Unfortunately, the small sample size ($n = 7$) prevented the

results from reaching statistical significance. While the author successfully eliminated same-

class polypharmacy for two clients, the remaining five clients were in the process of titrating

down. Taking clients off antipsychotics is a slow process, which first requires establishing

rapport with caregivers, many of whom are anxious about potential behavioral outbursts. In

Russell et al. (2011), the clinicians typically saw clients for six months. This project, however,

was only three months long, which may contribute to the difference in outcomes.

Benzodiazepine use. The project did not decrease rates of benzodiazepine prescriptions

for several reasons. First, the sample size was particularly small, as only five clients were

prescribed benzodiazepines at intake. Second, two of the five clients taking benzodiazepines also experienced antipsychotic polypharmacy. Given that the long-term risks antipsychotic use (e.g., heart disease, diabetes, tardive dyskinesia) are greater than that of benzodiazepines, the author chose to eliminate polypharmacy first, and then address the benzodiazepines. Had the project been longer, then the author would have weaned clients off benzodiazepines as well.

Provider attentiveness. This is the first project to measure caregiver satisfaction after receiving psychiatric care from a specialized PMHNP. Caregivers felt that the author was significantly more attentive (about 34% on average) than previous psychiatric providers. Given that caregivers of Oregonians with dual diagnosis are less satisfied with their mental health clinicians (10% below national average), this project's findings provide an avenue for remedying low satisfaction scores (NCI, 2014).

Economic feasibility. Given the dearth of psychiatric providers who are knowledgeable about clients with dual diagnosis, the author explored the possibility of taking over the care of this population for local mental health agencies. The results indicate that it would be possible for a PMHNP to care for LifeWorks' dual diagnosis population for about 2.5 days per week. Moreover, the author's revenue would exceed her cost to the agency. It appears that it would be cost-effective for the agency to hire an outside specialized PMHNP to provide care for their clients with dual diagnosis.

Impact on systems. This project demonstrates the need for intervention at the State level to require paid caregivers to provide pertinent records to psychiatric providers. While the author assumed that the LifeWorks record collection system was at fault, the project demonstrated that paid caregivers needed to be the target of change efforts. An effective way to leverage

compliance from paid caregivers would be to modify the Oregon Administrative Rules, which they must comply with for their licensure.

Unfortunately, the agency still does not have system for obtaining informed consent from clients who are nonverbal and are their own guardians. The author hoped that the project would draw the attention of agency leadership to this ethical dilemma. Instead, the author verified guardianship status for all clients in the project and received push-back from agency therapists when she asked for help contacting ODHS for clients who were not capable of consent.

Practice Implications and Limitations

This project demonstrates that it is feasible to implement best-practices for clients with dual diagnosis in a real-world community mental health center. The author utilized little-to-no agency resources, which was essential given the agency's limited financial coffers. Previous studies (i.e., Russell et al., 2011) took place in an academic medical center with significantly more resources. The findings indicate that this 'knowledgeable provider' clinic model may be one approach to optimize medications, decrease problem behaviors, and improve caregiver satisfaction.

The sustainability of this project is limited by agency politics, which dictate that clinicians cannot choose their own client populations. The way around this is to use the contractor-provider model, which was explored in the financial feasibility sections above. By establishing herself as an expert in dual diagnosis, the author positioned herself to informally increase her influence on provider attitudes and knowledge about dual diagnosis clients. For example, a few therapists at the agency reached out to the author for on-the-fly consults regarding challenging behaviors in their clients with ID.

Next Steps

The author will communicate the results of the project in a one-page summary to LifeWorks leadership. Moreover, she will encourage sustainability of the project by presenting best-practices for the dual diagnosis population at the agency's next psychiatric all-staff meeting. Additionally, the author seeks to publish this manuscript. It is essential to disseminate results of projects that support the role of PMHNP's in leadership and quality improvement roles. Lastly, the author will determine if it is financially feasible for her to proceed with the contract-provider model proposed in this paper.

Acknowledgements

Table 1.

Nurse Practitioner Maximum Allowable Reimbursement by Insurance Type.

	Regence (Commercial)	Medicare	Medicaid
CPT 99214 *(in-office)*	$128.78 [a]	$93.64[b]	$75.26[c]

Note. Fee-for-services rates are for credentialed nurse practitioners who work in a non-facility setting in Oregon with a moderate complexity client.

[a] Retrieved from Regence Blue Shield (2016, p. 746). [b] The author multiplied the physician fee from the American Medical Association (2016, p. 242) by 0.85, as nurse practitioners are paid 85% of the physician fee. [c] Retrieved from Oregon Health Authority (2016, p. 809)

Table 2.

Number of Clients with Diagnoses in DSM-V Categories at Referral and Final Follow-up Appointment.

DSM-V Category	At referral (N = 9) Total n	At follow-up (N = 9) Total n
Psychotic disorder		
Schizophrenia	1	0
Schizoaffective	4	3
Mood disorder		
Bipolar disorder	3	0
Brief depressive episode	0	1
Unspecified mood disorder	1	0
Anxiety disorder		
Unspecified anxiety disorder	0	3
Separation anxiety disorder	0	1
Post-traumatic stress disorder	1	3
Personality disorder		
Dependent personality disorder	1	1
Borderline personality disorder	2	2
Attention-deficit hyperactivity disorder	1	0
Psychogenic polydipsia	0	1
Autism spectrum disorder	0	3

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