Title Page

Cross-systems Care Integration Impact on Adults with Intellectual Disability Utilizing Risk Weight and Comorbidity Data: A comparative effectiveness study, 2014-2017

Authors

Thomas Wilson, PhD, DrPH
Trajectory® Healthcare, LLC
Loveland, OH 45140

Betty Geer, DNP, RN, CPNP
The Resource Exchange
Research Center
Colorado Springs, CO 80919

Nichole Guerra, MS, DBA
The Resource Exchange
Research Center
Colorado Springs, CO 80919

Brystal Karber, BA
The Resource Exchange
Developmental Disabilities Health Center
Colorado Springs, CO 80919

David A. Ervin, BSc, MA, FAAIDD, CEO
The Resource Exchange & Developmental Disabilities Health Center
Colorado Springs, CO 80919

Corresponding Author:
Nichole Guerra, DBA, Research Center Director
nguerra@tre.org
6385 Corporate Dr, Suite 301
Colorado Springs, CO 80919

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Abstract

Health disparities are documented between adults with intellectual and developmental disabilities (IDD) and neuro-typical peers. As progress has been slow in improving health outcomes in people with IDD, the aim of this retrospective study was to compare effectiveness of a new Cross-Systems Care Integration (CSCI) model of care coordination to standard care coordination for 927 adults with IDD receiving Medicaid services in central Colorado from 2014 through 2017. Health care cost risk weight decreased (not statistically significant) only in individuals receiving the CSCI intervention. Depression diagnoses remained statistically unchanged, while both hypertension and hyperlipidemia significantly improved in patients receiving CSCI. Further study is warranted to extend duration of study and to examine additional study variables including health-related quality of life.

Key words: Intellectual and Developmental Disabilities, Health Disparities, Care Coordination, Medicaid, Cost Risk Weight

Introduction

Health disparities among people with intellectual and developmental disabilities (IDD) have long existed and have often been linked to difficulties experienced in accessing high quality and culturally competent healthcare, economic deprivation, and lack of primary prevention efforts targeting this population (Anderson, Humphries, McDermott, Marks, Siserak, & Larson, 2013). In fact, many adults with IDD are prone to multiple chronic conditions, utilizing five times more healthcare dollars than for those without chronic conditions (Special Olympics, 2017). Results from the Adult Consumer Survey State Outcomes 2016–2017 of the National Core Indicators (NCI) showed hypertension and hyperlipidemia as two of the most prevalent health conditions among adults with IDD (Human Services Research Institute & The National Association of State Directors of Developmental Disabilities Services, 2018). Other less common conditions included cardiovacscular disease, diabetes, cancer, dysphagia, pressure ulcers, Alzheimer's and other dementias, oral/dental problems, and sleep apnea. Approximately one fifth of the NCI sample at both the national and Colorado state levels reported having hypertension or hyperlipidemia. Further, nearly half of the sample at the national and Colorado state levels alike reported taking psychotropic medications. Among the elements potentially inhibiting improved outcomes for this group of adults is the lack of person-centered coordination between the healthcare system and long term supports and services (LTSS). Cross-systems care integration (CSCI) is a proposed solution to bringing the healthcare system, long term services and supports system, and a person's community of naturally occuring social and developmental supports into common purpose in supporting the health of people with IDD.

Background

The Developmental Disabilities Health Center (DDHC) was formed as a healthcare collaborative. Partners in the collaborative initially included The Resource Exchange (TRE), a Colorado Community Centered Board (CCB) serving the Pikes Peak Region, Peak Vista Community Health Centers, the region's Federally Qualified Health Center (FQHC), Memorial Hospital (a Colorado Springs-based public hospital system), HealthSouth Rehabilitation Hospital of Colorado Springs, and AspenPointe, the region's community mental health center. As of this writing approximately 5000 persons with IDD access LTSS through TRE, which administers and coordinates Medicaid-financed home and community-based services for the Pike's Peak region. A major function of a CCB involves LTSS coordination and access to community resources that support persons with IDD to build independence and enhance their quality of life, including through health services. TRE supports persons with IDD across the lifespan in and around the Pikes Peak Region and Southern Colorado. In 2007, with supports provided by the Coleman Institute for Cognitive Disabilities, Colorado Health Foundation, JFK Partners–University Center of Excellence in Developmental Disabilities of the University of Colorado, and University of Colorado at Colorado Springs, TRE engaged numerous community agencies and national leaders in disability and healthcare who shared an interest in improved healthcare service models for people with IDD. By 2009, five Colorado Springs-based organizations combined to establish an integrated, collaborative, and interdisciplinary healthcare model that addressed primary, mental, and behavioral health, health promotion and wellness, and health education, all designed with and around the needs of people with IDD. Two years later, in 2011, the Developmental Disabilities Health Center (DDHC) was opened.

The clinic is physically located at a Peak Vista-owned facility. Even as partnerships have continued to evolve, DDHC maintains an integrated care model that is both co-located and collaborative, in which providers are specialized in working with adults with IDD and their caregivers to meet each patient's needs. Services are provided in the following areas: a) primary care; b) on-site integrated mental, behavioral, and psychiatric services; c) a referral system for allied health and specialty medicine; and d) both care coordination and cross-systems care integration in a manner that does not duplicate services. Formal care coordination, provided to DDHC patients beginning in 2012 through the addition to the healthcare collaborative of the region's accountable care organization (ACO) and borne of Colorado's adoption of the Accountable Care Collaborative platform (The Colorado Health Institute, 2017), focuses on integrating primary care with needed specialty medicine for Medicaid recipients. Soon after, DDHC patients and providers noted a gap in care coordination for patients who were also enrolled in community-based LTSS because care coordination traditionally has not included community-based supports and services. To address this gap, cross-systems care integration (CSCI) was implemented at the DDHC in 2015.

Cross-Systems Care Integration Project

In May of 2015, TRE entered into a formal partnership with Pikes Peak Community Health Partnership (PPCHP), the Medicaid financed ACO, known as a Regional Care Collaborative Organization (RCCO) for the region, to implement CSCI for patients of the DDHC. The purpose of the CSCI project was to expand the concept of traditional care coordination to include community-based LTSS coordination as well as patients' families, friends and other naturally occurring social and developmental supports. Figure 1 shows that

persons with IDD are at the intersection between healthcare, long term services, and social and developmental support and therefore require coordination via the CSCI model.

[Insert Figure 1]

Figure 1: *Cross-systems Care Integration Model*

Note. Adapted from Ervin, D. A., & Rubin, I. L. (2016). "A glimpse into the future." In I.L. Rubin, J. Merrick, D.E. Greydanus, & D.R. Patel, (Eds.), *Health Care for people with Intellectual and Developmental Disabilities across the Lifespan* (3rd ed., pp. 2293-2302). Berlin: Springer.

To develop CSCI from concept to practice, a pilot was developed that consisted of placing an experienced LTSS case manager, employed by TRE, among the medical providers and clinical staff at DDHC to develop the CSCI model and implement cross systems care coordination. When initially conceived, the assumed benefit of CSCI was that of a streamlined network of support systems that cohesively communicate and share information for the patient's benefit. The integration of systems of care was expected to improve health status and health related quality of life, as well as achieve greater cost effectiveness for DDHC patients (Ervin & Rubin, 2016). Metrics of three clinical measures and risk weight data were examined to assess the impact of care integration on the quality and cost-effectiveness of care. The aim of this paper is to report on the effectiveness of CSCI based on selected clinical measures and risk weight data, the implications of the findings, and recommendations for programs for people with IDD nationwide.

Research Methods

Study Design

A retrospective study design was used to examine the impact of CSCI to augment standard care on the health status and projected financial risk (risk weight) of Medicaid patients with IDD. To differentiate which services most influenced outcomes, comparisons were made

among groups of individuals. This preliminary analysis compared clinical measures for two samples: a) DDHC patients who received CSCI, and b) DDHC patients who did not receive CSCI. Clinical measures were selected based on prevalance (Human Services Research Institute & The National Association of State Directors of Developmental Disabilities Services, 2018) and completeness of data, this included hypertension, hyperlipidemia and depressoin data as it was collected on all individuals (e.g .as HbA1c was only potentially collected on diabetics it was excluded). Additionally, risk weight data were analyzed for each of those samples and compared to risk weight claims data for persons with IDD who were enrolled in LTSS, but were not DDHC patients and did not receive CSCI, termed "TREonly" here (no clinical data were available from the TRE only population). Analyses and management of personal health information were conducted in compliance with Health Insurance Portability and Accountability Act (HIPAA) standards.

Participants

Three mutually exclusive groups were identified using data combined from RCCO claims data, TRE, and DDHC records. Individuals within groups were tracked across years by their Medicaid identification numbers. After data were compiled for each group, the Medicaid data were destroyed per HIPAA standards and IRB protocol. Table 1 shows data availability for each group by year.

TRE only (N=600). Adults with IDD who received LTSS through TRE but were not patients at DDHC, thereby did not receive CSCI.

DDHC only (N=118). DDHC patients who were not enrolled in LTSS through TRE, thereby did not receive CSCI.

***TRE & DDHC* (N=209)**. DDHC patients who were enrolled in LTSS, therefore, did receive CSCI as of May 2015.

[Insert Table 1]

Definitions

Risk Weight. Risk weight is used by RCCO as a basis to calculate reimbursements paid to the contracted Medicaid plan and was provided to the authors. It is defined as projected financial risk of each individual; and, when aggregreated, it is the collective risk of the defined population.

Depression. Medical assistants asked all patients during new patient visits and annual physicals to complete the *PHQ-2* (Psych Congress Network, n.d.). The score on the *PHQ-2* dictated whether or not patients were then asked to complete the *PHQ-9* (UpToDate, n.d.). DDHC-based behavioral and mental health providers and/or the psychiatrist reviewed the *PHQ-2* and attempted to schedule a session to meet with the patient to administer the *PHQ-9*. The behavioral and/or mental health providers or psychiatrist then used information gathered from the *PHQ-9* and interview along with DSM criteria to diagnose depression.

Hypertension. When patient vital signs were measured, medical providers used the following chart (Table 2) to determine whether a series of readings needed to take place. If readings showed abnormal blood pressure, then patients or their caregivers were asked to measure their blood pressure 2-3 times per week for 6-8 weeks and review with provider at a follow up appointment. If a pattern of elevated blood pressure was observed (i.e. Hypertension Stage 1 and Hypertension Stage 2) or currently taking antihypertensive prescription medications, then the patient would be diagnosed with hypertension.

[Insert Table 2]

Hyperlipidemia. A patient was diagnosed as having hyperlipidemia if they did not have a diagnosis of diabetes or coronary heart disease (CHD) and had an HDL reading of ≤46 mg/dl, an LDL reading of ≥130 mg/dl, a Total Cholesterol of ≥200, a Trigyceride reading of ≥150 mg/dl, or currrently receiving cholesterol lowering (e.g. statin) therapy. Among those with a diagnosis of diabetes or CHD, the definition of hyperlipidemia included all the above, but in the LDL measure was lowered to <100 mg/dl. Among diabetic patients with known heart disease the threshold for LDL was lowered to <70 mg/dl to be diagnosed with hyperlipidemia.

Research Questions (RQ)

RQ1. Did the cross-systems care integration intervention in the *TRE & DDHC* group have any impact on risk weight compared to *DDHC only* and *TRE only* groups?

H_0: The CSCI intervention did not impact risk weight for any group.

H_1: The CSCI intervention positively impacted risk weight in the *TRE & DDHC* group.

RQ2. Did the cross-systems care integration intervention in the *TRE & DDHC* group have any impact onclinical measures when compared to the *DDHC only* group?

H_0: The CSCI intervention did not impact clinical measures for any group.

H_1: The CSCI intervention improved clinical measures for *TRE & DDHC* group.

Data Collection and Analyses

Risk weight data from 2014 through 2016 were collected from RCCO claims data available through PPCHP. Clinical data for DDHC patients on Medicaid were collected from 2014 through 2017 from the DDHC electronic health records. Clinical measures data were collected included diagnosed depression, hypertension, and hyperlipidemia. Risk weight was examined among individuals in the 3 groups. Only individuals where data were available on the risk weight variable each year from 2014-2016 (i.e., for those who received healthcare under

Medicaid) were included in the analyses on the three clinical measures and the risk factor data. Statistical tests on the average risk weight between specified years and groups were conducted using t-tests. Clinical measures data were only available in two groups, *TRE & DDHC* group and the *DDHC only* group, which were analyzed to better understand the benefits of CSCI to the health status of patients with IDD. Statistical significance was calculated by generating slopes for each clinical measure over time and comparing the slopes to each other for statistical significance using the generalized linear regression function (Proc Genmod) in SAS 9.4.

Results

Part 1: Risk Weight Between Groups

The risk weight category is a tool used by the state of Colorado to assess predicted risk of healthcare costs. Higher risk weights are predicted to correlate with higher healthcare costs in the future. It is worthwhile noting the difference in risk weight in Y2016 between *DDHC only* (mean=5.40, s.d.=5.96) and *DDHC & TRE* (mean=7.56, s.d.=7.919) was statistially significant (p=0.0017), which indicates that the risk weights for those groups were not equivalent at baseline, prior to implementing CSCI. However, an important difference between these two groups is the introduction of CSCI in the *DDHC & TRE* group at the beginning of May 2015 (Figure 2)); a slight decline between Y2015 (mean=7.338, s.d.=7.202) and Y2016 (mean=7.56, s.d.=7.919) in the *DDHC & TRE* group, while encouraging, was not statistically significant (p=0.7686). In contrast, risk weight data for the *TRE only* group, which was characterized by not receiving CSCI, steadily increased for three years (Figure 2). To summarize, the *TRE only* group's risk weight increased from 6.75 at baseline to 8.23 in Y2016. The *TRE only* and *DDHC & TRE* groups had equivalent risk weights in 2014 and 2015, but the latter decreased in 2016 while the former increased. The *DDHC only* group displayed the lowest Risk Weight of the two

groups, which remained fairly constant over three years. Thesefindings warrant continued tracking of risk weight to measure the impact of CSCI over time.

[Insert Figure 2]

Figure 2*: Risk Weight Comparison Across Three Groups*

Part 2: Clinical Markers Between Two DDHC Subsamples

To assess potential change in clinical risk factors over time, we examined data on age, gender, and three clinical measures (depression, hypertension, hyperlipidemia) from 2014 to 2017. At baseline (2014), 63.7% of *DDHC only* and 63.9% of *DDHC & TRE* were male (p=0.98). The mean age at baseline was 27.8 years (sd=9.9) for *DDHC only* and 31.9 years (sd=11.3) for *DDHC & TRE* (p=0.002).

The analyses of the three clinical measures included the least squares regression slopes were compared by using Proc Genmod, a generalized linear model in SAS 9.4 statistical software package to obtain the p-value for the difference in slopes. The prevalence of depression was high in both groups at the beginning of the reporting period (2014) and both groups trended downward over three years, but there is no statistically significant difference (p = 0.1042) between the two slopes (Figure 3). The DDHC clinic is an integrated healthcare clinic, offering mental and behavioral health services in addition to primary care and CSCI. Many patients seek healthcare at the DDHC in order to receive mental and behavioral health services, which might help to explain why patients' depression status is similar in both groups.

[Insert Figure 3]

Figure 3*: Depression Trends among the DDHC Population*

The prevalence of hypertension was greater for the *TRE & DHCC* group at the beginning of the reporting period (2014), but trended downward; meanwhile, the *DDHC only* group trended

upward (Figure 4). The difference between these two slopes is statistically significant ($p<0.0001$). The results indicate that among DDHC patients, hypertension decreased among those adults who received CSCI, but increased among adults who did not receive CSCI.

[Insert Figure 4]

Figure 4*: Hypertension Trends among the DDHC Population*

The prevalence of hyperlipidemia was greater in the *TRE & DHCC* group at the beginning of the reporting period (2014), but trended downward; the *DHCC only* group, conversely, trended upward (Figure 5). The difference in these slopes is statistically significant ($p<0.0001$). This indicates that among DDHC patients, the prevalence of hyperlipidemia decreased among adults who received CSCI, but increased among adults who did not receive CSCI.

[Insert Figure 5]

Figure 5*: Hyperlipidemia Trends among the DDHC Population*

Discussion

The analyses of these data demonstrate that the projection of financial risk, used in payments in health plans via the "Risk Weight" variable, trended downward following the introduction of CSCI in adults with IDD compared to those adults with IDD who did not recieve CSCI. This decline did not reach statistical significance, but is deemed to be clinically significant given the higher risk noted in risk weight elsewhere, most notably in the *TRE only* group . The reason for this decline is not clear, although it does coincide with the implementation of CSCI at DDHC. Statistically significant differences in rates of hypertension and hyperlipidemia were noted over time between *DDHC only* and *DDHC & TRE*. Although encouraging for the CSCI model, we cannot directly attribute these difference to CSCI. CSCI appears to have had little impact on rates of depression (which has a complex etiology and trajectory). In fact, depression

remains fairly high with minimal fluctuations despite the slight downward trend in rates throughout the study period for both groups. This is not surprising because many patients enroll at DDHC for its integrated mental and behavioral health, therefore, patients with dual diagnoses of IDD and mental health are likely overrepressented at DDHC. Although DDHC patients are not required to receive mental or behavioral health services at DDHC, they must receive primary care at DDHC in order to access the clinic's mental and behavioral health services. Measuring mental health outcomes should track the presence of mental health diagnoses in conjunction with symptom management and psychotropic prescriptions to increase the relevancy of the dataset.

The steady improvement of rates of hypertension and hyperlipidemia over three years among adults receiving CSCI, when compared to DDHC adults who were not receiving CSCI supports, suggests that the CSCI model implemented at DDHC may be partially responsible for that reduction. Looman et al. (2015) noted that care coordination activities include communicating patient care plans, connecting patients and their caregivers to community resources, exchanging information with community agencies, and advocating for referrals needed to other healthcare providers and community services. Maximizing these activities across systems with the CSCI model may improve the effectiveness of care coordination and improve health outcomes.

While the current research addresses clinical measures and risk weight data, additional measures of impact and efficacy of CSCI include factor such as healthcare utilization patterns (e.g., emergency department use, inpatient hospital admissions and 30-day readmission rates (Sun, Karaca, & Wong, 2018; Weiss, Isaacs, Diepstra, Wilton, Brown, McGarry, & Lunsky, 2018), total Medicaid and prescription expenditures), and health-related quality of life (Park, Ock, Lee, Lee, Han, Jo, & Park, 2018). Preliminary analyses suggest changes in certain

utlization patterns and lower costs overall for patients receiving CSCI, as well as higher self-reported quality of life among patients receiving CSCI. Quality of life measures were collected during the same timeframe to evaluate changes in DDHC patients' quality of life, the results of which will be reported separately. While not the focus of the current research, these are measures of impact that merit more in-depth review.

Limitations of the study

Limitations of this study were the short duration of data collection, limited analysis of comorbidities, the geographical limitation to one clinical practice, and the relatively small sample size. The assumption was that risk weight remains a valid marker for general confounding differences and a measure of the general severity of the patient's health . Data on the level of disability was not available for this study.The validity of the data was limited in that it only indirectly measured the impact of CSCI on patients' health outcomes. Given those limitations, it is encouraging that the trends for hypertension and hyperlipidemia reached statistical significance. The addition of other factors could have added gravity to the findings. Anderson et al (2013) described prevalence and risk factors relevant to health disparities in people with IDD. However, common and relevant co-occuring conditions or circumstances such as obesity, neuro-muscular disorders, oral health, and polypharmacy, were either not measured or not analyzed for their impact in this study. Additionally, analyses did not adjust for patient age or specific severity of either intellectual or physical disabilities, which could provide more insight into the effectiveness of CSCI for subgroups. Continued and perhaps broadened tracking of patients' health measures and CSCI activities is warranted to better understand the direct impact of CSCI on patients' health outcomes.

Future Study

Clinical practices focusing on the IDD population are encouraged to implement CSCI and attempt to collect cost effectiveness and clinical measure data to assess the impact of CSCI in their local communities. Using a comparative effectiveness method and biostatistical tools to measure the benefits of CSCI used within an integrated healthcare model for patients with IDD are useful approaches to examine the impact of augmented services to the IDD population, which healthcare providers are encouraged to adopt nationwide.

In addition, future research should consider examination of psychotropic polypharmacy data (McLaughlin-Beltz, Medgyesi, Boynton, & Nestell, 2015) and quality of care measures (United Healthcare, 2016) to measure the impact of CSCI models. Future studies should also include analyses of the effectiveness of CSCI by severity of intellectual and physical disability, age and gender measures, as well as the effect of co-morbidities. Finally, evidence suggests that care coordination can improve various outcomes for patients with complex healthcare needs (Looman, Hullsiek, Pryor, Mathiason, & Findeltein, 2018). Note that LTSS eligibility is based on an individuals' level of need, therefore, persons with IDD who are eligible for LTSS often have more complex healthcare needs than those who are ineligible or do not necessarily choose to enroll in LTSS. These complex healthcare needs (e.g., chronic conditions and mental illness) translate into higher utilization and higher costs. Wammes, Tanke, Westert, & Jeurissen (2018) called for tailored interventions to mitigate costs and meet patient needs. CSCI currently helps to expand traditional models of care coordination for persons with IDD who receive LTSS. CSCI, as outlined in this study, expands further to assure all systems of care, both formal and informal, are engaged in the health of the person with IDD being supported with CSCI.

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Table 1

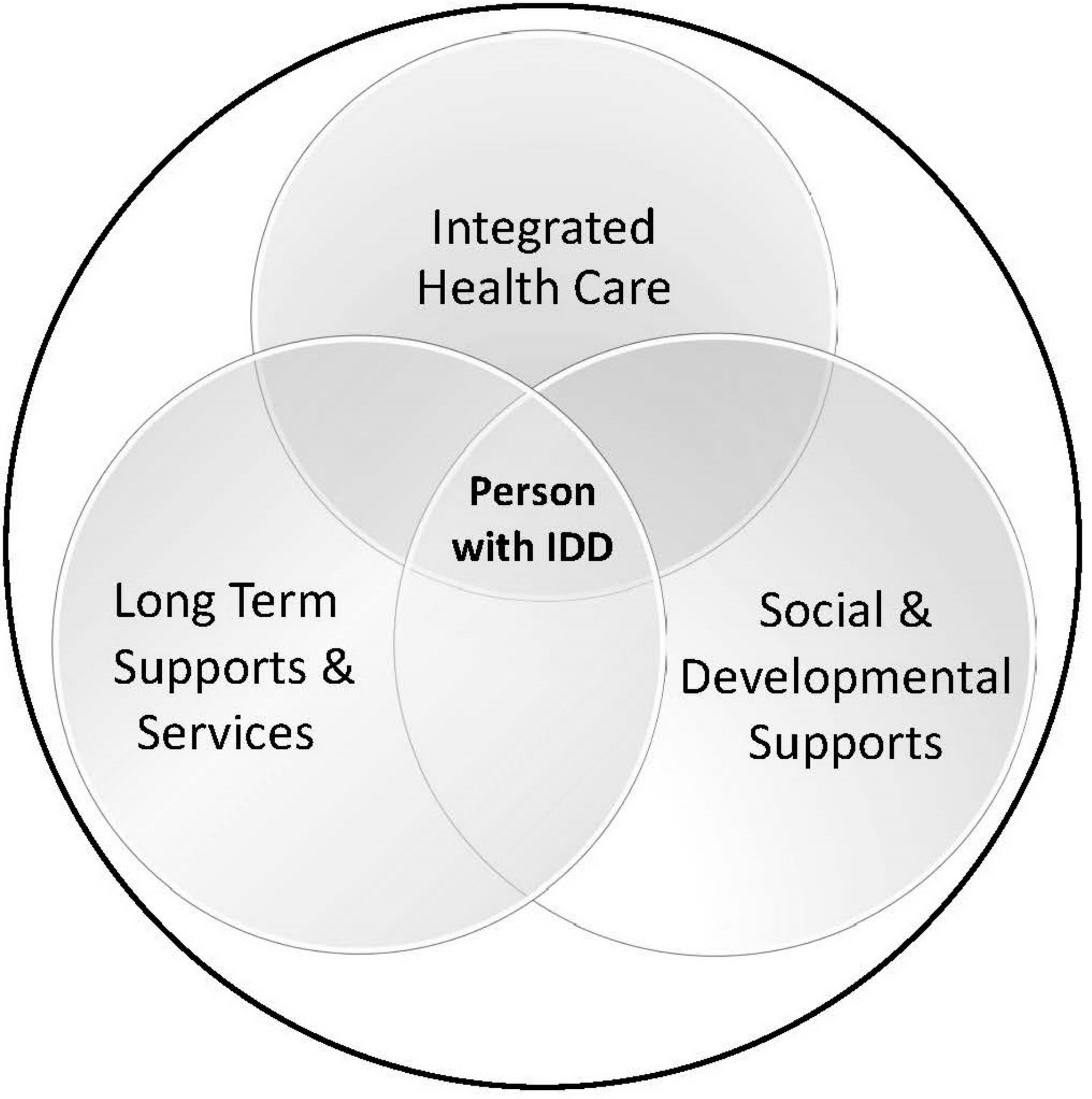
Types of Data Availability for Each Group

Group	2014	2015	2016	2017
TRE only	Risk Weight Data (no clinical measure data available)			
DDHC only	Risk Weight Data			
	Clinical Measure Data			
DDHC & TRE	Risk Weight Data			
	Clinical Measure Data			

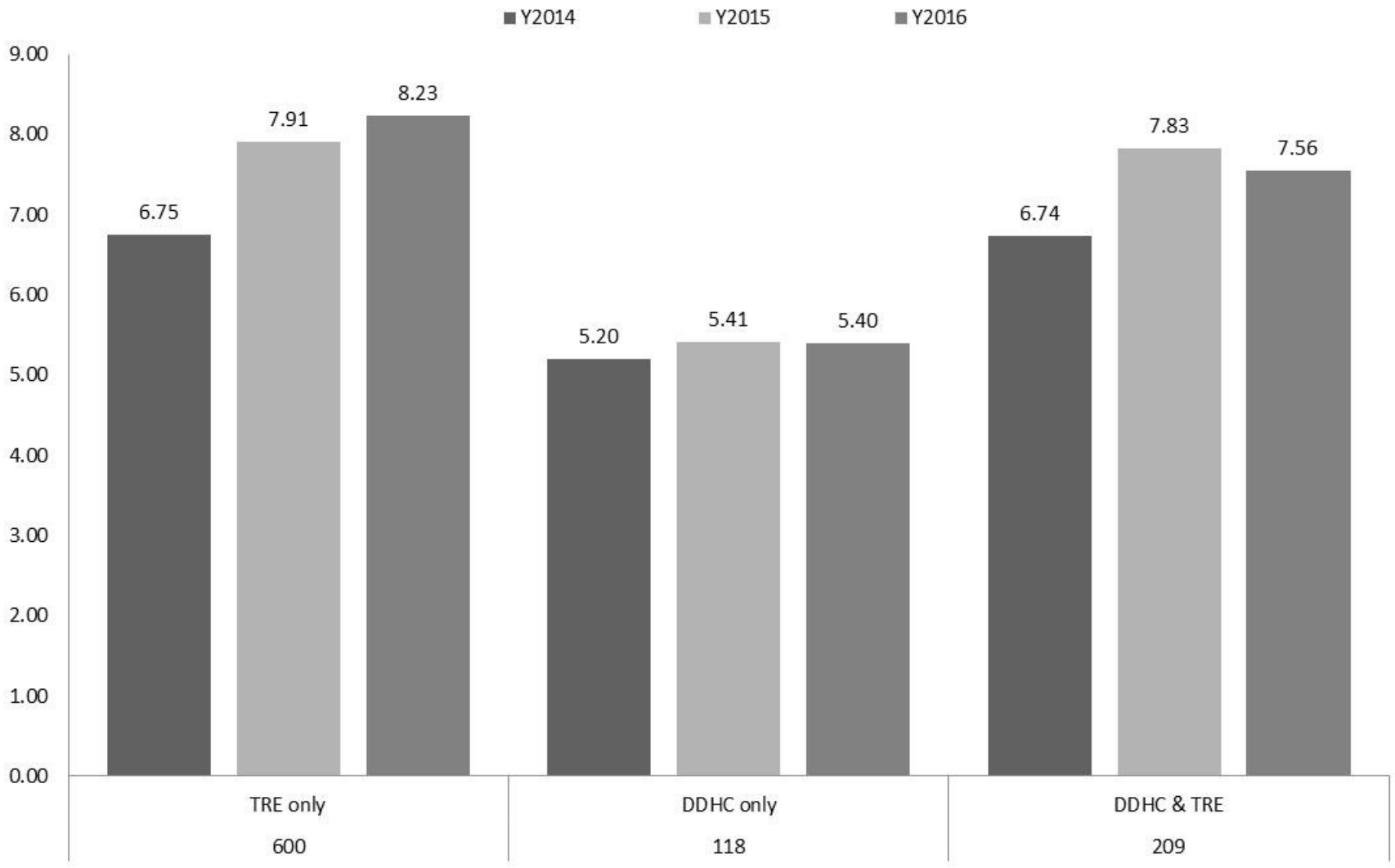
Table 2

Blood Pressure Parameters

BP Category	Systolic		Diastolic
Normal	Less than 120	And	Less than 80
Prehypertension	120-139	Or	80-89
Hypertension Stage 1	140-159	Or	90-99
Hypertension Stage 2	160 or higher	Or	100 or higher

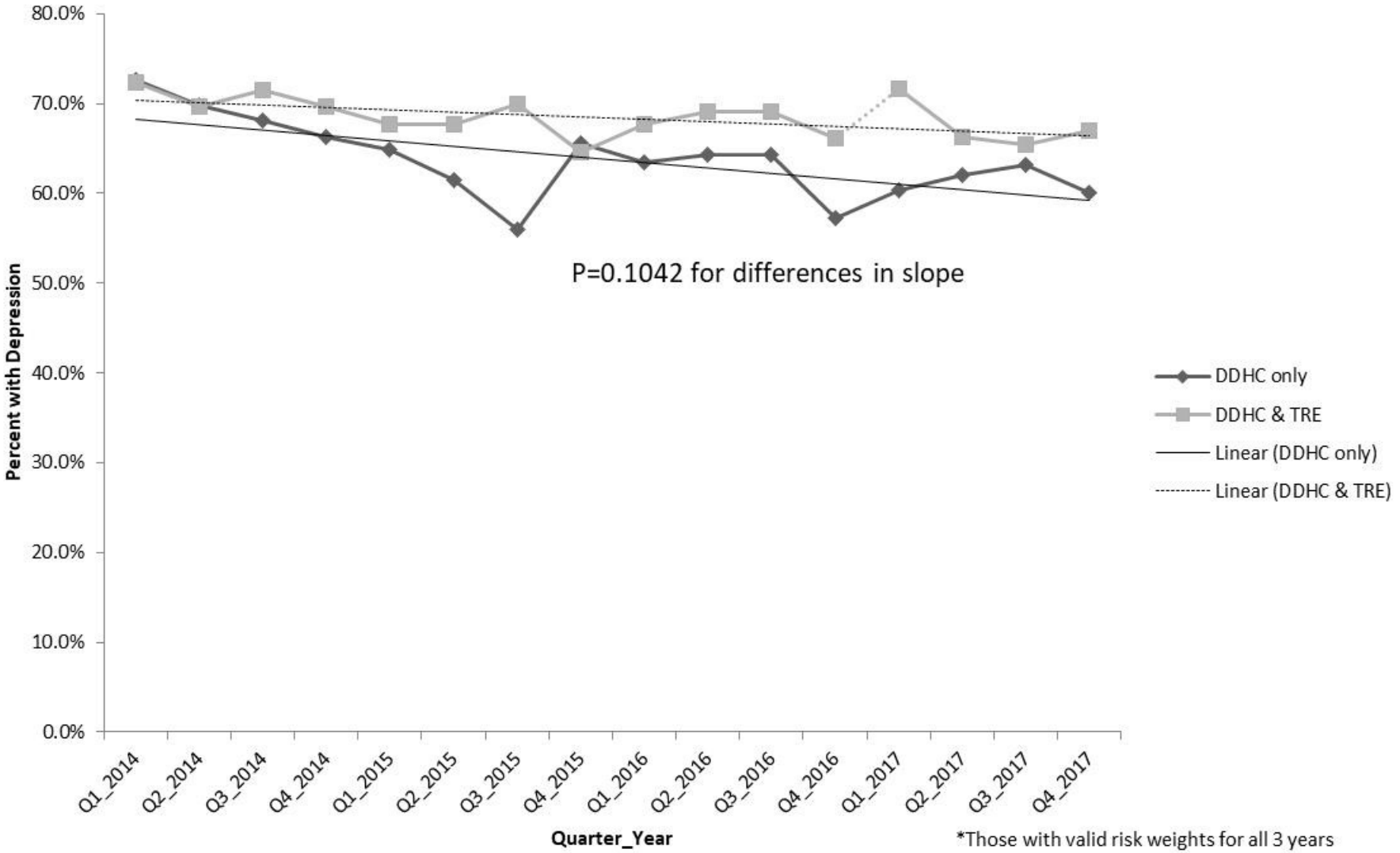

Integrated
Health Care
Person
with IDD
Long Term
Supports &
Services
Social &
Developmental
Supports

Risk Weight in Individuals* in the Three Groups, 2014-2016: TRE only, DDHC only, & DDHC & TRE



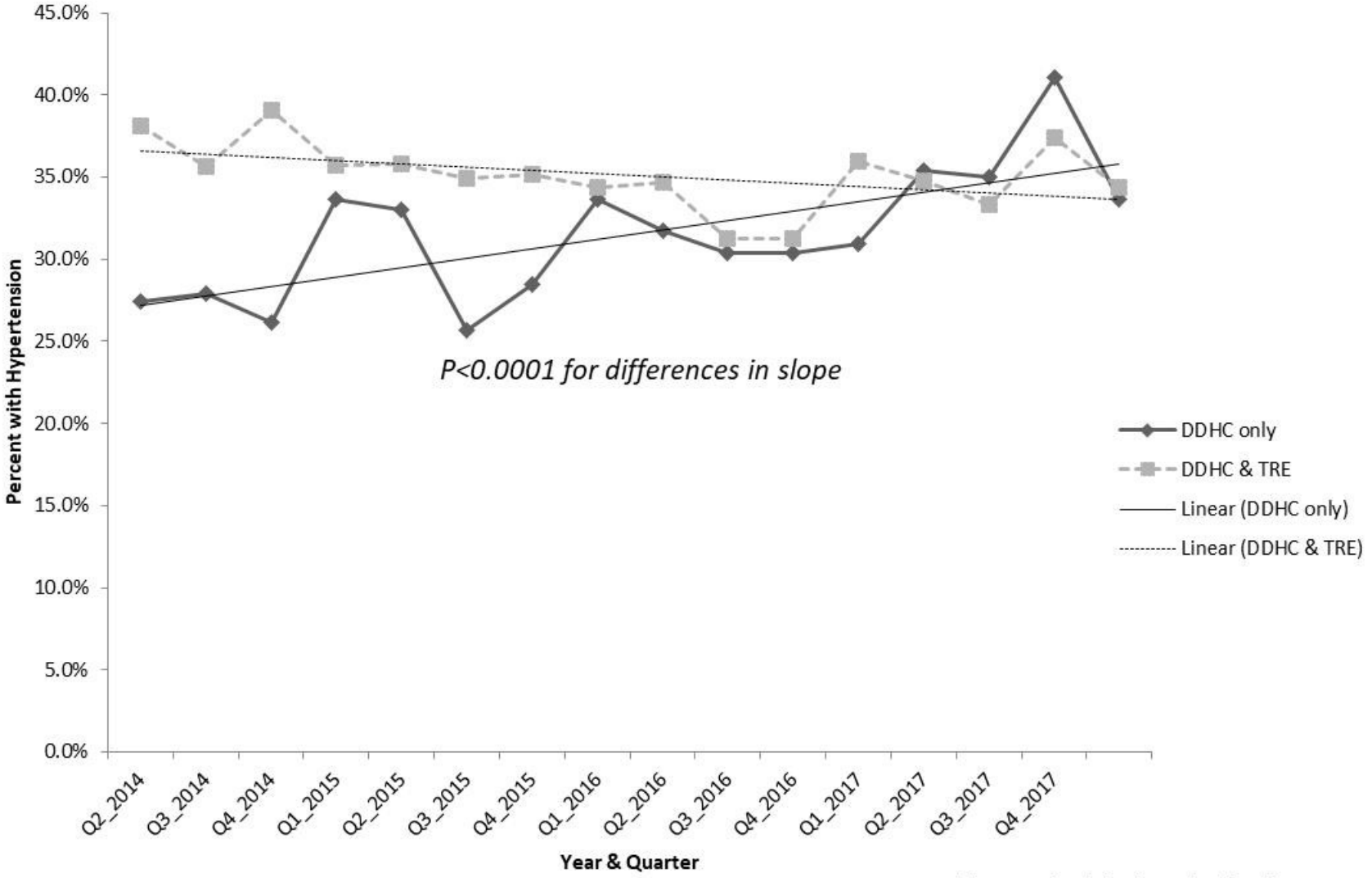
*Those with valid risk weights for all 3 years

Depression Trends in Individuals* in DDHC only Compared to Those in DDHC & TRE: By Quarter in 2014 to 2017



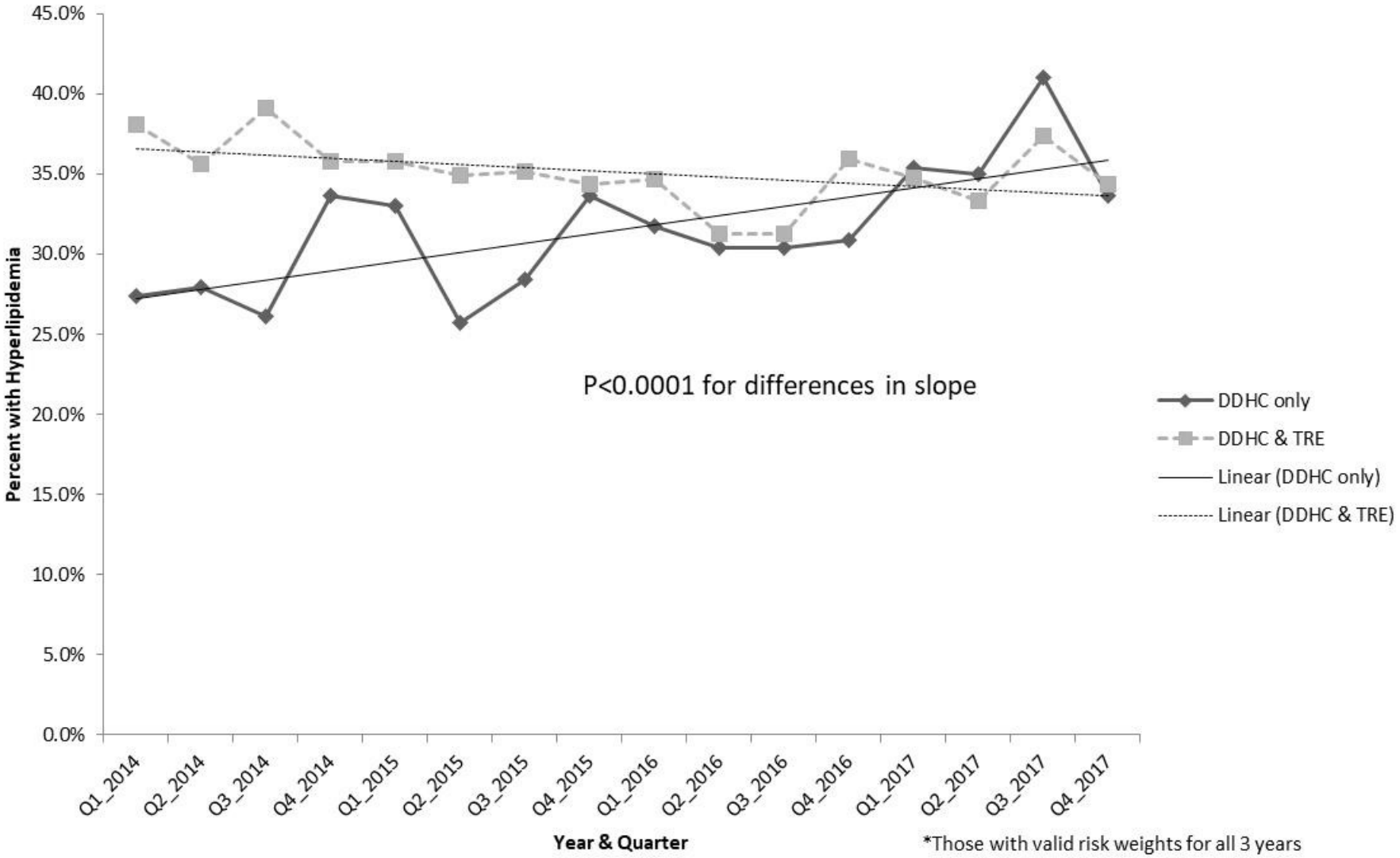
*Those with valid risk weights for all 3 years

Hypertension Trends in Individuals* in DDHC only Compared to Those in DDHC & TRE: By Quarter in 2014 to 2017



*Those with valid risk weights for all 3 years

Hyperlipidemia Trends in Individuals* in DDHC only Compared to those in DDHC & TRE: By Quarter in 2014 to 2017



*Those with valid risk weights for all 3 years