ABSTRACT

Title of Dissertation: THE HEALTH OF YOUNG ADULTS WITH

DISABILITIES IN THE UNITED STATES: THE

COLLECTIVE ROLES OF RISK FACTORS IN SOCIAL

ECOLOGIC FRAMEWORK

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Background: Over the last few decades, the prevalence of young adults with disabilities (YAD) has steadily risen as a result of advances in medicine, clinical treatment, and biomedical technology that enhanced their survival into adulthood. Despite investments in services, family supports, and insurance, they experience poor health status and barriers to successful transition into adulthood.

Objectives: We investigated the collective roles of multi-faceted factors at intrapersonal, interpersonal and community levels within the social ecological framework on health related outcome including self-rated health (SRH) of YAD. The three specific aims are:

1) to examine sociodemographic differences and health insurance coverage in adolescence; 2) to investigate the role of social skills in relationships with family and peers developed in adolescence; and 3) to collectively explore the association of sociodemographic characteristics, social skills, and community participation in adolescence on SRH.

Methods: Using longitudinal data (N=5,020) from the National Longitudinal Transition Study (NLTS2), we conducted multivariate logistic regression analyses to understand the association between insurance status as well as social skills in adolescence and YAD's health related outcomes. Structural equation modeling (SEM) assessed the confluence of

multi-faceted factors from the social ecological model that link to health in early adulthood.

Results: Compared with YAD who had private insurance, YAD who had public health insurance in adolescence are at higher odds of experiencing poorer health related outcomes in self-rated health [adjusted odds ratio (aOR=2.89, 95% confidence interval (CI): 1.16, 7.23), problems with health (aOR=2.60, 95% CI: 1.26, 5.35), and missing social activities due to health problems (aOR=2.86, 95% CI: 1.39, 5.85). At the interpersonal level, overall social skills developed through relationship with family and peers in adolescence do not appear to have association with health related outcomes in early adulthood. Finally, at the community level, community participation in adolescence does not have an association with SRH in early adulthood.

Conclusions: Having public health insurance coverage does not equate to good health.

YAD need additional supports to achieve positive health outcomes. The findings in social skills and community participation suggest other potential factors at play for health related outcomes for YAD and the need for further investigation.

THE HEALTH OF YOUNG ADULTS WITH DISABILITIES IN THE UNITED STATES: THE COLLECTIVE ROLES OF RISK FACTORS IN SOCIAL ECOLOGIC FRAMEWORK

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List of Abbreviations

ADHD Attention deficit hyperactivity disorder

AIC Akaike information criterion

aOR Adjusted odds ratios

ASD Autism spectrum disorder
BIC Bayesian information criterion

CDC Centers for Disease Control and Prevention

Disability-associated health-care

DAHE expenditures

DD Developmental disabilities

IDEA Individuals with Disabilities Education Act

IRB Institutional Review Board LEA Local education agencies

NCHS National Center on Health Statistics
NHIS National Health Interview Survey

NHW Non-Hispanic White

NLTS2 National Longitudinal Transition Survey 2 NSCH National Survey of Children's Health

PCMH Patient centered medical home

PSU Primary sampling unit

SEM Structural equation modeling

SES Socioeconomic status

YAD Young adults with disabilities

Chapter 1: Introduction

1.1 Background and Rationale

The public health issues surrounding the health of Young Adults with Disabilities (YAD) first rose to prominence in the 1980s as a result of two important national conferences: 1) the 1984 Conference on "Youth with Disability: The Transition Years" and 2) the 1989 Surgeon General's Conference on "Growing Up and Getting Medical Care: Youth with Special Health Care Needs". The two conferences produced recommendations for research and clinical practice that included improvement to existing models of medical care for YAD, health care financing, training of professionals with specialized expertise to serve YAD and advancing research. The health disparities experienced by YAD were further highlighted by findings from the 1984 National Health Interview Survey (NHIS) in which YAD had three times the doctor's visits and six times the number of hospital stays as compared with young adults without disabilities and one in five YAD was uninsured in 1984.

1.1.1 Rising prevalence of YAD

Over the last few decades, the prevalence of YAD has continued to rise as a result of advances in medicine, clinical treatment, and biomedical technology, which have enhanced their survival into adulthood. ^{4,5,6} From 2005 to 2010, the US Census Bureau reported an increase in the population of persons with disabilities from 47.5 million to 56.7 million people. ^{7,8} In the general population of young adults in the US, 15% have disabilities. ⁹ In 2010, 1.2 million individuals ages 16 to 20 in the US reported having one or more disabilities, which included but not limited to vision impairment, hearing loss, autism spectrum disorder, attention deficit hyperactivity disorder, intellectual disabilities, cerebral palsy, learning disabilities, and developmental delay. ¹⁰

1.1.2 Poor health status of YAD: a complicated and significant issue

The health disparities in conjunction with the increased in prevalence of YAD has heightened the public health concerns for this population. Building upon the research and programmatic gaps identified from the 1989 Surgeon General's Conference, researchers in the last two decades have primarily focused on factors associated with receipt of poor health care among YAD: 1) race/ethnicity minority status ^{11,12,13}; 2) lower socioeconomic status (SES)^{10,14}; 3) lack of insurance or gap in insurance coverage ^{10,11,15,16}; 4) financial burden of health care expenses ^{17,18}; 5) lack of knowledgeable adult health care provider with expertise in disabilities ^{15, 19}; 6) lack of access to a medical home with care coordination ^{10,20}; 7) lack of independent decision-making skills²¹; 8) ability to navigate through a complex public health service systems ²²; 9) severity of their physical, mental or emotional functional limitations ^{10,11,15}; 10) family support ^{12,23}; and 11) lack of usual source of care ¹³. To address the health care related factors, clinicians from the American Academy of Pediatrics, American College of Physicians, and American Academy of Family Physicians jointly developed a consensus statement in 2002 to highlight the need for effective health care transition planning, professional education, insurance adequacy, and healthcare payment reform.²⁴ Furthermore, various models of clinical care have been proposed over the years that included the person-centered model, a diseasefocused model, a hospital-based model, a team-based outside the health service, a named person, a voluntary organization a primary care model, and interdisciplinary team model. 25,26,27 Thus far, medical home, where medical care is accessible, continuous, comprehensive, family centered, and coordinated, has been endorsed as an effective model for implementing successful health care transitions for YAD. ^{28,29,30} However, the most significant barriers cited by programs

supporting YAD in medical homes have included availability of funding, access to adult primary care providers and adult subspecialists.³¹

1.1.3 Health of YAD: a continuing public health problem

Despite a decade passing since the consensus statement from clinical professional membership organizations and more than two decades since the Surgeon General's Conference, high quality and effective health care transition service as a means for improved health status of YAD has not been implemented in basic health care provisions. ¹⁸ More importantly, persons with disabilities continued to experience poor health status and increased risks for secondary conditions and morbidity.³² Clinicians have reported the emotional and social issues of YAD that are associated with perceptions of being disabled within their family, peer groups, and community, which suggest that the health status of YAD extend beyond individual attributes and receipt of quality health care to multi-level factors. 33 Furthermore, entrance into young adulthood for those with disabilities can be an especially vulnerable time as they mature, develop healthrelated habits, and potentially engage in risky behaviors. 34,35,36,37 Achieving positive perceived health for YAD is an important component for successful transition into adulthood, improvements in well-being, and active participation in community.³⁸ If YAD are able to achieve positive health during the transition to the critical period of adulthood, then benefits will include reductions in risk of preventable diseases, health care costs, and the utilization of social service system.³⁹

1.1.4 Current Policy and Research Gaps on the health of YAD

Current federal policies aimed at improving the health of YAD consisted of expansion in dependent coverage to age 26 and Medicaid eligibility through the Patient Protection and

Affordable Care Act of 2010. ^{40,41} While policymakers have equated increasing individual access to health services as a proxy for improving health, this approach precluded the effects of the social determinants of health. ⁴² Although health insurance is an important enabling resource for YAD to receive access to health care, it has limited effect on reducing differences on health care access and utilization by race, ethnicity, and SES. ⁴³ Studies on the health of YAD have primarily used proxy measure such as access to usual source of medical care, transition to adult medical care, emergency department utilization, and continuity of health insurance coverage into adulthood. ^{14,44,45,46} Very little research has explored the impact of different causal pathways and environmental triggers on health status of YAD from a longitudinal perspective.

1.1.5 Preliminary findings

The findings of my independent study project conducted in fall of 2012 using data from the 2007 National Survey of Adult Transition Health indicated that YAD had nearly **five times the adjusted odds ratio (aOR)** to receive Medicaid insurance (aOR=5.26, 95% CI= 3.74, 7.40) than young adults with other special health care needs. In addition, they were more likely to need extra help in arranging their medical care (aOR=1.52, 95% CI= 1.07, 2.61) and to need a referral for specialty medical services (aOR=1.54, 95% CI= 1.18, 2.01) in the past 12 months.
Furthermore, when examining the transition outcome related to independent living, the analysis indicates negative associations for YAD in financial, social, and personal decision-making. Finally, YAD were more likely to live with their parents (aOR=1.68, 95% CI= 1.29, 2.19) in adulthood. The results from my independent study demonstrated that access to health insurance such as Medicaid benefits alone does not guarantee positive health for YAD.⁴⁷

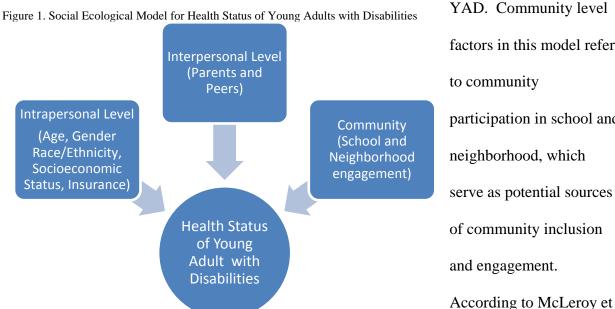
1.2 Objectives

Given the emergence of public health issues surrounding YAD, this dissertation study was undertaken to investigate the risk factors impacting the health and health related outcomes among YAD, including their self-rated health (SRH) using the social ecological theoretical framework and longitudinal analysis. The first manuscript (Chapter 3) examines the association between health related outcomes of YAD and insurance status from adolescence to early adulthood with exploration into sociodemographic differences of intrapersonal characteristics among YAD. The second manuscript (Chapter 4) focuses on the association of health related outcomes and social skills of YAD in their relationship with family and friends at an interpersonal level. The third and final manuscript (Chapter 5) collectively investigates risk factors at the intrapersonal, interpersonal, and community levels of the social ecological model to uncover potential levers for positive SRH among YAD.

1.3 Theoretical/Conceptual Model and Hypothesis

We need a comprehensive theoretical framework such as the social ecological model to understand the confluences of environmental and personal factors linking behaviors and health related outcomes for YAD. The majority of previous studies focused on the factors at a personal level and did not examine the collective roles of potential determinants at the intrapersonal, interpersonal, and community levels. We propose to use the social ecological model to identity risk and protective factors associated with health related outcomes for YAD at the intrapersonal, interpersonal, and community level with the assumptions that health behaviors are fostered based

upon our beliefs, understandings and theories of the determinants of behavior. (See Figure 1). ^{48,49,50,51} The hypothesis is that YAD will have poorer health if they have disadvantages in SES, lack the presence of forming strong interpersonal relationships and lack active community participation. The social ecologic model integrates individual, interpersonal, and environmental determinants of behaviors to better explain the dynamic nature of health status of YAD. 52,53 Interpersonal factors in this model refer to sociodemographic and socioeconomic variables of age, gender, race/ethnicity, insurance status and household income. Interpersonal factors in this model refer to peers and parents who represent potential sources of relationships and support for



YAD. Community level factors in this model refer to community participation in school and neighborhood, which serve as potential sources of community inclusion and engagement.

al., central to the ecological perspective is the idea of the interaction between the individual with his or her social and physical environment or community. 40 The environment has been defined as the social or physical space in which a variety of factors exogenous to the individual interact to influence their health. Research on the impact of multi-level factors on health related outcomes will provide useful information for the development of intervention programs targeting improvement of YAD overall health.

1.4 Innovation and Significance

The study was innovative in three ways: 1) use of longitudinal data, 2) use of the social ecological model as theoretical framework, and 3) use of advanced statistical methods such as structural equation modeling to investigate the causal pathways between multi-level factors. The National Longitudinal Transition Study 2 (NLTS2) is the most recent, nationally representative sample of YAD exploring their educational and life experiences as they transitioned from adolescences into early adulthood over a period of ten years. The longitudinal design of the data set afforded the opportunity to look at health related outcomes including SRH over time and establish causal relationship and statistical associations. The use of social ecological model in understanding SRH contributes to health behavioral science research. The sample size allowed for the national exploration into risk factors at the intrapersonal, interpersonal, and community level within the social ecological model for YAD.

Existing research on health of YAD has been limited by cross-sectional data that hindered the ability to investigate relationships between risk factors and health related outcomes including SRH of YAD. Furthermore, existing studies lacked theoretical frameworks, use of valid and reliable instruments, and research designs with adequate controls examining the multidimensional aspects of health of YAD such as family and peers social relationships as well as community participation. ^{54,55} The research proposed in this application utilizes a comprehensive social ecological model framework to examine the confluence of individual and environmental level risk factors as well as social influences that contribute to the health related outcomes including SRH of YAD.

This new and substantively departure from looking at surrogate health-related measures such as receipt of high quality health care to directly investigate the health related outcomes

including SRH of YAD is expected to overcome the persistent problems of developing interventions based upon proximal levers. The results from our study will elucidate the influences from the social-ecological framework on the health related outcomes including SRH of YAD that will lead to the development of effective health promotion interventions, disease prevention strategies and enhanced personalized care and supports for YAD.

Chapter 2 - Methods

2.1 Detailed Information about Study Design

To enhance the understanding the epidemiology of YAD, we need to comprehensively elucidate changes health related outcomes including self-rated health (SRH) over time and factors predicting the changes. ⁵⁶ More importantly, we need to identify innovative strategies that can incorporate the social determinants of health to address the health of YAD and reduce future financial burden. ^{18,57} The national population-based NLTS2 survey offers a unique opportunity to longitudinally examine the status of YAD and its potential intrapersonal factors.

2.1.1 National Longitudinal Transition Study 2 (NLTS2) Dataset

The overall strategy of this dissertation was to conduct epidemiologic analyses using the survey data from the NLTS2 to investigate the association between the health related outcomes including SRH of YAD and risk factors from the intrapersonal, interpersonal, community levels of the social ecological model. NLTS2 was funded by the US Department of Education to conduct a ten year, (2001-2010) nationally representative longitudinal study of YAD that followed a cohort of students through high school and into early adulthood focusing on spectrum of critical issues for YAD including academic experience, postsecondary education and training, health, vocation, independent living, and community integration and participation.

The National Longitudinal Transition Study 2 (NLTS2) is a ten-year, nationally representative longitudinal dataset for YAD conducted from 2001 to 2010 and commissioned by the US Department of Education that documented the experiences of a national sample of students with disabilities receiving special education services in the US. The NLTS2 longitudinal

study is designed to follow a cohort of students through high school and into early adulthood focusing on spectrum of critical issues for YAD including academic experience, postsecondary education and training, health, vocation, independent living, and community integration and participation. The objectives of the NLTS2 are as follow: 1) to study longitudinally the educational, vocational, social, and personal achievements of students with disabilities during adolescence and early adulthood together with the familial, social, institutional, and cultural factors that account for the variability in those outcomes; 2) to inform key stakeholders of parents, teachers, administrators, researcher, and policy makers at the local, state and federal level about challenges, barriers, opportunities, and successes confronted by YAD; and 3) to use this information to suggest improvements to public policy, implementation, and practice.

2.1.2 NLTS2 Sample Size

NLTS2 includes sample size of more than 11,000 youth nationwide who were ages 13 through 16 on December 1, 2000. Surveys administered over a period of 10 years from parents, youth, and schools provide a national picture of the experiences of YAD as they transition into early adulthood. Unlike cross-sectional studies where temporal ambiguity bias exists and causation cannot be inferred, the longitudinal data allows the tracking of the individuals and observation of differences in their responses over time. The longitudinal dataset provides repeated observations of the same variables over the five waves of data collections, which enables more accurate discovery of potential predictors of positive health status for YAD over time.

Table 1. NLTS2 Data Collection Timeline.					
Survey	Wave 1	Wave 2	Wave 3	Wave 4	Wave 5
Parent/Youth Phone Interview and/or Mail Survey	2001*	2003	2005	2007	2009
School Characteristic Survey	2002				
School Program Survey	2002	2004			
Teacher Survey	2002	2004			
Student Assessment	2002	2004			
Transcript	2002	2003/04	2005	2006/07	2008/09
Source: NLTS2 Website (http://www.nlts2.or	rg/)				
*Only parent interviews collected in Wave 1					

2.1.3 Survey Participants and Criteria for Selection (Sampling Strategy and Weights)

NLTS2 included five waves of survey administration with repeated measures over a tenyear period (2001-2010, See Table 1 for NLTS2 Data Collection Timeline). The eligibility
criteria for students to participate in this study included those receiving special education and
those between the ages of 13 to 16 years old in 2000. The NLTS2 used a two stage process to
generate the required sample size of students. First, the NLTS2 sample was generated by
randomly selecting students receiving special education from rosters of local education agencies
(LEAs) as the primary sampling unit (PSU) and state supported schools that served students of
the appropriate ages in special education. Second, the universe of eligible LEAs and special
schools was stratified by socio-demographic factors of the students as the secondary sampling
unit, which took into account factors such as geographic region, district enrollment and district
and community wealth to enhance national representativeness. The NLTS2 weighting procedures
are as follows: 1) An LEA student sampling weight was computed for each LEA sampling cell as
a ratio of the number of students in participating LEAs in that cell, divided by the number of
students in all LEAs in that cell in the universe of LEAs; 2) the number of students in each

disability category was estimated by multiplying the number of students with that disability on the rosters of participating LEAs in a cell by the adjusted LEA student sampling weight for that cell (for students enrolled in state schools, the number of students in each disability category was estimated by multiplying the number of students with that disability on the rosters by the inverse of the proportion of state schools that submitted rosters); 3) the initial student sampling weights were adjusted by disability category so that the sum of the weights was equal to the number of students in the geographical and wealth cells of each size strata; and 4) the weights were adjusted so that they summed to the number of students in each disability category.^{58,59}

NLTS2 survey respondents included YAD, parents/guardians, teachers and principals who participated in phone interviews and/or completed mail surveys during the data collection period. The four NLTS2 surveys are as follows: 1) parent survey; 2) youth survey; 3) school characteristic survey; and, 4) teacher survey. Only YAD whose households included an adult member who spoke English or Spanish were included in NLTS2 interviews. 97% of interviews were conducted in English. The response rates for each wave are described in table 2:

Table 2: NLTS2 Response Rate across Five Waves of Survey Administration

	Eligible Sample	Number with Subjects Interviewed	Response Rate
Wave 1			
Parent interviews/mail survey	11,246	9,230	82.10%
Student's School Program Survey	10,517	5,588	53.10%
General Education Academic Teacher Survey	7,114	2,577	36.20%
School Characteristics Survey	10,517	5,956	56.60%
Student Assessment	5,071	3,193	63.00%
Wave 2			
Parent interviews/mail survey	11,228	6,859	61.10%
Student's School Program Survey	7,815	4,078	52.20%

General Education Academic Teacher	4,866	1,983	40.80%
Survey			
Student Assessment	4,343	3,135	72.20%
Wave 3			
Parent/youth interviews/youth survey	11,227	5,657	50.40%
Wave 4			
Parent/youth interviews/youth survey	11,132	5,574	50.10%
Wave 5			
Parent/youth interviews/youth survey	11,082	5,318	48.00%
Student Transcripts	11,272	9,072	80.50%

Source: NLTS2 Database Overview

The wave 5 response rate indicated respondent attrition occurred from wave 1 to wave 5 that could lead to potential bias of respondents remaining in the survey as compared to those who dropped out. Table 3 contained a comparison of respondents who responded to both wave 1 and wave 5 and those who only responded to wave 1. The weighted percentages are calculated using wave 1 weights. The chi-square test indicated no statistical differences with respect to gender, race/ethnicity, self-rated health from Wave 1 and report of any health problems in wave 1. However, the chi-square test indicated statistical difference for race/ethnicity, household income, insurance status, disability type, functional limitations.

Table 3. Sociodemographic Characteristics of Young Adults with Disabilities by Participation in Wave 1 (W1) and Wave (W5)

Weighted Percentage	W1 & W5 Respondents	W1 Respondents Only	P-value
Gender			0.17
Male	47.4	52.6	
Female	51.0	49.0	
Race/Ethnicity			< 0.01
Non-Hispanic White	54.5	45.5	
Non-Hispanic Black	39.4	60.6	
Hispanic	39.2	60.8	
	4.5		

Other	31.2	68.8	
Mean Age in Wave 1	15.2	15.3	
Household income in Wave 1			< 0.01
\$25,000 or less	39.9	60.1	
\$25,001- \$50,000	52.0	48.0	
More than \$50,000	58.9	41.1	
Insurance Status			< 0.01
Private	52.6	47.4	
Public	43.2	56.8	
Other	60.6	39.4	
Uninsured	37.1	62.9	
Disability Type			< 0.01
Learning Disability	45.7	54.3	
Speech Impairment	53.0	47.0	
Mental Retardation	55.1	44.9	
Emotional Disturbance	46.1	53.9	
Hearing Impairment	58.7	41.3	
Visual Impairment	59.3	40.7	
Orthopedic Impairment	60.5	39.5	
Other Health Impairment	58.0	42.0	
Autism	68.5	31.5	
Traumatic Brain Injury	53.9	46.1	
Multiple Disabilities	57.0	43.0	
Deaf Blindness	58.5	41.5	
Functional Limitations			< 0.01
0 to 1 limitation	43.5	56.5	
2 limitations	52.2	47.8	
3 or more limitations	51.5	48.5	
Self-Rated Health			0.63
Excellent	50.8	49.2	
Very Good	48.2	51.8	
Good	46.8	53.2	
Fair/Poor	48.4	51.6	
	4 -		

Any Health Problems			0.89
Yes	51.6	48.4	
No	51.0	49.0	

Source: National Longitudinal Transition Survey 2 - Wave 1 and Wave 5

2.2 Assessment of Potential Biases, Confounding and Interaction Effects

Potential confounders that will introduce bias in the estimation of the association between health related outcomes including SRH and variables at the intrapersonal, interpersonal, and community level may include disability type and severity as YAD with more complex disabilities may experience more intensive and ongoing medical needs that could potentially adversely affect their health related outcomes. The range of disabilities of the NLTS2 is very broad and includes autism, deaf-blindness, deafness, developmental delay, emotional disturbance, hearing impairment, intellectual disability, multiple disabilities, orthopedic impairment, other health impairments, learning disabilities, speech or language impairment, traumatic brain injury, and visual impairment as defined by the Individuals with Disabilities Education Act, or IDEA. 60 In addition, the disability types and severity of YAD may have reverse causation on SES factors. For example, among some YAD, their families may experience poverty as a result of significant out of pocket expenses from child's required medical care. If the analysis of covariate determines its property to be a confounding factor, we adjust in the analysis to eliminate spurious effect towards SRH of YAD. However, health status differences between disability types have been found to be reduced when controlling for factors such as gender, age, race/ethnicity, family income, and insurance type or status. 61 We further investigate these aspects with NLTS2 sample to determine the role of disability type and functional limitations in the areas of seeing, hearing, communicating, walking or running, learning, and paying attention on health related outcomes.

Confounding or effect modification as a result of socioeconomic disadvantage experienced during childhood may influence the association between social relationship factors and SRH of YAD. Lower socioeconomic position as identified by household income, parental educational attainment and occupation relates to potentially adverse health exposures and behaviors such as poor diet and inadequate physical activity. 62,63 Upon stratification of the covariates, we sought to adequately control for possible confounding socioeconomic variables. If the stratum-specific effect measures yield evidence of heterogeneity, then we report findings of effect modifications. We did test the interaction between race categories and insurance status. However, we decided not to test interaction between income and insurance status as income is in many circumstances an eligibility criteria for receipt of public insurance benefits. The majority of interaction terms had confidence intervals that included 1. (See Table 3) For health-related outcomes of Missed Activities due to Health Problems and Spending Time on Medical Needs, there were three interaction terms with p-value ≤ 0.05 . In addition, a Wald test was performed to examine significance at ($p \le 0.05$). Furthermore, an interaction term was created for functional limitation and SSRS to test effect modification. Table 4 contains the result of the analysis, which demonstrated that all interaction terms were not statistically significant.

Table 4. Effect Modification of Insurance Status and Race/ Ethnicity on Health-Related Outcome among Young Adults with Disabilities (YAD)

Table 4. Effect Modification of insurance Status and Race/ Ethnicity on Health-Related Outcome among Toung Adults with Disabilities (TAD)										
	Fair/Poor Self-Rated Health		-	Problems with neral Health	•	ed Social Activities Health Problem	Spending Time on Medical Needs			
Adjusted Odds Ratio (aOR)		(95%CI)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)		
Poor Health-Related Outcome (Wave 1)	2.731	(1.226, 6.087)	5.428	(2.958, 9.959)	n/a		n/a			
Insurance Status (Wave 1)										
Private	1.000	Ref	1.000	Ref	1.000	Ref	1.000	ref		
Public	1.670	(0.710, 3.925)	2.104	(1.017, 4.353)	2.624	(1.208, 5.700)	0.133	(0.026, 0.682)		
Uninsured	0.838	(0.175, 4.17)	1.051	(0.272, 4.068)	1.779	(0.525, 6.033)	0.058	(0.003, 0.979)		
Race/Ethnicity										
Non-Hispanic White	1.000	Ref	1.000	ref	1.000	ref	1.000			
Non-Hispanic Black	1.071	(0.287, 3.996)	1.504	(0.584, 3.875)	0.690	(0.302, 1.576)	0.019	(0.002, 0.223)		
Hispanic	0.821	(0.249, 2.711)	3.189	(1.265, 8.040)	3.292	(0.977, 11.095)	0.021	(0.002, 0.258)		
Other	0.441	(0.010, 1.948)	0.307	(0.074, 1.281)	0.138	(0.045, 0.427)	_	_		
Insurance Status & Race/Ethnicity		(0.577						(2.770		
Public & Non-Hispanic Black	2.989	(0.567, 15.739) (0.368,	1.888	(0.503, 7.091)	1.600	(0.504, 5.083)	60.337	(2.779, 1310.064)		
Public & Hispanic	2.403	15.674) (0.240,	0.758	(0.191, 3.007) (0.204,	0.373	(0.066, 2.114) (30.973 ,	1.274	(0.054, 30.044)		
Public & Other	2.972	36.735) (0.075,	1.969	19.030)	361.948	4229.657)	_	_		
Uninsured & Non-Hispanic Black	0.985	12.963) (0.040,	0.364	(0.043, 3.010)	6.826	(1.048, 44.447)	_	— (0.429,		
Uninsured & Hispanic	0.643	10.430)	0.133	(0.012, 1.418)	0.156	(0.017, 1.455)	26.608	1651.703)		
Uninsured & Other	_	_	_	_	_	_	_	_		

Gender								
Male	1.000	Ref	1.000	ref	1.000	ref	1.000	ref
Female	1.304	(0.743, 2.288)	0.975	(0.580, 1.639)	2.137	(1.363, 3.350)	0.312	(0.085, 1.139)
Mean Age (Wave 1)	1.138	(0.900, 1.438)	1.204	(0.996, 1.457)	1.026	(0.866, 1.217)	0.424	(0.223, 0.808)
Household income (Wave 1)								
\$25,000 or less	1.000	ref	1.000	ref	1.000	ref	1.000	ref
\$25,001- \$50,000	1.283	(0.487, 3.382)	1.149	(0.538, 2.452)	0.573	(0.267, 1.229)	22.766	(3.089, 167.779)
More than \$50,000	1.205	(0.629, 2.307)	0.936	(0.531, 1.645)	2.137	(1.363, 3.350)	0.536	(0.134, 2.141)
Functional Limitations								
0 to 1 limitations	1.000	ref	1.000	ref	1.000	ref	1.000	ref
2 limitations	1.302	(0.670, 2.531)	1.612	(0.935, 2.781)	1.596	(0.998, 2.552)	0.250	(0.043, 1.459)
3 or more limitations	1.705	(0.784, 3.710)	1.586	(0.834, 3.015)	1.663	(0.900, 3.072)	0.207	(0.048, 0.884)

Source: National Longitudinal Transition Survey 2 - Wave 1 and Wave 5

Table 5. Effect Modification of Functional Limitations and Social Skills on Health-Related Outcome among Young Adults with Disabilities (YAD)								
Odds Ratios	Fair/Poor Self-Rated Health		Any Problems with General Health		Any Missed Social Activities due to Health Problem		Spending Time on Medical Needs	
	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)
Social Skills								
Low	0.986	(0.582, 4.768)	0.686	(0.260, 1.806)	1.047	(0.472, 2.324)	0.362	(0.043, 3.055)
Medium	1.000	Ref	1.000	ref	1.000	ref	1.000	Ref
High	1.666	(0.582, 4.768)	1.478	(0.260, 1.806)	0.466	(0.223, 0.976)	1.940	(0.275, 13.689)
Poor Health-Related Outcome in Wave 1	2.490	(1.147, 5.404)	5.338	(2.768, 10.294)	n/a		n/a	
Gender								
Male	1.000	Ref	1.000	ref	1.000	ref	1.000	Ref
Female	1.252	(0.719, 2.182)	0.995	(0.589, 1.680)	2.196	(1.402, 3.439)	0.303	(0.083, 1.109)
Race/Ethnicity								
Non-Hispanic White	1.000	Ref	1.000	ref	1.000	ref	1.000	Ref
Non-Hispanic Black	1.690	(0.817, 3.496)	2.035	(1.083, 3.826)	0.913	(0.523, 1.592)	0.211	(0.023, 1.949)
Hispanic	1.150	(0.431, 3.071)	2.352	(1.152, 4.805)	1.494	(0.642, 3.477)	0.043	(0.008, 0.218)
Other	0.697	(0.195, 2.494)	0.467	(0.147, 1.481)	1.365	(0.283, 6.586)		
Mean Age in Wave 1	1.124	(0.900, 1.404)	1.196	(0.989, 1.446)	1.014	(0.853, 1.206)	0.414	(0.230, 0.746)

Household income in Wave 1								
\$25,000 or less	0.831	(0.317, 2.176)	0.960	(0.421, 2.187)	1.664	(0.928, 3.604)	0.040	(0.045, 1.411)
\$25,001- \$50,000	0.977	(0.402, 2.377)	0.901	(0.401, 2.024)	1.828	(0.771, 3.593)	0.025	(0.004, 0.387)
More than \$50,000	1.000	Ref	1.000	ref	1.000	ref	1.000	Ref
Insurance Status								
Private	1.000	ref	1.000	ref	1.000	ref	1.000	Ref
Public	2.929	(1.241, 6.911)	2.657	(1.323, 5.336)	2.767	(1.379, 5.550)	0.226	(0.046, 1.116)
Uninsured	0.684	(0.190, 2.470)	0.445	(0.133, 1.485)	1.740	(0.664, 4.559)	0.083	(0.007, 1.011)
Functional Limitations								
0 to 1 limitations	1.000	ref	1.000	ref	1.000	ref	1.000	Ref
2 limitations	1.546	(0.746, 3.204)	1.359	(0.649, 2.848)	1.504	(0.799, 2.830)	0.188	(0.014, 2.599)
3 or more limitations	1.536	(0.580, 4.070)	1.250	(0.548, 2.850)	1.749	(0.729, 4.191)	0.253	(0.045, 1.411)
SSRS & Functional Limitations								
High SSRS and 2 limitations	0.303	(0.055, 1.680)	0.661	(0.132, 3.316)	1.765	(0.526, 5.925)	0.094	(0.003, 3.331)
High SSRS and 3 or more limitations	0.252	(0.032, 1.994)	0.551	(0.109, 2.786)	0.630	(0.143, 2.768)		
Low SSRS and 2 limitations	0.956	(0.226, 4.053)	2.095	(0.579, 7.576)	0.847	(0.271, 2.645)	6.891	(0.209, 227.005)
Low SSRS and 3 or more limitations	1.586	(0.324, 7.770)	2.095	(0.516, 8.513)	0.580	(0.152, 2.217)	2.696	(0.160, 45.332)

Source: National Longitudinal Transition Survey 2 - Wave 1 and Wave 5

aOR=Adjusted Odds Ratio

n/a = health related outcome not collected in Wave 1

2.2.1 Power analysis

Since the current study is a secondary analysis, sample sizes cannot be altered. The US

Department of Education funded SRI International to conduct a power analysis of NLTS2, which

demonstrated that the 497 local education agencies (LEAs) represented an appropriate sample size

when stratified by region, district size (student enrollment), and community wealth. To allow for

selection of sufficient student samples in the second sampling stage, 501 LEA rosters were required.

Invitations to participate in the NLTS2 were originally sent to 3,634 LEAs serving student with

disabilities, and an overall 14% response rate would be sufficient to generate the 501 LEAs

needed. The survey's specific response rates for each wave and surveys of NLTS2 are delineated
in Table 2.

The power analysis was conducted with alpha=0.05 and power =0.80. We used SAS 9.3 Proc Power procedure to calculate the effect sample size. Our preliminary power analysis resulted in an effect sample size of 779 at alpha=0.05 and power =0.80. The survey respondents in NLTS2 greatly exceeded the effect size from our preliminary calculations as evidenced in sample size reported in Table 2. Thus, we were confident of sufficient power in our analytics.

2.2.2 Outcome variable: Self-rated health and other health related outcomes

To advance understanding of critical factors influencing health of YAD, the dissertation will examine self-rated health (SRH) as the outcome of interest and factors affecting SRH in YAD during adolescence. SRH is a single-item ordinal measure with 5 levels (Excellent, Very Good, Good, Fair and Poor) that is commonly utilized as an indicator of general health status in national surveys

conducted by the National Center on Health Statistics (NCHS) at the Centers for Disease Control and Prevention (CDC) such as the National Survey of Children's Health (NSCH), the Behavioral Risk Factor Surveillance Systems (BRFSS), and National Health and Nutrition Examination Survey (NHANES) as well as other epidemiologic health research in the US and abroad. 65,66,67 The wide adoption of SRH can be attributed to its validity as assessed by statistical association with measures of morbidity, utilization of health services, and subsequent mortality especially in older populations. 68,69,70 The other three health related outcomes of interest included 1) having problems with general health, which was reported by dichotomous response of "Yes" or "No"; how often health/emotional problems caused YAD to miss a social activity in the past month, which had the following three response categories: 1) never missed a social activity; 2) missed social activities just a few times; 3) missed social activities about once a week or more; and whether YAD spend time getting therapies/ medical attention/ visiting doctor/ recovering from illness/injury with a dichotomous response of "Yes" or "No."

2.2.3 Independent Variables

The independent variables of interests are risk factors representing the intrapersonal level from the theoretical model. Chapter3 (Manuscript 1) will examine the sociodemographic variables of age, gender, race/ethnicity, insurance status and household income with an in-depth investigation into how insurance status in adolescence impact health related outcomes in young adulthood. Chapter 4 (Manuscript 2) and Chapter 5 (Manuscript 3) build upon Chapter 3 and explore the interpersonal and community variables of social skills manifested in family and peer relationship and community participation respectively. Method sections of Chapters 3-5 describe the variables of interest in detail.

2.3 Statistical Approaches to Test Hypotheses

The health related outcome variables are dichotomized for the multivariate logistic regression analysis to model associations and estimate adjusted odds ratios. The multivariate logistic regression model is used to estimate the effects of intrapersonal and interpersonal factors on the changes health related outcome from adolescence to early adulthood. The structural equation modeling (SEM) enabled us to test the intrapersonal, interpersonal, and community level factors from the social ecological model and to estimate of direct and indirect relationships between risk factors in the model and SRH of YAD with empirical data from NLTS2 to draw conclusion about the potential cause and effect of community level risk factors on health status of YAD. The measurement model demonstrates the relation between latent constructs and their indicators/markers. 71,72 The relative fit of models is determined through statistical comparison. To bring together the multi-level risk factors in the social ecological model, we explored the confounding resulting from intrapersonal as well as interpersonal factors. Similarly, the role of social skills in relationships with family and peers on the association between community participation and SRH of YAD is investigated. To ascertain the presence of a mediator, we checked to see if the total effects indicate an association where the direct effect is null. An alternative mediator scenario is where mediators attenuate the total effect and partially represent the effects of exposure on outcome on the causal pathway.

Structural equation modeling with maximum pseudolikelihood parameter estimation was used to test the hypothesized relationship taking into account survey weights. The Akaike information criterion (AIC) and Bayesian information criterion (BIC) are used as criteria for model evaluation. Among a set of candidate models for the data, the model with the lowest AIC and BIC is preferred. Both are based upon the likelihood function. Stata 14 statistical software was used to conduct all statistical analysis, which supports survey data analysis in generalized structural equation models (gsem). Stata gsem command was utilized since SRH is an ordinal variable. The gsem

procedure also allows for models that are linear regression, gamma regression, logit, probit, ordinal logit, ordinal probit, Poisson, negative binomial, and multinomial logit. Fit indices such as CFI, TLI, and RMSEA are not available after gsem command. Since gsem models are a function of the model chi-squared test, which involves an estimate of the variances and covariances of observed exogenous variables, Stata cannot estimate the model chi-squared test and other statistics that are functions of this test. The SEM analyses allowed for making inferences about population difference among the four categories of SRH of YAD. The distinct advantages of SEM compared to other statistical methods are the ability to test construct level hypotheses and to examine the interrelationship and depict the potential causal paths.

The sociodemographic information was mostly complete with less than 10% of subjects with missing data. Given the large sample size of NLTS2 and the potential bias introduced through missing data handling strategies, we do not plan to conduct imputation.

2.4 Study Strengths and Limitations

The strengths of the study included the use of longitudinal data and the use of multivariate logistic regression and structural equation modeling. The model accommodated the ordinal outcome measure of SRH and the examination of the effects of SRH of YAD across the waves of survey administration while accommodating for random effects. There are inherent limitations of secondary data analysis. The data collection limitations included sample design, response rate, and non-response bias. As discussed previously, the interviews were not conducted for young adults who did not have an English-speaking adult in the household. Therefore, we cannot make inferences about YAD from non-English speaking households.

2.5 Human Subjects/Ethical Considerations

The research is conducted through secondary data analysis of the NLTS2 dataset funded by the US Department of Education. Our study would be considered among the federally defined exempt categories of data from anonymous surveys/interviews. We have submitted Institutional Review Board (IRB) application seeking exemption status to the University of Maryland, College Park IRB and received approval on October 10, 2014. IRB application Part 1 and 2 have been included in the Appendix A.

Chapter 3 – Longitudinal Analysis of the Relationship between Health Insurance Status and Health –Related Outcomes among Young Adults with Disabilities in the United States (Manuscript 1)

3.1 Introduction

From 1997-2008, the prevalence of children with disabilities in the United States (US) surged to 17% and reached nearly 3 million children having a disability in 2010. 75,76 The Individuals with Disabilities Education Act (IDEA) defines a child with disabilities as any child who has learning disabilities, speech or language impairment, mental retardation, emotional disturbance, hearing impairment, visual impairment, orthopedic impairment, other health impairments, autism, traumatic brain injury, multiple disabilities, and deaf-blindness. Children with disabilities were more likely to experience fair or poor health, to frequently utilize health care services, and to have more medical as well as emergency room visits than their peers without disabilities. Marked socioeconomic gradients have been observed for children with low socioeconomic background, who had over 3 times higher odds of disability and nearly 7 times the odds of being uninsured than their affluent peers; moreover, socioeconomic differences attribute to 24.4% and 60.2% of racial/ethnic variations in child health insurance and disability respectively.

In the US adult population, over 53 million people, or 1 in 5 adults, have a disability.⁸² Higher percentages of Non-Hispanic Black (29.0%) and Hispanic (25.9%) adults reported having a disabilities than non-Hispanic White (20.6%); furthermore 24.4% of adult women reported having a disability as compared to 19.8% of men.⁸³ In comparison with adults without disabilities, adults with disabilities were more likely to report poorer health^{84,85,86}, to be overweight or obese, to smoke, to drink alcohol, and to have hypertension, heart disease, stroke, diabetes, or cancer^{87,88,89}, to

encounter barriers in obtaining and accessing health care⁹⁰, to confront the financial burden of significant out of pocket medical expenses.^{91,92} Reports of fair or poor health among adults with a disability were most common among Hispanics and American Indian/Alaskan Native (55.2% and 50.5%, respectively) and least common among Asians (24.9%).⁹³ Moreover, adults with a disability are less likely to receive preventive screening such as Pap test, mammograms, and annual dental checkups.⁹⁴

Much of the disability-related health service research has focused on children and adults with disabilities. Fewer population-based studies exist on health related outcomes and disparities pertaining to young adults with disabilities (YAD), in particular as youth with disabilities transition into adulthood. IDEA required the provisions of special education and health related services through the completion of high school. As soon as individuals with disabilities age out of IDEA, parents and teachers often refer to this as "falling off the cliff," due to the loss of services and supports and the paucity of replacement adult programs and services. ⁹⁵ Given that the significant disability-associated health-care expenditures (DAHE) for US adults reaching \$400 billion in 2006, we need to enhance the understanding of risk and protective factors that contribute to the maintenance of positive health of YAD in order to reverse the economic costs down stream. ^{96,97}

In the 2009 Institute of Medicine (IOM) report on America's Uninsured Crisis: Consequences for Health and Health Care, the IOM highlighted the health disparities between people with and without health insurance that lead to premature morbidity and mortality due to lack of access to effective health care services. 98 The Patient Protection and Affordable Care Act of 2010 sought to provide health insurance coverage as a critical link to health and well-being through Medicaid expansion, insurance marketplace and expansion of dependent coverage to age 26. 99,100 While policymakers have equated increasing individual access to health services as a proxy for improving

health, this approach precluded the effects of the social determinants of health. ¹⁰¹ Existing research conducted on the impact of health insurance on working age adults and older adults with disabilities, have lumped YAD into the overall adult population; however, few studies comprehensively examined the role of health insurance coverage and sociodemographic factors in mitigating health disparities experienced by YAD alone from a longitudinal perspective. ^{102,103,104,105} Thus, we seek to advance the research by understanding the impact of insurance status in adolescence to health related outcomes in young adulthood for YAD. The study uses data from the National Longitudinal Transition Study 2 (NLTS2) to investigate the primary hypothesis that YAD who were uninsured in adolescence will experience poorer health related outcomes than YAD who had private or public insurance coverage.

3.2 Method

3.2.1 Data Source

The data used in this study comes from wave 1 and wave 5 of the NLTS2 collected in 2001 and 2009 respectively. NLTS2 is a ten-year, nationally representative longitudinal dataset for YAD conducted from 2001 to 2010, which is comprised of five waves of data collection. NLTS2 is sponsored by the US Department of Education to document the experiences of a national sample of students with disabilities receiving special education services from high school and into early adulthood focusing on spectrum of critical issues for YAD including academic experience, postsecondary education and training, health, vocation, independent living, and community integration and participation. The objectives of the NLTS2 are threefold: 1) to study the familial, social, institutional, and cultural factors influencing the achievements of students with disabilities transition from youth to early adulthood; 2) to inform key stakeholders at the local, state and federal level about challenges, barriers, opportunities, and successes experienced by YAD; and 3) to inform

improvements to public policy and practice. Wave 1 of NLTS2 began with sample size of more than 11,000 youth nationwide who were ages 13 through 16 on December 1, 2000.

The NLTS2 used a two stage process to generate the needed sample of students by randomly selecting students receiving special education from rosters of local education agencies (LEAs) as the primary sampling unit (PSU) and stratified by socio-demographic factors of the students as the secondary sampling unit, which took into account factors such as geographic region, district enrollment and district and community wealth to enhance national representativeness. ¹⁰⁶

Detailed sampling strategy and questionnaire design have been described elsewhere. ¹⁰⁷

For this study, data from wave 1 and wave 5 time points were chosen to determine the causal effects of insurance coverage during adolescence on health related outcomes in young adulthood by allowing for induction period between adolescence and early adulthood. The parents completed all response items in wave 1 when YAD were adolescents. The health related outcome items in wave 5 came from the Young Adult Survey of NLTS2. The NLTS2 respondents included respondents with all 12 disability types in the IDEA. Given functional status may vary across the twelve disability types, we examined functional limitations in the areas of seeing, hearing, communicating, walking or running, learning, and paying attention. ¹⁰⁸

3.2.2 Outcome Variables

Overall, the study examined four health related outcomes collected in NLTS2. The first outcome of interest is self-rated health (SRH) as reported by parents and/or YAD to assess perceptions of health status. SRH measure has been widely used as a valid measure of physical health status. Subjects responded to the question, "In general, how would you rate your health?" by selecting one of the five categories: 1) Excellent, 2) Very Good, 3) Good, 4) Fair and 5)

Poor. Fair and poor health categories were combined to model for YAD with poorer health status, which has been used frequently in health services research conducted by CDC. 111,112 A second outcome of interest is whether YAD reported having problems with general health, which was reported by dichotomous response of "Yes" or "No." The third outcome of interest is how often health/emotional problems caused YAD to miss a social activity in the past month, which had the following three response categories: 1) never missed a social activity; 2) missed social activities just a few times; 3) missed social activities about once a week or more. Finally the fourth outcome of interest is whether YAD spend time getting therapies/ medical attention/ visiting doctor/ recovering from illness/injury with a dichotomous response of "Yes" or "No."

3.2.3 Exposure Variable: Health Insurance Coverage

Wave 1 collected information on the following four insurance types: 1) Private Health Insurance; 2) Government Assisted Public Health Insurance; 3) Other Health Insurance; and 4) Uninsured. Given the small sample size of respondents who had other health insurance, we examined YAD with private insurance, public insurance and those who were uninsured in the multivariate model.

3.2.4 Confounders

Sociodemographic variables included gender, race/ethnicity, age, and household income using wave 1 baseline data. Gender was comprised of two categories: 1) Male; and 2) Female.

Race/ethnicity are divided into four groups: 1) Non-Hispanic White; 2) Non-Hispanic Black; 3)

Hispanic; 4) Other, which comprised of Asian/Pacific Islander and American Indian/Alaska Native.

Age was treated as a continuous variable. Household income had the following three categories: 1) \$25,000 or less; 2) \$25,001- \$50,000; and 3) More than \$50,000.

Following the IDEA disability definition, disability type included twelve categories: learning disabilities, speech or language impairment, mental retardation, emotional disturbance, hearing impairment, visual impairment, orthopedic impairment, other health impairments, autism, traumatic brain injury, multiple disabilities, and deaf-blindness. As previously mentioned that functional status may vary across the twelve disability types, we examined functional limitations in the following categories: 1) having 0-1; 2) having 2; 3) having 3 or more functional limitations. Also, health-related outcome variables collected at wave 1, specifically SRH and any problems with general health, were included in the multivariate model as potential confounders.

3.2.5 Analytic Strategy

Bivariate analysis generated descriptive statistics that compared sociodemographic characteristics of gender, race/ethnicity, age, household income in wave 1, disability type, and functional by wave 1 insurance coverage type. In addition, bivariate analysis was conducted on health related outcomes reported in wave 5 by insurance coverage type in adolescence from wave 1. Pearson's chi-squared test was applied to evaluate the statistical likelihood that the observed difference between the categorical data set occurred by chance.

Multivariate logistic regression analyses accounting for survey weights were conducted to understand the association of insurance status in adolescence and YAD's health related outcomes, while controlling for the sociodemographic characteristics and health related outcomes reported in wave 1. Parameter estimates were weighted to the population level, and variances were adjusted in

accordance with the complex sampling and weighting design of NLTS2. We reported adjusted odds ratios (aOR) and 95% confidence intervals. We discussed statistically significant findings at the p-value ≤0.05. STATA 14 was used to carry out all statistical analysis. ¹¹³

3.3 Results

The final analytic dataset is comprised of the sample of parents and/or YAD who responded to the SRH questions at baseline in wave 1 and wave 5 of NLTS2 (N=5020). Table 6 delineated the sociodemographic characteristics of the sample. Males and Non-Hispanic White (NHW) YAD comprised over 60% of the study sample. 77% of NHW YAD had private insurance while 54% of Hispanic YAD had public insurance in adolescences. Over 90% of respondents with household income more than \$50,000 had private insurance. Among those with household income less than \$25,000, 61% had public insurance and nearly 10% were uninsured. Across the twelve disability types, YAD with private insurance ranged from 49% (mental retardation) -76% (other health impairment). No significant statistical difference observed for insurance type among functional limitation categories.

Table 7 delineated the distribution of health related outcomes reported by YAD in adulthood by insurance status in adolescence. Over 50% of the YAD who had public insurance responded with fair/poor health in adulthood, problems with general health and missed social activities about once a week or more due to health/emotional problems. Among YAD with private insurance, over 70% reported excellent health in adulthood, no problems with general health, and never missed a social activity due to health/emotional problems. Nearly 99% of all YAD reported that they did not spend time getting therapies/ medical attention/ visiting doctor/ recovering from illness/injury.

In Table 8, the multivariate logistic regression analysis indicated that YAD with public insurance in adolescence had 2.89 times the odds of reporting fair/poor health, 2.60 times the odds of reporting any problems with general health, and 2.86 times the missing any social activities due to health problem. However, the results from confounding variables indicated that YAD who were uninsured in adolescence had 92% less odds of spending time on medical needs such as getting therapies, medical attention, visiting doctor, and recovering from illness or injury. Female YAD had 2.18 times the odds of missing any social activities due to health problem. Non-Hispanic Black and Hispanic YAD had 1.99 and 2.31 times the odds of reporting any problems with their general health respectively. However, YAD who were Hispanic or with 3 or more functional limitations had nearly 95% less odds of spending time on medical needs. However, YAD with household income less than \$25,000 had 20.74 times the odds of spending time on medical needs. Finally, YAD with 3 or more functional limitations had 1.63 times the odds of reporting any problems with general health. YAD with poorer SRH as adolescents were at 2.67 times the odds of reporting poorer SRH in young adulthood. Similarly, YAD who reported any problems with general health as adolescents had 5.52 times the odds of reporting any problems with general health as young adults.

3.4 Discussion

The study demonstrated evidence of health disparities encountered by YAD by insurance status, gender, race, household income and functional limitations. First, we found much higher odds of YAD with public insurance reporting poorer self-rated health, any problems with their health, missing social activities as a result of health or emotional problems in young adulthood. This is contrary to our initial hypothesis that YAD with any insurance as a teenager would experience more positive health related outcomes. This may suggest that the requirement in the Affordable Care Act

for YAD whose parents have private insurance. While there is concurrence that children and youth with disabilities need adequate health insurance that enables improved access to health care services and continuity of care in mitigating health problems, our findings indicated that public insurance coverage may not be sufficiently supporting their health and well-being. ^{114,115} This may be due to the distinction between public insurance's ability to provide equitable access to primary and preventive care similar to private insurance; however, access to specialty care, in particular identifying clinicians willing to access public insurance, continues to be a significant challenge. ^{116,117,118} Furthermore, adequate health insurance for children and youth with disabilities needs to be complemented by access to comprehensive and coordinated medical home that can enhance the monitoring of quality and health outcomes to ensure that children youth with disabilities receive cost-effective and equitable care. ¹¹⁹

Second, we observed gender disparities among female YAD to miss social activities due to health/emotional reasons. Previous research demonstrated overall poorer outcomes among female students with disabilities receiving special education services where they are less likely to obtain a high school diploma, to be employed, and to earn less income. ¹²⁰ Gender disparities among YAD may require further research and identification of promising practices to support better outcomes among females with disabilities. ¹²¹

Third, our findings of higher odds among non-Hispanic Blacks and Hispanic in reporting health problems, which is aligned with previous research demonstrating the presence of racial and ethnic disparities in overall health and essential areas of health care utilization. Furthermore, our study showed that Hispanic American were at lower odds of spending time to obtain medical care in young adulthood, which support Hispanic American as disproportionately disadvantaged in receipt

of health care visits and often report no doctor visits annually at all. ^{123,124} Fourth, YAD who resided in households with income less than \$25,000 had significantly higher odds of spending time getting therapies, medical attention, visiting doctor, or recovering from illness/injury, which resonate with previous research of low socioeconomic status as a risk factor. ¹²⁵

The study had some limitations. The NLTS2 was conducted in English and Spanish, which may bias the non-English respondents towards those who are more educated and fluent in English, resulting in a likely underestimate of risk for respondents in other racial/ethnic minority groups. Respondent attrition occurred from wave 1 to wave 5. This could lead to potential bias of respondents who continued to participate in the survey as compared to those who dropped out. Therefore, this would confine the generalizability of our findings to all YAD. Furthermore, NLTS2 did not conduct physical examination to obtain objective health measures. Thus, although SRH is an established and widely used measure for health status, we are unable to assess the concordance between biological and self-reported measures. We compared self-rated health status between YAD who had public insurance and YAD who had private insurance. As YAD who were covered by private insurance had high social economic status, the difference social economic status may confound the reported association. In addition, the dichotomization of the health related outcome in the multivariate analysis may have led to loss of power and residual confounding. Finally, we used the concise measure of childhood activity limitations developed by Wells and Hogan in 2003 for the functional limitations variable, which was controlled for in the multivariate model. Although this provided an objective measure of functional limitations, it did not capture self-perceptions of disability severity, which could influence self-reported health related outcomes, which was not collected as part of the NLTS2 survey. The study had several strengths. NLTS2 contained the most recent, national data examining the transition of youth to adulthood for individuals with disabilities.

The sample size allowed for the investigation into potential sociodemographic disparities. Finally, the longitudinal design of the data set afforded the opportunity to look at change in SRH over time and establish causal relationship of statistical associations.

3.5 Conclusion

Since 2000, the number of children who qualify for Medicaid benefits has risen nearly 40%. 126,127 Although health insurance is an important enabling resource for YAD to receive access to health care, our study found disparities exist in health care access and utilization by health insurance in adolescence. 128 Thus, even though YAD have had significantly higher odds of receiving public insurance benefits in adulthood, future research should explore beyond sociodemographic and health insurance factors into interpersonal and community factors that drive positive health related outcomes for YAD. 129

Table 6. Sociodemographic Characteristics of Young Adults with Disabilities by Types of Insurance

Weighted Percentage N= 5020 N=3383 N=1363 N=45 D Gender Male 64.7 67.9 24.9 1.4 Female 35.3 59.5 33.7 0.2 Race/Ethnicity Non-Hispanic White 62.5 77.0 16.3 1.0 Non-Hispanic Black 20.2 50.3 42.9 0.7 Hispanic 14.4 33.0 54.5 1.5 Other 3.0 61.9 36.9 0.7 Mean Age in Wave 1 15.2 15.3 15.1 15.0 Household income in Wave 1 \$25,000 or less 36.3 27.9 61.4 0.8 \$25,001-\$50,000 29.6 77.7 15.0 0.5 More than \$50,000 34.1 92.2 4.5 1.2	N= 229 5.9 6.6	value
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Mean Age in Wave 1 15.2 15.3 15.1 15.0 Household income in Wave 1 \$25,000 or less 36.3 27.9 61.4 0.8 \$25,001-\$50,000 29.6 77.7 15.0 0.5	9.1	
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\$25,000 or less 36.3 27.9 61.4 0.8 \$25,001- \$50,000 29.6 77.7 15.0 0.5	15.2	0.23
\$25,001-\$50,000 29.6 77.7 15.0 0.5		< 0.01
	9.8	
More than \$50,000 34.1 92.2 4.5 1.2	6.8	
	2.2	
Disability Type		< 0.01
Learning Disability 62.0 68.0 25.0 0.9	6.1	
Mental Retardation 12.2 48.9 42.2 1.7	7.3	
Emotional Disturbance 11.4 58.5 34.1 0.2	7.2	
Other Health Impairment 4.5 75.8 18.9 1.1	4.2	
Speech Impairment 4.0 72.1 21.9 1.3	4.6	

Table 6. Sociodemographic Characteristics of Young Adults with Disabilities by Types of Insurance cont.

Weighted Percentage	Total N= 5020	Private Health Insurance N=3383	Public Health Insurance N=1363	Other Health Insurance N=45	Uninsured N= 229	P- value
Multiple Disabilities	1.8	56.8	37.9	2.2	3.1	
Hearing Impairment	1.3	65.8	25.7	1.4	7.1	
Orthopedic Impairment	1.2	68.4	27.7	0.7	3.2	
Autism	0.7	73.9	23.4	0.2	2.5	
Visual Impairment	0.5	66.1	27.6	2.2	4.1	
Traumatic Brain Injury	0.3	69.1	24.8	0.0	6.2	
Deaf Blindness	0.2	61.2	32.8	1.0	5.1	
Functional Limitations						0.16
0 to 1 limitations	56.7	67.6	24.2	0.9	7.4	
2 limitations	31.7	60.3	34.6	1.0	4.0	
3 or more limitations	11.6	64.8	28.1	1.3	5.8	

Source: National Longitudinal Transition Survey 2 - Wave 1 and Wave 5 $\,$

Table 7. Health-Related Outcome by Baseline Insurance Status for Young Adults with Disabilities (YAD)

Weighted Percentage	Total	Private Health Insurance N=3383	Public Health Insurance N=1363	Other Health Insurance N=45	Uninsured N= 229	P- value
<u> </u>						
Self-Rated Health						< 0.0
Excellent	21.2	73.4	21.8	0.2	4.6	
Very Good	32.9	75.3	18.2	0.2	6.2	
Good	32.5	70.6	21.4	0.0	7.9	
Fair/Poor	13.4	44.0	50.7	1.7	3.6	
Problems with general health						< 0.0
Yes	14.8	42.7	52.1	2.4	2.8	
No	85.2	70.3	22.9	0.3	6.5	
Missed social activity due to health/emotional problem	ı					< 0.0
Never missed a social activity	65.3	74.7	19.6	0.2	5.6	
Missed social activities just a few times	24.7	66.4	25.8	0.9	6.9	
Missed social activities about once a week or more	10.0	39.8	52.4	0.2	7.6	
Spend time getting therapies/ medical attention/ visiting	ng doctor/ recov	ering from illness/ir	njury			0.68
Yes	1.4	59.0	39.4	0.0	1.6	
No	98.6	68.0	25.5	0.7	5.9	

Source: National Longitudinal Transition Survey 2 - Wave $1\ \text{and}\ \text{Wave}\ 5$

Table 8. Odds Ratios of Health-Related Outcome among Young Adults with Disabilities (YAD)

Tueste	0. 04451	Turios of frontiff for	ciarea our	come among Young		Missed Social	/	
	Fair/P	Fair/Poor Self-Rated Health		Problems with eneral Health		es due to Health Problem	•	nding Time on edical Needs
A 11 - 1011 P - 1 (OP)	0.0							
Adjusted Odds Ratio (aOR)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)
Insurance Status (Wave 1)								
Private	1.000	Ref	1.000	ref	1.000	ref	1.000	ref
Public	2.893	(1.158, 7.226)	2.601	(1.263, 5.354)	2.856	(1.393, 5.851)	0.222	(0.043, 1.137)
Uninsured	0.700	(0.196, 2.495)	0.462	(0.140, 1.524)	1.748	(0.656, 4.654)	0.082	(0.007, 0.983)
Poor Health-Related Outcome (Wave 1)	2.671	(1.237, 5.766)	5.524	(2.867, 10.644)	n/a		n/a	
Gender								
Male	1.000	Ref	1.000	ref	1.000	ref	1.000	ref
Female	1.272	(0.725, 2.231)	1.007	(0.599, 1.692)	2.182	(1.396,3.410)	0.306	(0.084, 1.115)
Race/Ethnicity								
Non-Hispanic White	1.000	Ref	1.000	ref	1.000	ref	1.000	ref
Non-Hispanic Black	1.744	(0.821, 3.704)	1.994	(1.052, 3.779)	0.916	(0.525, 1.598)	0.204	(0.023, 1.800)
Hispanic	1.167	(0.426, 3.199)	2.309	(1.104, 4.828)	1.469	(0.624, 3.457)	0.042	(0.008, 0.207)
Other	0.703	(0.193, 2.567)	0.425	(0.131, 1.374)	1.344	(0.261, 6.911)	N/A	
Mean Age (Wave 1)	1.119	(0.890, 1.407)	1.200	(0.991, 1.452)	1.016	(0.857, 1.205)	0.417	(0.218, 0.798)

Table 8. Odds Ratios of Health-Related Outcome among Young Adults with Disabilities (YAD) cont.

	Fair/P	oor Self-Rated Health	•	Problems with eneral Health	Activiti	Missed Social es due to Health Problem	Spending Time on Medical Needs		
Adjusted Odds Ratio (aOR)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)	
Household income (Wave 1)									
\$25,000 or less	1.181	(0.436, 3.201)	0.904	(0.512, 1.594)	0.595	(0.273, 1.297)	20.739	(2.574, 167.102)	
\$25,001- \$50,000	1.190	(0.622, 2.278)	1.049	(0.455, 2.4179)	1.105	(0.648, 1.885)	0.523	(0.127, 2.143)	
More than \$50,000	1.000	ref	1.000	1.000 ref		ref	1.000	ref	
Functional Limitations									
0 to 1 limitations	1.000	ref	1.000	ref	1.000	ref	1.000	ref	
2 limitations	1.269	(0.658, 2.448)	1.561	(0.898, 2.712)	1.637	(1.019, 2.629)	0.256	(0.045, 1.446)	
3 or more limitations	1.667	(0.771, 3.600)	1.536	(0.795, 2.970)	1.554	(0.823, 2.933)	0.231	(0.054, 0.984)	

Source: National Longitudinal Transition Survey 2 -Wave 1 and Wave 5

Chapter 4 Social Skills Developed in Adolescence and Health Related Outcomes in Adulthood for Young Adults with Disabilities in the United States (Manuscript 2)

4.1 Introduction

In the US, over 53 million people in the adult population or 1 in 5 adults, have a disability. The adults with disabilities are at higher risk for developing chronic disease and experiencing adverse health outcomes as compared to adults without disabilities. The programs of medical home, family support, and insurance coverage, individuals with disabilities including young adults with disabilities (YAD) continue to encounter more health risks, lack of access to care, and barriers to transition readiness from pediatric to adult-oriented care that negatively impacted their health status. The programs of the programs o

Social integration and high quality social ties are associated with improved health outcomes for adult population. Similarly, for individuals with disabilities, social relationships and participation are protective factors in improved physical, psychosocial and emotional health. Thus, the understanding of the multidimensionality of social relationship and adaptational outcomes would advance the identification of interpersonal social risk factors and health outcomes. All

Previous research demonstrated that YAD have complex interactions in their interpersonal relationships with their families as well as social environments with regards to participation, receipt of social support, social membership and connectedness. ^{142,143,144} A child's health status is integrally connected to the parental provision of social relationship, socialization, and life skills. ¹⁴⁵ Significant support from parents of YAD begin in early childhood, when parents start the long journey of advocating on behalf of their child in obtaining special education and medical services, potentially experiencing lower full-time employment or career

challenges, and confronting financial hardship as a result of out of pocket expenses for health care. 146,147 Families play a critical role in development of social skills in children with disabilities. 148 Attainment of positive health outcomes through reduced engagement in health risk behaviors among young people is associated with better parent—child and overall family relationships. 149,150

The peer relationships and friendship initiated in early childhood have significant impact on happy childhood as well as cognitive and emotional processes of psychological development. Overall, youth with disabilities have similar experiences in building peer relationships and friendships as peers without disabilities. However, youth without disabilities may display diverse spectrum of positive to negative attitudes about peers with disabilities as a result of social comparison and competition. For instance, among youth with intellectual disabilities, low friendship quality has been characterized by lack of warmth, closeness, and positivity reciprocity has been observed when compared with friendships of their typically developing peers. See In addition, for youths with autism spectrum disorder, social participation was significantly lower where they are less likely to see friends out of school, to receive calls from friends, and to be invited to social activities. The health of YAD can be adversely affected by negative peer attitudes, lack of quality friendship, and barrier to full social inclusion at school for children and youth with disabilities.

The role of social support on positive health outcomes have been established, including for persons with disabilities. ^{158,159,160} However, the activation of social support is influenced by social skills, which are critical for survival and developing adaptive strategies in social settings that include developing relationships, coping, conflict resolution and independent living. ^{161,162,163,164} Social skills are especially critical for people with disability in helping them

to overcome social stigmatization, to request for assistance, to foster ease and comfort in social relationships, to elicit social feedback and positive relationships building. 165,166,167,168 However, research on the role of social skills on health of YAD has been limited. The primary purpose of this study is examine the relationship between the social skills developed in adolescence and health related outcome at young adulthood for YAD to advance knowledge of the contexts and mechanisms towards achievement of positive health related outcomes.

4.2 Methods

4.2.1 Data Source

The study is a secondary analysis of data from Wave 1 and Wave 5 of the National Longitudinal Transition Study 2 (NLTS2), which is a national longitudinal survey funded by the US Department of Education. NLTS2 was administered between 2001 and 2009 and comprised of five waves of data collection. The NLTS2 to document the experiences of a nationally representative sample of students with disabilities receiving special education services from high school and into early adulthood while focusing on spectrum of critical issues for YAD including academic experience, postsecondary education and training, health, vocation, independent living, and community integration and participation. Data from NLTS2 informed the following three main objectives: 1) to study factors influencing the achievements of students with disabilities as they transition from youth to early adulthood from the familial, social, institutional, and cultural perspective; 2) to advance understanding of key challenges, barriers, opportunities, and successes experienced by YAD for stakeholders at the local, state and federal level; and 3) to inform future public policy and practice. The NLTS2 sample is comprised of more than 11,000 youth nationwide who were ages 13 through 16 at the beginning of data collection on December 1,

2000. The NLTS2 used a two stage process to generate the needed sample of students by randomly selecting students receiving special education from rosters of local education agencies (LEAs) as the primary sampling unit (PSU) and stratified by socio-demographic factors of the students as the secondary sampling unit, which took into account factors such as geographic region, district enrollment and district and community wealth to enhance national representativeness. ¹⁶⁹ Details about the sampling strategy, methodology and questionnaire design are described elsewhere. ¹⁷⁰

4.2.2 Exposure Variable: Social Skills

The social skills scale consists of three subscales: assertion, self-control, and cooperation in NLTS2. The overall social skills in adolescence were assessed by asking parents questions regarding 11 aspects of social interactions drawn from the Social Skills Rating System. ¹⁷¹ (Crohnbach alpha = 0.54) For each social interaction, parents were asked to respond with the following choices: "never," "sometimes," or "always." A numerical scale was created from categorical response to each item under the subscales. For assertion subscale or adolescent's ability and willingness to engage in social activities, there were four questions: 1) Makes friends easily; 2) Seems confident in social situations, such as parties or group outings; 3) Starts conversations rather than waiting for others to start; and 4) Joins group activities without being told to, such as a group having lunch together. For self-control subscale, or the adolescent's ability in coping and conflict resolution, the following four questions were asked: 1) Avoids situations that are likely to result in trouble; 2) Controls his or her temper when arguing with peers other than siblings; 3) Ends disagreements with parent calmly; and 4) Receives criticism well. Finally, three questions were used to assess cooperation subscale or an adolescent's ability cooperate and focus on the task at hand: 1) Speaks in an appropriate tone at home; 2) Keeps

working at something until he or she is finished, even if it takes a long time; and 3) Behaves at home in a way that causes problems for the family. Categories of high, medium, and low scales was determined by national mean and standard deviation, which were defined following the methodology delineated in *The Individual and Household Characteristics of Youth with Disabilities. A Report from the National Longitudinal Transition Study-2*. ¹⁷² For assertion, ratings between 0-3 were low, 4-7 were medium, and 8 was high. For self-control, ratings between 0-2 were low, 3-7 were medium, and 8 was high. For cooperation, ratings between 0-2 were low, 3-4 were medium, and 5-6 was high.

4.2.3 Outcome Variables

The four health related outcomes of interests, which were collected in NLTS2, are as follows: 1) self-rated health (SRH) as reported by parents and/or YAD to investigate perceptions of health status; 2) problems with general health; 3) frequency at which health or emotional problem hindered participation in social activities; and 4) spending time on medical needs. SRH is determined by subject response to the question, "In general, how would you rate your health?" by selecting one of the five categories: 1) Excellent, 2) Very Good, 3) Good, 4) Fair and 5) Poor. Fair and Poor SRH categories were combined to model for YAD with poorer health status, which has been used frequently in health services research conducted by CDC and used as a valid measure of physical health status. 173,174,175,176 In the multivariate model, SRH was dichotomized into better (included Excellent, Very Good, and Good SRH) and poorer health status (included Fair and Poor SRH). Problems with general health and spending time on medical needs were both reported by dichotomous response of "Yes" or "No." Frequency of health/emotional problems causing YAD to miss a social activity in the past month had the following three response categories: 1) never missed a social activity; 2) missed social activities just a few times;

3) missed social activities about once a week or more. This variable was further dichotomized in the multivariate model into any or never missed a social activity.

4.2.4 Confounders

The sociodemographic variables from wave 1 of NLTS2 included gender, race/ethnicity, age, and household income. Gender was comprised of two categories: 1) Male; and 2) Female. Race/ethnicity are divided into four groups: 1) Non-Hispanic White; 2) Non-Hispanic Black; 3) Hispanic; 4) Other, which comprised of Asian/Pacific Islander and American Indian/Alaska Native. Age was treated as a continuous variable. Household income had the following three categories: 1) \$25,000 or less; 2) \$25,001- \$50,000; and 3) More than \$50,000. Since NLTS2 sample is comprised of students with disabilities receiving special education services, the disability type included twelve categories defined in the Individuals with Disabilities Education Act (IDEA): learning disabilities, speech or language impairment, mental retardation, emotional disturbance, hearing impairment, visual impairment, orthopedic impairment, other health impairments, autism, traumatic brain injury, multiple disabilities, and deaf-blindness. As functional status may vary across the twelve disability types, we further investigated functional limitations in the areas of seeing, hearing, communicating, walking or running, learning, and paying attention and categorized functional limitations into the following: 1) having 0-1; 2) having 2; 3) having 3 or more functional limitations. ¹⁷⁷ Finally, health-related outcome variables collected at wave 1, specifically SRH and any problems with general health, were included in the multivariate model as potential confounders.

4.2.5 Analytic Strategy

Descriptive statistics compared sociodemographic characteristics by overall social skills scales and by the three subscale of assertion, self-control, and cooperation using baseline data from NLTS2 wave 1 as well as health related outcomes reported in wave 5. Data from wave 1 and wave 5 time points have been selected to detect the effects of social skills developed in adolescence on health related outcomes by allowing for induction period between causal action and health related outcome change.

Bivariate and multivariate analyses accounting for survey weights were conducted to understand the association of adolescent social skills and YAD's health related outcomes and to produce nationally representative estimates. Multivariate logistic regression models was used to examine the significance to the variables of interests, while controlling for sociodemographic confounders. Individuals in the medium categories for overall social skills were used as the reference category. Parameter estimates were weighted to the population level, and variances were adjusted in accordance with the complex sampling and weighting design of NLTS2. We reported adjusted odds ratios (aOR) and 95% confidence intervals and discussed statistically significant findings at the p-value ≤0.05. We used STATA 14 to conduct all statistical analysis.¹⁷⁸

4.3 Results

The final analytic dataset consist of subjects who responded to the social skills and health related outcome questions in both wave 1 and wave 5 of NLTS2 (N=5143). Table 9 delineates the sociodemographic characteristics of the sample. Over 50% of the sample was comprised of males and Non-Hispanic White (NHW). Significant differences in assertion were observed across several sociodemographic variables. Among racial/ethnic groups, NHW had the highest percentage of high assertion where as Other group had the lowest percentage for high assertion.

Individuals with private insurance and from households of more than \$50,000 income had the highest percentage on the assertion and overall social skills scale. Among the twelve IDEA disability types, individuals with autism had the highest percentage of low assertion (60.5%) and overall social skills (55.9%). Only gender difference was observed for self-control where females with high weighted percentage of having low self-control as compared with males (19.8% versus 9.9%). There were no statistically significant differences for the cooperation scale across all sociodemographic characteristics. When examining social skills and functional limitation, adolescents with disabilities with 3 or more functional limitation comprised of half of those with low social skills.

Table 10 describes the distribution of health related outcomes reported by YAD in adulthood by assertion, self-control, and cooperation. Among individuals who had low self-control, a combined 34.8% reported excellent, very good, or good health as compared to 18.8% among individuals with high self-control. Among individuals with high self-control, 30.9% reported yes to spending time on medical needs, which includes getting therapies, medical attention, visiting doctor, or recovering from illness and injury as compared to 6.0% reporting no. For adolescents with high social skills 19.3% reported never missing social activities due to health problems, whereas 51.7% with low social skills reported missing social activities about once a week or more.

The multivariate analysis in Table 11 indicates that YAD with high social skills in adolescence had 48% less odds of missing any social activities due to health problem. Female YAD had 2.2 times the odds of missing any social activities due to health problems. YAD with poorer SRH as adolescents were at 2.7 times the odds of reporting poorer SRH in young adulthood. Similarly, YAD who reported any problems with general health as adolescents had

5.5 times the odds of reporting any problems with general health as young adults. African American and Hispanic YAD are at 2.0 times and 2.4 times odds of reporting any problems with general health as young adults respectively. For YAD who received public insurance in adolescence, they had 2.9 times the odds of reporting poorer SRH, 2.6 times the odds of reporting any problems with general health, and 2.8 times the odds of missing any social activities due to health problems. Finally, Hispanic YAD had 96% less odds of spending time on medical needs.

4.4 Discussion

Our findings indicate that YAD with high overall social skills were not at risk for poorer SRH, report of problems with general health, or spending time on medical needs. This coincides with the expectation that those with high social skills developed in adolescence would tend to have better health in adulthood. The finding also suggests that YAD with higher social skills may have advantages in having the knowledge and ability to integrate skills from the assertion, self-control, and cooperation subscales that enable their participation in social activities while managing their health problems. However, our study did find YAD who were female and had public insurance as an adolescent to be at higher odds for missing social activities dues to health problems, which is aligned with previous research of women with disabilities experiencing health disparities as a result of encountering social barriers.¹⁷⁹

In addition, our findings demonstrated that those who reported poorer SRH and problems with general health continued to be at higher odds for reporting the similar poorer outcomes in young adulthood. Previous research studies have documented the enduring effects of poor childhood health on poorer health in early adulthood and later adulthood among the general

population. ¹⁸⁰ These effects may be further exacerbated for YAD, in particular to more vulnerable subpopulations including African American, Hispanics, and those with public health insurance as adolescents identified through our study.

The bivariate analysis of high self-control and spending time on variety of medical needs ranging from obtaining therapies, receiving medical attention, visiting doctor, or recovering from illness and injury was statistically significant. Among the key attributes of self-control is the ability to avoid situations that are likely to result in trouble and may indirectly reduce the events of injury and needs for medical attention. This finding also resonates with previous research that individuals with high self-control tend to adhere to healthy habits due to higher levels of self-efficacy, stronger intentions, and more action planning towards achieving health-related goals. 181,182

The study had some limitations. First, the Crohnbach α for SSRS was 0.54, which is lower than the reliability coefficient of 0.70 or higher to be considered "acceptable." Thus, the low Crohnbach α raise concerns about the reproducibility and repeatability of the SSRS in the sample. Lack of reliability could lead to information bias towards the null value, which could potentially explain the null findings. Second, social skills development may be influenced personality traits as demonstrated among individuals without disabilities in previous research. ^{183,184,185} However, questions pertaining to personality trait such as those measured through Big Five were not available through the NLTS2. ¹⁸⁶ Future research could explore the role of personality trait on social skills development to influence health-related outcome longitudinally. Third, the NLTS2 was administered in English and Spanish language only, which may bias the non-English respondents towards those who are more educated and fluent in English, resulting in a likely underestimate of risk for respondents in other racial/ethnic minority

groups. Fourth, the respondents from wave 1 to wave 5 represents just over 50% of the original wave 1 sample. NLTS2 survey administrators had conducted the bias analysis on wave 1 and wave 2 datasets and found the weighting resulted in the respondent sample resembling very closely to the characteristics of the total eligible sample. However, subsequent analysis of data from other waves were not reported by NLTS2 survey administrators. Fifth, NLTS2 is not a health focused survey focus on health and thus did not conduct physical examination to obtain objective health outcome measures. Hence, although SRH is an established and widely used measure for health status, the concordance between biological and self-reported measures of health could not be ascertained.

4.5 Conclusion

Enhanced interpersonal relationships can be perceived as preventive medicine, especially the relationships with family and peers that serve as primary vehicles where an individual received social support. ^{187,188} Individuals with disabilities are less likely to have positive perceptions of their social relations and lack of social skills. ^{189,190,191} The null findings from the present study has further contributed to the literature by delineating the lack of effects social skills developed in adolescence on health related outcomes in YAD. Future research is needed to advance the understanding of associations between other variables at the interpersonal level from the social ecological model beyond social skills and health related outcomes that can inform the future development of interventions that have constructive influences on health outcomes for YAD. ¹⁹²

Table 9. Sociodemographic Characteristics of Young Adults with Disabilities by Social Skills

	Table 9. Socio	<u>acmograpm</u>	· charac			elf-	With Disac	onicies of	Бостаг				
	m . 1	Asser	tion		Cor	ntrol		Coope	eration		Socia	l Skill	
Weighted Percentage	Total N=5143	Low	High	P- value	Low	High	P- value	Low	High	P- value	Low	High	P- value
Gender				0.25			< 0.01			0.84			0.73
Male	64.7	23.7	11.7		9.9	4.7		17.9	12.9		30.7	15.1	
Female	35.3	26.4	7.6		19.8	6.7		19.7	13.5		32.3	12.9	
Race/Ethnicity				< 0.01			0.63			0.74			0.37
Non-Hispanic White	62.5	22.7	13.6		14.2	5.6		17.6	13.6		28.2	16.4	
Non-Hispanic Black	20.2	21.2	5.7		12.3	2.7		22.6	12.0		34.0	11.4	
Hispanic	14.4	34.4	3.4		10.6	7.7		18.7	10.9		39.3	9.9	
Other	3.0	41.4	2.8		17.0	9.6		8.2	19.2		38.6	12.2	
Mean Age in Wave 1		15.2	15.6		15.1	15.1		15.3	15.1		15.2	15.2	
Household income in Wav	ve 1			< 0.01			0.82			0.75			< 0.01
\$25,000 or less	36.3	29.8	4.0		12.6	5.2		16.5	16.0		39.0	11.8	
\$25,001- \$50,000	29.6	20.3	9.7		11.7	3.9		15.0	13.2		30.7	14.5	
More than \$50,000	34.1	17.6	17.4		9.8	6.0		18.2	12.1		20.8	18.6	
Insurance Status				< 0.01			0.40			0.39			< 0.01
Private	64.9	19.4	14.0		11.7	5.8		17.8	13.1		26.0	16.9	
Public	28.0	34.2	2.6		16.5	5.6		17.3	15.9		41.6	9.3	
Uninsured	7.1	28.3	6.7		8.6	3.7		22.0	5.2		32.4	10.0	
Disability Type				< 0.01			0.06			0.06			< 0.01

Learning Disability	62.0	22.5	11.1	13.6	5.1	16.8	12.0	29.0	15.6	
Speech Impairment	4.0	24.1	10.0	6.8	9.9	14.2	17.5	24.5	20.8	
Mental Retardation	12.2	26.7	6.2	12.9	7.1	25.2	14.4	34.2	10.4	
Emotional Disturbance	11.4	30.1	8.2	17.3	1.9	22.3	15.0	42.7	6.9	
Hearing Impairment	1.3	21.5	14.4	4.7	8.3	16.7	20.5	23.3	28.7	
Visual Impairment	0.5	17.9	17.2	5.5	6.3	12.3	11.3	19.6	29.8	
Orthopedic Impairment	1.2	24.5	12.7	6.2	12.2	20.4	14.7	26.8	20.4	
Other Health Impairment	4.5	26.1	13.3	12.4	6.2	17.7	12.2	30.4	15.2	
Autism	0.7	60.5	2.1	12.2	3.6	15.6	19.6	55.9	3.8	
Traumatic Brain Injury	0.3	11.4	9.7	7.1	9.2	12.1	14.5	27.7	5.3	
Multiple Disabilities	1.8	37.8	12.4	15.3	8.5	24.8	3 13.7	37.7	15.2	
Deaf Blindness	0.2	40.8	7.0	16.6	12.8	17.8	3 17.8	38.2	16.0	
Functional Limitations				0.12		0.24		0.24		< 0.01
0 to 1 limitations	56.7	22.2	10.0	12.8	6.7	18.4	14.8	27.1	17.8	
2 limitations	31.7	24.6	11.8	12.1	3.6	16.6	11.9	31.9	11.9	
3 or more limitations	11.6	36.5	7.2	19.3	4.2	24.4	7.7	50.0	3.9	

Source: National Longitudinal Transition Survey 2 - Wave 1

Table 10. Health-Related Outcome by Baseline Social Skills for Young Adults with Disabilities (YAD)

		Δοορ	ertion			elf- ntrol		Coope	eration			cial ills	
		Asse	nuon	P-	Coi	11101	P-	Соор	cration	P-) N	.1115	P-
Weighted Percentage	Total	Low	High	value	Low	High	value	Low	High	value	Low	High	value
Self-Rated Health				0.33			< 0.01			0.10			0.13
Excellent	21.2	17.1	11.0		9.6	5.8		11.8	12.7		25.3	20.8	
Very Good	32.9	20.9	16.5		5.5	8.9		17.3	11.7		20.0	16.8	
Good	32.5	24.0	10.3		19.7	4.1		24.8	11.5		34.1	12.2	
Fair/Poor	13.4	25.1	6.0		7.8	7.6		14.8	22.5		32.0	18.2	
Problems with general health				0.18			0.97			0.32			0.49
Yes	14.8	25.7	5.6		13.4	6.3		15.9	17.9		29.4	14.2	
No	85.2	24.5	11.1		13.8	5.7		19.0	12.4		35.9	14.4	
Missed social activity due to health/emotional p	problem			0.38			0.18			0.53			< 0.01
Never missed a social activity	65.3	20.6	12.4		10.1	6.9		17.9	14.6		25.7	19.3	
Missed social activities just a few times Missed social activities about once a week or	24.7	19.0	12.5		10.2	5.7		20.1	12.4		21.0	12.4	
more	10.0	32.7	7.7		23.5	5.8		13.4	7.7		51.7	7.6	
Spend time addressing medical needs				0.95			0.04			0.40			0.17
Yes	1.4	18.1	12.8		1.6	30.9		14.5	31.2		27.7	15.6	
No	98.6	21.8	11.6		11.9	6.0		18.0	12.9		17.2	43.7	

Source: National Longitudinal Transition Survey 2 - Wave 1 and Wave 5

Table 11. Odds Ratios of Social Skills and Health-Related Outcome among Young Adults with Disabilities (YAD)

	Fair/l	Poor Self-Rated Health	•	Problems with neral Health	Act	Missed Social ivities due to alth Problem	Spending Time on Medical Needs		
Odds Ratios	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)	aOR	(95%CI)	
Social Skills									
Low	1.068	(0.568, 2.010)	1.086	(0.626, 1.884)	0.910	(0.539, 1.536)	0.746	(0.192, 2.901)	
Medium	1.000	ref	1.000	ref	1.000	Ref	1.000	ref	
High	1.276	(0.541, 3.011)	1.319	(0.606, 2.870)	0.523	(0.296, 0.923)	1.858	(0.282, 12.257)	
Poor Health-Related Outcome in Wave 1	2.655	(1.218, 5.786)	5.517	(2.837, 10.728)	n/a		n/a		
Gender									
Male	1.000	ref	1.000	ref	1.000	ref	1.000	ref	
Female	1.272	(0.726, 2.228)	1.011	(0.603, 1.696)	2.177	(1.393, 3.402)	0.326	(0.093, 1.143)	
Race/Ethnicity									
Non-Hispanic White	1.000	ref	1.000	ref	1.000	ref	1.000	ref	
Non-Hispanic Black	1.752	(0.820, 3.744)	2.021	(1.059, 3.859)	0.903	(0.522, 1.563)	0.203	(0.022, 1.847)	
Hispanic	1.174	(0.435, 3.166)	2.352	(1.137, 4.867)	1.463	(0.627, 3.418)	0.044	(0.009, 0.216)	
Other	0.710	(0.193, 2.610)	0.435	(0.135, 1.405)	1.339	(0.261, 6.867)			
Mean Age in Wave 1	1.118	(0.895, 1.396)	1.198	(0.992, 1.446)	1.017	(0.855, 1.209)	0.404	(0.221, 0.737)	
Household income in Wave 1								(2.547	
\$25,000 or less	1.168	(0.441, 3.089)	1.037	(0.458, 2.350)	0.595	(0.274, 1.289)	24.399	(2.547, 233.700)	

\$25,001- \$50,000	1.191	(0.623, 2.277)	0.901	(0.507, 1.600)	1.094	(0.642, 1.863)	0.585	(0.140, 2.443)
More than \$50,000	1.000	ref	1.000	ref	1.000	ref	1.000	ref
Insurance Status								
		_		_				_
Private	1.000	ref	1.000	ref	1.000	ref	1.000	ref
Public	2.935	(1.221, 7.055)	2.626	(1.300, 5.303)	2.789	(1.390, 5.594)	0.229	(0.046, 1.130)
Uninsured	0.707	(0.199, 2.510)	0.461	(0.139, 1.527)	1.711	(0.654, 4.475)	0.085	(0.007, 1.049)
Functional Limitations								
0 to 1 limitations	1.000	ref	1.000	ref	1.000	ref	1.000	ref
2 limitations	1.304	(0.692, 2.455)	1.584	(0.920, 2.726)	1.541	(0.952, 2.494)	0.283	(0.055, 1.453)
3 or more limitations	1.718	(0.814, 3.624)	1.562	(0.814, 2.997)	1.420	(0.741, 2.720)	0.290	(0.078, 1.080)

Source: National Longitudinal Transition Survey 2 Wave 1 and Wave 5 Multivariate model adjusted for health related outcome at Wave 1, gender, race, age, household income, insurance and functional limitations

aOR=Adjusted Odds Ratio

n/a =health related outcome not collected in Wave 1

Chapter 5: Social Skills, Community Participation, and Self-Rated Health among Young Adults with Disabilities in the United States: a Structural Equation Model Analysis (Manuscript 3)

5.1 Introduction

In the United States, 22% of the adult population has a disability. ¹⁹³ Adults with disabilities are four times more likely to report fair or poor health and have higher risk for tobacco use, obesity, hypertension, depression, and cardiovascular disease as compared to peers without disabilities. ^{194,195,196} Furthermore, although they have higher rates of chronic disease, they continually encounter significant challenges and delays in receipt of preventive primary and oral health care. ^{197,198,199} The health disparities and excess burden of disease confronting individuals with disabilities can be attributable to risk factors at the personal level such as sociodemographic and socioeconomic status, as well as at the social and community level. ^{200,201} This in turn fosters a negative cycle of secondary chronic conditions development, increasingly poorer health, and progressive functional limitations. ²⁰²

The life course perspective recognized critical periods where cumulative exposure to life experiences and environment can have profound influence on health and disease across the life span .^{203,204,205} Adolescence is one of the critical periods, which is characterized by significant changes in biology, social role and psychology; and the way in which adolescents adjust and mature will set the stage for the transition into early adulthood.²⁰⁶ The Patient Protection and Affordable Care Act of 2010 sought to improve health for young adults through health insurance coverage by staying on parents' health plan until 26, purchasing student health plan while in school, and expanding Medicaid coverage.^{207,208} However, disparities in health care access and utilization by public health insurance, race/ethnicity, and SES among adults with disabilities may

not be remedied with insurance coverage alone. ²⁰⁹ Successful community-based health promotion approaches have been built upon the social ecological framework, where individuals' health and their behaviors are shaped and influenced by the factors at intrapersonal, interpersonal and community level. ^{210,211} Perceived positive community participation has been linked to improved self-rated health (SRH) and maintenance of functional independence in older adults. ^{212,213,214,215} In addition, individual community service group membership and interpersonal trust were beneficial to SRH whereas lower social and community participation has been linked to poorer quality of life. ^{216,217,218} However, the intrapersonal, interpersonal, and community determinants of health status have not been comprehensively explored for young adults with disabilities (YAD).

What is known is that high-quality social relationships with family and professionals are critical to the health and well-being of YADs. ²¹⁹ Furthermore, YAD appear to have complex interaction with their interpersonal and community environments with regards to participation, receipt of social support, social membership and connectedness. ^{220,221} However, the triggering of social support may be influenced by individual social skills level that allow persons with disability to overcome social stigmatization, to request assistance, to foster ease and comfort in social relationships, to elicit social feedback and positive relationship building. ^{222,223,224,225} Research from the United Kingdom has provided some evidence to suggest that the health inequalities experienced by people with intellectual disabilities may be partially attributable to their less favorable perceptions of important neighborhood characteristics and lower levels of social and civic participation. ²²⁶ However, studies examining the association between community participation and SRH in YAD across the spectrum of disability types have been limited.

Using the social ecological model, we comprehensively investigated the intrapersonal, interpersonal, and community level factors impacting SRH of YAD from adolescence to adulthood by examining the longitudinal influence of social skill level and community participation experienced during adolescence on YAD's SRH. Examining the underlying relationship of intrapersonal sociodemographic characteristics, interpersonal social skills, and community level participation would increase our understanding of the factors that contribute to positive SRH for YAD. The primary research question is: Do social skills and community participation in adolescence predict SRH for YAD in early adulthood?

5.2 Methods

5.2.1 Data Source

The study conducted a secondary analysis using data from wave 1 and wave 5 of the National Longitudinal Transition Study 2 (NLTS2). The US Department of Education administered the NLTS2 to collect longitudinal data on the educational, health, vocational, and personal experiences of a nationally representative sample of students with disabilities receiving special education services from adolescence and into early adulthood. The primary objectives of NLTS2 were to achieve the following: 1) to explore risk factors influencing the achievements of students with disabilities transition from youth to early adulthood from the familial, social, institutional, and cultural perspective; 2) to ascertain critical challenges and opportunities experienced by YAD for stakeholders at the local, state and federal level; and 3) to inform future public policy and practice. To generate the required sample, the NLTS2 used a two stage process of randomly selecting students receiving special education from rosters of local education agencies (LEAs) as the primary sampling unit (PSU) and stratified by socio-demographic factors

of the students as the secondary sampling unit, which took into account factors such as geographic region, district enrollment and district and community wealth to enhance national representativeness.²²⁷ Details about the sampling strategy, methodology and questionnaire design are described elsewhere.²²⁸

The NLTS2 was administered between 2001 and 2009 with five waves of data collection and initial sample of more than 11,000 youth nationwide who were ages 13 through 16 or adolescence at the wave 1. At wave 5, NLTS2 participants had reached early adulthood. As previously mentioned in the introduction, we are interested in investigating SRH from adolescence to adulthood for YAD and in examining the causal effect of social skills and community participation in adolescence in predicting SRH in early adulthood. Thus, we have chosen to use data from wave 1 and wave 5 to allow for induction period between adolescence and early adulthood to take place.

5.2.2 Outcome Variable

The primary outcome of interest is SRH was measured using the following question: "In general, how would you rate your health?" The response is comprised of five ordinal categories:

1) Excellent, 2) Very Good, 3) Good, 4) Fair and 5) Poor. In our study, categories of "Fair" and "Poor" SRH were combined to model for YADs with poorer health status, which has been used frequently in health services research conducted by CDC and used as a valid measure of physical health status. SRH is one of the most frequent assessment of health perceptions in epidemiological studies with a growing body of literature demonstrating that self-perceptions of health predict future morbidity and mortality. SRH is one of the most frequent assessment of health perceptions of health predict future morbidity and mortality.

5.2.3 Exposure Variables

Community participation. Four items were used to assess the latent construct of community participation in adolescence: 1) Youth participated in community activities; 2) Youth has done volunteer/community service in past 12 months; 3) Youth participated in school activity outside of class; and 4) Youth has taken lessons or classes outside of school. wave 1 respondents could reply with yes or no to each of the four questions. The community participation construct was previously used and reported in NLTS2 reports.²³⁵ (Crohnbach alpha = 0.57)

Social Skills. The social skills in adolescence were assessed in wave 1 through eleven questions on social interactions drawn from the Social Skills Rating System, which includes questions on assertion, self-control, and cooperation. 236 (Crohnbach alpha = 0.54) The response options included "never," "sometimes," or "always." The four questions on assertion or adolescent's ability and willingness to engage in social activities, were: 1) Makes friends easily; 2) Seems confident in social situations, such as parties or group outings; 3) Starts conversations rather than waiting for others to start; and 4) Joins group activities without being told to, such as a group having lunch together. For self-control, or the adolescent's ability in coping and conflict resolution, the following four questions were asked: 1) Avoids situations that are likely to result in trouble; 2) Controls his or her temper when arguing with peers other than siblings; 3) Ends disagreements with parent calmly; and 4) Receives criticism well. Three questions were used to measure cooperation or an adolescent's ability cooperate and focus on the task at hand: 1) Speaks in an appropriate tone at home; 2) Keeps working at something until he or she is finished, even if it takes a long time; and 3) Behaves at home in a way that causes problems for the family. 5.2.4 Confounders

Sociodemographic characteristics included gender, race/ethnicity, age, insurance type, household income, and disability type. Gender categories consisted of male and female.

Race/ethnicity was divided into four groups: 1) Non-Hispanic White; 2) Non-Hispanic Black; 3) Hispanic; 4) Other, which included of Asian/Pacific Islander and American Indian/Alaska Native. Age was treated as a continuous variable. Insurance coverage consisted of three types: private, public, and uninsured. Household income in NLTS2 is reported in the following three categories: 1) \$25,000 or less; 2) \$25,001- \$50,000; and 3) More than \$50,000. The disability types are the twelve categories defined in the Individuals with Disabilities Education Act (IDEA): learning disabilities, speech or language impairment, mental retardation, emotional disturbance, hearing impairment, visual impairment, orthopedic impairment, other health impairments, autism, traumatic brain injury, multiple disabilities, and deaf-blindness. Since disability types may not clearly delineate functional status, we utilized an existing definition of functional limitations that accounts for seeing, hearing, communicating, walking or running, learning, and paying attention. ²³⁷ The functional limitation variable was further categorized into the following: 1) having 0-1; 2) having 2; 3) having 3 or more functional limitations.

5.2.5 Analytic Strategy

Sociodemographic characteristics are analyzed for subjects who participated in survey data collection for both NLTS2 wave 1 and wave 5. Bivariate analysis was conducted for each exposure and confounding variable. SEM analyses accounting for survey weights were conducted to understand the association among adolescent social skills, community participation and YAD's SRH while controlling for sociodemographic variables. Parameter estimates and 95% confidence intervals were adjusted for NLTS2's complex survey design to take into account sampling weights, primary and secondary sampling units, and stratification.

Structural equation modeling (SEM) was used to test the variables in the social ecological model. The measurement model demonstrates the relation between latent constructs and their indicators markers. ^{238,239} SEM is designed to test theoretical relationships between latent constructs and does not assume that all variables are measured perfectly. The SEM analyses allowed for making inferences about population differences among the four categories of YAD's SRH. The distinct advantages of SEM compared to other statistical methods are the ability to test construct level hypotheses and to examine the interrelationship and depict the potential causal paths.

The Akaike information criterion (AIC) and Bayesian information criterion (BIC) are used as criteria for model evaluation. Among a set of candidate models for the data, the model with the lowest AIC and BIC is preferred. Both are based upon the likelihood function. We used STATA 14 to conduct all statistical analysis, which supports survey data analysis in generalized structural equation models (gsem). We used STATA gsem command since SRH is an ordinal variable. The gsem procedure also allows for models that are linear regression, gamma regression, logit, probit, ordinal logit, ordinal probit, Poisson, negative binomial, and multinomial logit. Fit indices such as CFI, TLI, and RMSEA are not available after gsem command. Since gsem models are a function of the model chi-squared test, which involves an estimate of the variances and covariances of observed exogenous variables, STATA cannot estimate the model chi-squared test and other statistics that are functions of this test.

5.3 Results

Table 12 contains the descriptive sociodemographic characteristics of the study population comprised of NLTS2 respondents of wave 1 and wave 5 of NLTS2 (N=5020). The

study population was predominantly male (65%) with a mean age of 15 years old. Among the race/ethnicity groups, Non-Hispanic White (NHW) was the largest group, which comprised of over 60%, followed by Non-Hispanic Black at 20%. The majority of sample had private insurance coverage (65%) while 28% had public insurance in adolescence. 34% of sample reported household income more than \$50,000. Among the twelve disability types, learning disability was the predominant type at 62%. Over 50% of the respondents reported 0-1 functional limitation.

In the bivariate analysis delineated in Table 13, three variables were statistically significant at the p≤0.05 level to SRH in early adulthood: 1) SRH in adolescence or wave 1 (β =0.39; 95% Confidence Interval (CI)= 0.20, 0.58; p<0.01); 2) social skills (β =-0.06; 95% CI= 0.10, -0.01; p=0.01); and 3) functional limitations (β =-0.27; 95% CI= 0.05, 0.49; p=0.02). Other sociodemographic variables of gender, race/ethnicity, age, insurance coverage, and household income were not statistically significant. Community participation had a β =0.06 as indicated in Figure 2.

Results from the SEM analysis are presented in Table 14. None of the sociodemographic variables, namely, gender, race/ethnicity, age, insurance, and household income, were statistically significant at the p \leq 0.05 level to SRH in early adulthood. Similarly, social skills developed in adolescence was not associated with SRH in early adulthood. However, SRH in adolescence (β =0.34; 95% CI= 0.13, 0.54; p<0.01) and functional limitations (β =0.26; 95% CI= 0.01, 0.52; p=0.04) were associated with SRH in early adulthood. Community participation had a β =3.7x10⁻¹⁴. Association between SRH in adolescence and functional limitation was statistically significant (β =0.39; 95% CI= 0.17, 0.60; p<0.01), while association between functional limitation and community participation was not (β =-6.02x10⁻⁹; 95% CI= -3.67x10⁻⁸, 2.47x10⁻⁸;

p=0.70). The AIC and BIC for the intrapersonal model were 2946365.00 and 2946524.00 respectively. For the intrapersonal and interpersonal model, the AIC and BIC were 2930422.00 and 2930487.00. Finally, the AIC and BIC for the social ecological model including intrapersonal, interpersonal, and community level factors were both 17600000.00. Table 15 delineated the relative model fit test, which indicated that the intrapersonal and interpersonal model had the lowest AIC and BIC statistics.

5.4 Discussion

The major statistically significant predictors of SRH in early adulthood were the YAD's functional limitations and SRH in adolescence. Furthermore, functional limitation in adolescence was also associated with SRH in adolescence. We can draw upon parallels between our study and international studies that have demonstrated single measure questions of functional status and self-rated health are strong and complementary predictors of mortality in the adult population. ^{242,243}

Neither social skills nor community participation in adolescence predicted SRH in early adulthood. Although social skills activate social support, we were unable to test the effects of social support as the NLTS2 lack social support construct in the survey. Thus, future research may need to explore the association between social support and SRH for YAD. Despite the effects of community participation on SRH for elderly adults, it may not influence YAD's SRH through a similar pathway. Other community level variables may be at play that influences SRH for YAD that requires future research.

Moreover, functional limitation was not associated with community participation at adolescence. These findings contradict those in the literature, which show that community participation is associated with functional abilities especially for children with disabilities who

experience lower frequency of participation and less involvement in community activities as compared with children without disabilities. ^{244,245} Since our study population comprised only of YAD, we can neither compare community participation levels between YAD and young adults without disabilities nor contrast the differences in resources and opportunities required for participation in community activities.

Several study limitations are notable. First, the psychometric analysis of community participation construct from NLTS2 yielded Cronbach α=0.57, which is well below the 0.7 threshold of acceptability. This suggests the lack of reliability of the community participation construct that potentially lead to non-differential misclassification of the exposure status. Second, due to the nature of the multi-level data, model fits were not well assessed. Third, the components of SSRS and community participation may be correlated as confidence in social situation from strong social skills may lead to more active community participation. Future research could explore latent and measured variable from interpersonal and community level of the social ecological model that are not correlated. Fourth, personality traits of YAD could potentially influence social skills development as well as community participation as previous literature documented its role in healthy aging among individuals without disabilities.^{246,247} However, due to secondary data analysis limitation, we could not test the effects of personality traits in the analyses. Fifth, community participation may be influenced by parental and child preferences. Parents may not push their child to community participation activities. Child may not be inclined to community participation as a personal choice. Sixth, NLTS2 was conducted to evaluate the special education programs administered under the Individuals with Disability Education Act with emphasis on understanding education, vocation, and independent living outcomes for YAD. Thus, the survey contained a limited number of health-related outcome

questions. Seventh, despite the fact that our conceptual model was based upon the social ecological model, other plausible models could be tested using these same variables. Finally, the NLTS2 was conducted in English and Spanish, which may bias the non-English respondents towards those who are more educated and fluent in English, resulting in a likely underestimate of risk for respondents in other racial/ethnic minority groups.

5.5 Conclusion

When adolescents with disabilities transition into adulthood, health and adult services systems are often not ready to support their needs. ²⁴⁸ Although the study did not identify any association between social skills and community participation in adolescence and SRH in early adulthood, the study was limited by the variables available for secondary analysis through NLTS2, which was designed as survey to assess special education outcomes rather than health outcomes. Thus, additional exploration into social support and patterns of community participation, environment supports, and barriers may be helpful in further elucidating influential factors for SRH in early adulthood. ^{249,250}

Table 12. Demographic Characteristics of Young Adults with Disabilities (N= 5020): National Longitudinal Transition Survey 2 (NLTS2)

Characteristic	Weighted %	
Gender		
Male	64.7	
Female	35.3	
Race/Ethnicity		
Non-Hispanic White	62.5	
Non-Hispanic Black	20.2	

Hispanic	14.4
Other	3.0
Mean Age	15.2
Insurance Coverage	
Private Insurance	64.9
Public Insurance	28.0
Uninsured	7.1
Household income	
\$25,000 or less	36.3
\$25,001- \$50,000	29.6
More than \$50,000	34.1
Disability Type	
Learning Disability	62.0
Mental Retardation	12.2
Emotional Disturbance	11.4
	4.5
Other Health Impairment	4.3
Speech Impairment Multiple Disabilities	1.8
Multiple Disabilities	1.8
Hearing Impairment	1.3
Orthopedic Impairment	
Autism	0.7
Visual Impairment	0.5
Traumatic Brain Injury	0.3
Deaf Blindness	0.2
Functional Limitations	
0 to 1 limitations	56.7
2 limitations	31.7
3 or more limitations	11.6

Table 13. Bivariate Association Between Self-Rated Health, Social Skills, Community Participation, and Demographic Characteristics: National Longitudinal Transition Survey 2 (NLTS2)

		95% Con	fidence	
Variables	Coefficient	Interval		P-Value
Self-Rated Health at Baseline	0.39	0.20	0.58	< 0.01
Social Skills	-0.06	-0.10	-0.01	0.01
Community Participation	1.00	constrained		
Gender	0.30	-0.06	0.66	0.11
Race/Ethnicity	-0.48	-2.11	1.15	0.57
Age	0.02	-0.12	0.16	0.77
Insurance Coverage	0.18	-0.35	0.71	0.51
Household Income	-0.19	-0.43	0.05	0.12
Functional Limitations	0.27	0.05	0.49	0.02

Table 14. SEM Parameter Estimates of Self-Rated Health in Early Adulthood with Sociodemographic Characteristics, Social Skills, Community Participation: National Longitudinal Transition Survey 2 (NLTS2)

Variables	Coefficient	95% Confidence Interval		P- Value
Self-Rated Health Adolescence	0.34	0.13	0.54	< 0.01
Social Skills	-0.03	-0.09	0.03	0.36
Community Participation	1.00	constrained		
Gender	0.19	-0.20	0.57	0.35
Race/Ethnicity	-0.37	-2.05	1.32	0.67
Age	0.07	-0.09	0.22	0.41
Insurance Coverage	0.22	-0.12	0.56	0.21
Household Income	0.05	-0.28	0.38	0.77
Functional Limitations	0.26	0.01	0.52	0.04

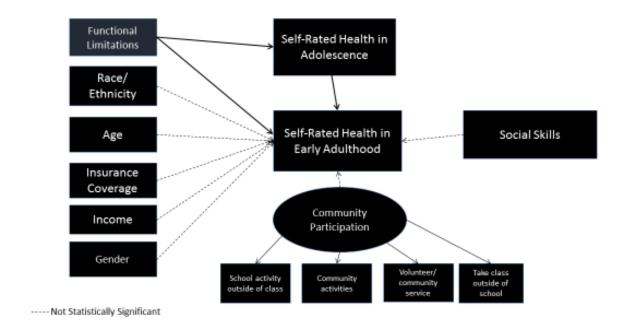


Figure 2. SEM Analysis of Self-Rated Health in Early Adulthood with Sociodemographic Characteristics, Social Skills, and Community Participation.

Table 15. Evaluate Relative Quality of Models using AIC and BIC

Model	df	AIC	BIC
Intrapersonal Model	10	2946365.00	2946424.00
Intrapersonal and Interpersonal Model	11	2930422.00	2930487.00
Intrapersonal, Interpersonal, and Community Model	23	17600000.00	17600000.00

Chapter 6: Conclusions

6.1 Conclusion of Findings

The study used the social ecological model to advance the knowledge of the complex causal pathways operating between the health related outcomes of YAD beyond proximal healthcare measures such as access to usual source of medical care, transition to adult medical care, emergency department utilization, and continuity of health insurance coverage into adulthood, to understand risk factors from the intrapersonal, interpersonal and community level leading to poorer health in early adulthood, and to address the need for comprehensive theoretical framework in the identification of targets of intervention and effective supports for YAD. Our findings suggest significant health disparities exist for adolescents with disabilities with public health insurance coverage with respect to health related outcomes of self-rated health, reports of problems with health, and missing social activities due to health problems in early adulthood. Thus, even with expansion of Medicaid benefits for children with disabilities, health insurance coverage does not equate to good health. At the interpersonal level, social skills developed through relationships with family and peers in adolescence do not have an association with health related outcomes in early adulthood. Finally, at the community level, community participation in adolescence does not have an association with SRH in early adulthood. The null findings in social skills and community participation suggests other factors at play for SRH and health related outcomes for YAD and the need for investigation into other risk factors in interpersonal and community level of the social ecological model beyond aspects that could be explored using the NLTS2 data set.

6.2 Public Health Implications

The disparities in health related outcomes among YAD with public insurance in adolescence suggest that they and their families need additional supports to achieve positive outcomes in early adulthood. The additional supports can come from having access to medical care provided through the patient-centered medical home (PCMH) model from childhood to adulthood that ensures accessible, continuous, comprehensive, family-centered, and coordinated medical care. However, well-trained healthcare workforce is critical in the effective implementation of PCMH. Currently, the US does not have a healthcare workforce of adult primary care providers and adult subspecialists with expertise to provide comprehensive, interdisciplinary and culturally competent care for YAD. Thus, future federal funding to support workforce training and development would be instrumental in providing the backbone for delivery of care through PCMH that can in turn support the positive attainment of health outcomes for YAD.

In addition to improvements in health care delivery through PCMH and investments in workforce training, public health systems at the state level will need to be further transformed to better support YAD. Parents and families continue to face many challenges as they transition into adulthood. The demand on educational and medical systems to provide services to YAD will continue to increase across the country. Similar system changes have taken place for younger children with developmental disabilities in early identification and intervention services that can serve as a model to facilitate engagement among key stakeholders in states so that they could begin to systematically identify opportunities and challenges in the serving the needs of YAD. The Act Early Regional Summit is one such models that examined how development of

concerted, comprehensive state plans through engagement of key state stakeholders would foster improved outcomes in the early identification, diagnosis, and coordination of early intervention service systems for children with ASDs and related developmental disabilities (DD) from all racial, ethnic, geographical and socioeconomic backgrounds. ²⁵¹ Act Early State team created task forces on education/training, clinical services, family/advocacy, legislation, and research. Each task force has begun work on specific state-wide projects. Through this model, medical and educational providers work together to design intervention programs that address medical, behavioral, educational, and health disparity needs. Furthermore, public agencies joined together to promote system level thinking and changes, and to enhance public awareness of disparate health outcomes experienced by YAD.

6.3 Limitations of the Study

The study included some limitations. The NLTS2 was not a health focused survey that had stronger emphasis on understanding the educational experience, the vocational attainment, and independent living outcomes for YAD. Thus, the survey contained a limited number of health related questions including SRH. Although SRH is an established and widely used measure for health status, NLTS2 did not collect data from physical examination to obtain objective health measures and to allow for ascertainment of concordance between biological and self-reported measures. Furthermore, given the limitations of secondary data analysis, there are other variables at the interpersonal and community level within the social ecological model that were not available through NLTS2 dataset. Thus, we were only able to test the social skills and community participation variables.

In addition, respondent attrition occurred throughout the administration of NLTS2 as with other national longitudinal surveys from wave 1 to wave 5. Non-response bias occurs in statistical surveys if response from respondents who participated throughout all five waves of NLTS2 differ from those who did not participate in NLTS2 as well as those who dropped out. Thus, this could potential limit the generalizability of our findings to all YAD. Moreover, the NLTS2 was conducted only in English and Spanish, which could also contribute to non-response bias; in particular, bias towards YAD from non-English households that are more educated and fluent in English, resulting in a likely underestimate of risk for respondents from other racial/ethnic minority groups as well as non-Spanish speaking immigrants.

6.4 Future Directions

The support and entitlement programs for children with DD ends when transitioning into adulthood. Current studies on YAD are few and of poor quality.²⁵² We need to further investigate system supports and services that can foster a successful transition into adulthood with respect to health care, employment, and independent living. Among the future research priorities are as follows:

• Advance understanding on engagement of families from underserved families in paths to seek services and to serve their specific needs. Insurance coverage alone may not be a sufficient indicator in assessing the quality and comprehensiveness of services of access to care. Early diagnosis is critical for children with DD in order to receive much needed health services required for healthy development. 253 However, DD is more likely to be diagnosed in NHW boys from middle class ad wealthy families thereby leading to health disparities in under or delayed diagnosis of children from African American, Hispanic,

and immigrant families and those of low socioeconomic status. ^{254,255,256,257} Future studies will need to examine families' pathways in seeking services and to potentially develop new model of care-based cultural competency, personalization of care, provider and family partnership, and health literacy.

- Conduct translational research studies. Disconnect exists between research and the
 translation into practice. We need methods to operationalize research in a clinical setting
 and to reduce barriers in adoption of science, provider and family resistance, and system
 coordination.
- Focus on immigrant families. The limitations section alluded to the fact that NLTS2 may not have non-response bias as well as underrepresentation from different immigrant groups. Children from US immigrant families, who are defined as individuals under the age of 18 in families with at least one foreign-born parent, comprised of 22% of all US children in 2008. Many of these children live in households with low incomes, have parents with low education levels and limited English proficiency, interact less often with their parents, and use less health care benefits than children of natives. 258 Immigrant families are driving rapid population increase and growing race and ethnic diversity in local communities and school districts across the country. ²⁵⁹ This significant demographic shift presents a unique set of social and economic challenges for access to health care, and health outcomes. Immigrant family type is a complex variable and the different combinations have been shown to confer differential risks on children's health care access and utilization outcomes. ²⁶⁰ In addition to the differential eligibility for resources, there is great heterogeneity of health status of children with special health care needs including children with disabilities from immigrant households depending on the

family's racial/ethnic background. ²⁶¹ Furthermore, important areas of deficits in the health care experiences of children with ASD and select DD from immigrant households have already been identified that have public policy implications of increasing access to existing insurance programs, augmenting public awareness resources for ASD and select DD, and offering assistance to immigrant families that are struggling with the medical needs of their children. ²⁶², ²⁶³There has been limited research exploring the impact of different causal pathways and environmental triggers on SRH of YAD from immigrant households through a longitudinal perspective. A comprehensive social ecological model framework would provide the opportunity to examine the confluence of individual and environmental level risk factors as well as social influences that contribute to the health outcomes of YAD from immigrant households and lead to the development of effective health promotion interventions, disease prevention strategies and enhanced personalized care and supports for YAD from different immigrant populations.

The DAHE for US adults had already reached nearly \$400 billion since 2006. Despite the rise in disability population and associated economic cost, public health agencies, policies and health care systems have not increased their capacity to support the attainment of positive health status for YAD. Compounded with the growing immigrant children population that will eventually transition into adulthood, innovative strategies are needed to address the health of YAD from immigrant families to assist in reducing future financial health care spending burden.

Furthermore, it will advance the scholarly research on the application of social ecological models to explain how multi-level factors affect the health of YAD from immigrant families and emphasize the multi-dimensionality of achieving positive health status for these YAD

Appendix A – IRB application

University of Maryland College Park Institutional Review Board IRB Initial Application - Part 1

Last edited by: S	ue Lin				Full
Last edited on: S	eptember 19, 2014				Expedited
[click for checklist]				~	Exempt
ROLES OF RI	E HEALTH STATUS OF YOUNG ADI SK FACTORS IN SOCIAL ECOLOGI estions on this form completely, included and your department IRB Liaison prior	C FRAMEWOR	kK and obtain signatures o		
I. Principal	Investigator				
Name: Department:	Sue Lin, MS EPIB- Epidemiology and Biostatistic	Status:	Graduate Student		
Phone:	301-906-9415	Email:	sclin@umd.edu		
Address:	2114 Darcy Green Place Silver Spri	ng, MD 20910			
II. Faculty A	dvisor				N/A 🗀
	advisor is required if the PI is a stud age through IRBNet. Hongjie Liu	ent resident or f	ellow and the Faculty A	dvis	or MUST
Department:	EPIB- Epidemiology and Biostatistic	s			
Phone:	301-405-3102	Email:	hliu1210@umd.edu		
Address:	SPH Building 255 Rm 2234A, University	ersity of Marylar	nd College Park, MD 20	1742	
III. Co-Invest	igators				N/A 🔽
	vestigators MUST sign this package t	hrough IRBNet			
IV. Funding I	nformation				N/A 🔽
	of the awarded grant application (minu	us budgetary int	formation) must be prov	rided	_
			The property and the prove		

- 1 -

Status	Funding Type	Sponsor Name	ORAA#	COI
Funding	ı Title:			
V. Pr	oject Information			
Lay Su	ımmary:			
disabili linking The ob interpe through	ties. This health disparity behaviors and health, wh vjective of the proposed s rsonal and community lev	ADs) have poorer health status when columny result from confluences of environmere less is known about how multi-level study is to investigate the collective roles within the social ecological framework data from the National Longitudinal Traition.	mental and persona factors determinan of risk factors at in rk on the health sta	al factors its of health. htrapersonal, atus of YADs
Reque	sted Review Path:			
	Full			
	Expedited			
V	Exempt			
Projec	ted Completion Date:	12/31/2015		
Resea	rch Category:			
	Faculty or Staff Research	ch		
V	Graduate Student Rese	earch		
	Student/Faculty Collabo	pration		
	Undergraduate Student	Research		
	Other:			
Acade	mic Committee Review:			
	Yes - Masters committe			
V	Yes - Dissertation comm	nittee		
	No additional academic	review required		
VI. Pe	rformance Sites			
	mance Sites Engaged in the research will be cond	n Human Subject Research:		
,	UMCP - Campus:	•		
	University of Maryland -	Extension:		
	Campus Health Center			
	Universities at Shady G	rove:		
	Schools:			

- 2 -

□ Prison/Jail: □ Other:
Is this an international study? Yes [complete Section 10 of Initial Application Part 2]
▼ No
If yes: International Sites:
n you. International order.
VII. Subject Information
Targeted Populations:
Normal adult/healthy persons
☐ Cognitively impaired persons
☐ Economically disadvantaged persons
☐ Educationally disadvantaged persons
☐ Elderly/aged persons
☐ Hospital patients or outpatients
☐ Illiterate persons
Individuals with physical disabilities
☐ Minority group(s)
☐ Non-English speakers
☐ Pregnant women
Prisoners
☐ Students (non-minors)
☐ UMCP employees
Other special characteristics and special populations:
Youth receiving special education services in secondary school
Informed Consent Process:
 Informed consent will be obtained from subjects and documented with a signed, written consent form
Informed consent will be obtained from subjects, but no signed consent form will be used. This includes oral consent and implied consent (e.g., completing a survey). [please see the Requesting a Waiver of Informed Consent Guidance]
Fully informed consent will not be obtained from all subjects. This includes deception, withholding information, etc. [please see the Requesting a Waiver of Informed Consent Guidance]
Will health information be collected?

- 3 -

(See th	e <u>HIPAA section of the IRB website</u> for more information and additional resources.)
	No
V	Yes, data are de-identified or constitute a limited data set.
	Yes, subject's authorization will be obtained or a waiver or alteration of authorization will be
	requested. [complete IRB Form HIPAA]
VIII.Re	search Procedures
Resear	rch Procedures:
	Records review - retrospective
	Records review - prospective
	Education research
	Behavioral experiments
	Behavioral observation
	Questionnaires/surveys
	Interviews
	Audiotaping/videotaping
	The Internet
	Deception [describe debriefing process in Section 7 of Initial Application Part 2]
V	None of the above
Biome	dical Procedures:
	Tissue banking
	Biopsy
	Blood draw:
	Use of pre-existing tissues
	Clinical tests
	Radiology
	Radiation/X-ray/DEXA
	fMRI [use IRB fMRI templates]
	Pregnancy screening
	EKG
	EEG
	Genetic analysis
✓	None of the above
IX. As	surances and Signatures
Assura	nnces

- 4 -

This research, once approved, is subject to continuing review and approval by the IRB. The principal investigator will maintain records of this research according to IRB guidelines. If these conditions are not met, approval of this research could be suspended or terminated.

Electronic signatures certify that:

- The signatory agrees that he or she is aware of the policies on research involving participants of the University of Maryland College Park and will safeguard the rights, dignity, and privacy of all participants.
- · The information provided in this application form is correct.
- The principal investigator will seek and obtain prior written approval from the IRB for any substantive modification in the proposal, including but not limited to changes in cooperating investigators/ agencies as well as changes in procedures.
- Unexpected or otherwise significant adverse events in the course of this study which may affect the risks and benefits to participation will be reported to the IRB.
- The research will not be initiated and subjects cannot be recruited until <u>final written approval</u> is granted.

The following signatures are required for new project submissions:

- · Principal Investigator
- · Research Advisor(s)
- · IRB Liaison (click here for list)

INSTRUCTIONS TO RESEARCHERS

[top]

Now that you have completed this document, check your work, attach all appropriate documents, electronically sign and submit your work. Based on your responses, the following additional documentation must be included with this package before submission. Upload additional documentation in the Designer.

Documents available in the IRBNet Forms and Templates Library:

No additional documents from the Library are required for this project.

Additional required documentation:

- · Parental Consent Form
- · Request for Consent Waiver

If you have any questions, please refer to the guidelines in the IRBNet Forms and Templates Library or contact irb@umd.edu.

UNIVERSITY OF MARYLAND COLLEGE PARK

Institutional Review Board: Initial Application Part 2

1. Abstract:

The health of young adults with disabilities (YAD) is impacted by functional limitations resulting from physical, mental or emotional impairments. Overall, YAD have poorer health status compared to peers without disabilities. This health disparity may result from confluences of environmental and personal factors linking behaviors and health, where less is known about how multi-level factors determine their health status. The objective of the proposed study is to investigate the collective roles of risk factors at intrapersonal, interpersonal and community levels within the social ecological framework on the health status of YAD. Using nationally representative longitudinal data from the US Department of Education National Longitudinal Transition Study (NLTS2), the dissertation proposal will address the following three specific aims through secondary data analysis: Specific Aim 1 – To examine the trend of health status of YAD in the US; Specific Aim 2 – To investigate the association between the interpersonal network of parents, teachers, and peers and the health status of YAD; and Specific Aim 3 – To study the associations of community level factors of school, neighborhood, and geography leading to differential health status for YAD. The results will inform policymakers and public health practitioners on how to develop efficacious, timely, and cost-effective health promotion interventions for YAD.

2. Subject Selection:

a. Recruitment: The samples for NLTS2 were constructed from a stratified random sample of Local Education Agencies (LEAs) that was selected from the universe of operating LEAs that served students receiving special education in at least one grade from 7th through 12th grades in the 1999-2000 school years. These LEAs and all state-supported special schools that served primarily students with hearing and vision impairments and multiple disabilities were invited to participate in the study. NLTS2 study administrators set targets of recruiting 497 participating LEAs and 12,000 students. The roster of all students receiving special education from each participating LEA and special school was stratified by disability and age. Students then were selected randomly from each disability category and age group. A total of 11,276 students were selected and eligible to participate in the NLTS2 parent interview/surveys.

NLTS2 administrators sent letters to parents of youth in each to notify them that their child had been selected for study participation and that an interviewer would attempt to contact them by telephone. The letters for both studies included a toll-free telephone number for parents to call to be interviewed if they did not have a telephone number where they could be reached reliably or if they wanted to make an appointment for the interview at a specific time.

- **Eligibility criteria:** The eligibility criteria for students to participate in this study included those receiving special education and those between the ages of 13 to 16 years old in 2000. The NLTS2 used a two stage process to generate the needed sample of students. First, the NLTS2 sample was generated by randomly selecting students receiving special education from rosters of local education agencies (LEAs) as the primary sampling unit (PSU) and state supported schools that served students of the appropriate ages in special education. Second, the universe of eligible LEAs and special school was stratified by socio-demographic factors of the students as the secondary sampling unit, which took into account factors such as geographic region, district enrollment and district and community wealth to enhance national representativeness. Subjects in our study included YAD, parents/guardians, teachers and principals who participated in phone interviews and/or completed mail surveys during the data collection period. The four surveys from NLTS2 that will be analyzed for our study are as follows:1) parent survey, 2) youth survey, 3) school characteristic survey, and 4) teacher survey. Only YAD whose households included an adult member who spoke English or Spanish were included in NLTS2 interviews
- c. Rationale: We propose to use the social ecological model to identity risk and protective factors associated with positive health status of YAD at the intrapersonal, interpersonal, and community level with the assumptions that health behaviors are fostered based upon our beliefs, understandings and theories of the determinants of behavior. The social ecological model integrates individual, interpersonal, and environmental determinants of behaviors to better explain the dynamic nature of health status of YAD. The data from the four surveys from NLTS2 will provide data to carry out the secondary data analysis using the social ecological model.
- d. Enrollment numbers: Not applicable in secondary data analysis project

3. Procedures:

Our study will conduct a secondary data analysis using NLTS2. We will use the mixed effects multinomial logistic regression model to examine the association between YAD self-reported health status and multi-level factors within the social ecological model at the intrapersonal, interpersonal and community level. The four surveys within the NLTS2 from which we will extract data points are as follows:1) parent survey, 2) youth survey, 3) school characteristic survey, and 4) teacher survey.

4. Risks:

a. Recruitment: The samples for NLTS2 were constructed from a stratified random sample of Local Education Agencies (LEAs) that was selected from the universe of operating LEAs that served students receiving special education in at least one grade from 7th through 12th grades in the 1999-2000 school years. These LEAs and all state-supported special schools that served primarily students with hearing and vision impairments and multiple disabilities were invited to participate in the study. NLTS2 study administrators set targets of recruiting 497 participating LEAs and 12,000 students. The roster of all students receiving special education from each participating LEA and special school was stratified by disability and age.

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- b. Eligibility Criteria: The eligibility criteria for students to participate in this study included those receiving special education and those between the ages of 13 to 16 years old in 2000. The NLTS2 used a two stage process to generate the needed sample of students. First, the NLTS2 sample was generated by randomly selecting students receiving special education from rosters of local education agencies (LEAs) as the primary sampling unit (PSU) and state supported schools that served students of the appropriate ages in special education. Second, the universe of eligible LEAs and special school was stratified by socio-demographic factors of the students as the secondary sampling unit, which took into account factors such as geographic region, district enrollment and district and community wealth to enhance national representativeness. Subjects in our study included YAD, parents/guardians, teachers and principals who participated in phone interviews and/or completed mail surveys during the data collection period. The four surveys from NLTS2 that will be analyzed for our study are as follows:1) parent survey, 2) vouth survey, 3) school characteristic survey, and 4) teacher survey. Only YAD whose households included an adult member who spoke English or Spanish were included in NLTS2 interviews.
- c. Rationale: We propose to use the social ecological model to identity risk and protective factors associated with positive health status of YAD at the intrapersonal, interpersonal, and community level with the assumptions that health behaviors are fostered based upon our beliefs, understandings and theories of the determinants of behavior. The social ecological model integrates individual, interpersonal, and environmental determinants of behaviors to better explain the dynamic nature of health status of YAD. The data from the four surveys from NLTS2 will provide data to carry out the secondary data analysis using the social ecological model.
- d. Enrollment Numbers: Not applicable in secondary data analysis project. The data set from the US Department of Education does not include personal identifying information (e.g. names and addresses). Hence, there are minimal risks for subjects. All data will be stored in a password protected computer. In addition, all data will be summarized and reported in aggregate form.

5. Benefits:

There are no direct benefits to participants. Advancing the knowledge of risk factors for positive health status for YAD in the social ecological framework by using NLTS2 data will improve the understanding of the health disparities experienced by YAD. Furthermore, the results will inform policymakers and public health practitioners on how to develop efficacious, timely, and cost-effective health promotion interventions for YAD.

6. Confidentiality:

All data will be summarized and reported in aggregate form. The NLTS2 data set does not include personal identifying information (e.g. names and addresses). NLTS2 is a restricted-use data. The investigators will follow the procedures delineated by the National Center on Education Statistics (NCES), Institute of Education Sciences (IES), at the US Department of Education. The investigators will submit the following documents to IES/NCES:

- 1. Online Formal Request through the NCES electronic application system
- 2. Signed License document
- 3. Affidavits of Nondisclosure
- 4. Security Plan Form.

The investigators will follow the security requirements stipulated by IES/NCES for storage and access of the data that include the following:

- 1. Restrict key access to secure project office to license users only
- 2. Use data at licensed project office site only
- 3. Limit data access only to users with an affidavit on file with IES
- 4. Permit read-only access to data only
- 5. Permit users to access only data listed on their own affidavit

Upon completion of the study, the investigators will return original data to IES.

7. Consent Process:

The investigators are requesting a waiver of consent as the research involves no more than minimal risk to the subjects. In our study, the investigators seek to conduct a secondary data analysis using data from the NLTS2. The data set does not contain personal identifying information such as name, address, telephone number, social security number, identification number, medical record number, license number, photographs, voice recording, and biometric information. Hence, there are minimal risks for subjects. In addition, the data analysis will summarized and reported all research findings in aggregate form.

8. Conflict of Interest:

None

9. HIPAA Compliance:

N/A

10. Research Outside of the United States:

N/A

11. Research Involving Prisoners:

N/A

12. SUPPORTING DOCUMENTS

Your Initial Application must include a **completed Initial Application Part 1 (On-Line Document)**, the information required in items 1-11 above, and all relevant supporting documents including: consent forms, letters sent to recruit participants, questionnaires completed by participants, and any other material that will be presented, viewed or read to human subject participants.

For funded research, a copy of the Awarded Grant Application (minus the budgetary information) must be uploaded. If the Grant has not been awarded at the time of submission of this Initial Application, a statement must be added to the Abstract Section stating that an Addendum will be submitted to include the Grant Application once it has been awarded.

THE IRB OFFICE WILL NO LONGER STAMP CONSENT FORMS. THE CONSENT FORMS IN YOUR APPROVED <u>IRBNET PACKET</u> MUST BE USED. THESE ARE YOUR APPROVED CONSENT FORMS.

Bibliography

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