SOCIAL CAPITAL AND DEVELOPMENTAL DISABILITIES: INTERDEPENDENCE TO PROMOTE HEALTH

by

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ABSTRACT

JESSICA N. HOYLE. Social Capital and Developmental Disabilities: Interdependence to Promote Health. (Under the direction of DR. JAN WARREN-FINDLOW and DR. SARAH LADITKA)

Approximately one quarter of American adults have at least one disability that influences their ability to participate in activities of daily life. Individuals with disabilities beginning in childhood may experience reduced social opportunities as they age. Social capital, the resources exchanged among individuals through their relationships with each other, is a key component to understanding how people experience the world around them. This dissertation describes the findings from three studies examining the research question: "how do people with developmental disabilities experience social capital from childhood to young adulthood?"

The first study follows Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) standards for a scoping literature review to investigate the ways social capital is currently conceptualized and applied to developmental disability research from childhood to emerging adulthood (ages 5-29 years). Results describe how social capital is defined, measured and applied to disability research and identify gaps in the literature. This study addresses the gap in our knowledge caused by the dispersion of social capital and developmental disability literatures across many disciplines. This review also identifies measurements and proxies for social capital in extant literature, informing the conceptualization and application of social capital in my other two dissertation studies. Results help us understand the current knowledge of social capital for people with developmental disabilities and areas in need of further research.

The second study describes results of an analysis of extracurricular participation rates between children with and without DD and the associations of childhood-adolescent extracurricular participation with mental health outcomes in young adulthood. Results show differences in the rates of extracurricular activity participation between children with and without developmental disabilities. Results also show that extracurricular activity is associated with lower psychological distress and higher levels of flourishing among individuals with and without developmental disabilities.

The third study addresses, “for young adults with intellectual and developmental disabilities, what does it mean to be interdependent?” Using photovoice methods, college students with intellectual and developmental disabilities described their experience of interdependence with their photos and stories. Participants described their openness to being helped, the role of their families in forming and maintaining interdependence, the role of others as they do new and challenging things, and the perceived vulnerability associated with helping others.

Taken as a whole, these studies extend our understanding of the role of social capital in the lives of people with disabilities by: mapping the current definition, measurement, and application of social capital in the developmental disability literature; using a nationally representative, longitudinal dataset including people with and without developmental disabilities to highlight a population that is often hidden in nationally representative data; and including the voices of people with intellectual and developmental disabilities describing their lived experience of interdependence.

Recognizing the role of social capital in the lives of individuals with developmental disabilities helps to identify needed policies and supports that may enhance the overall quality of life for individuals with developmental disabilities throughout their lives. This research serves as a stepping stone toward a more inclusive and supportive society for individuals with developmental disabilities, highlighting their agency and contributions in developing social capital and fostering interdependent relationships.

Keywords: Developmental Disability; Intellectual Disability; Social Capital; Interdependence; Childhood; Adolescence; Young Adulthood; Emerging Adulthood

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DEDICATION

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"Here's another way to put it: You're here to be light, bringing out the God-colors in the world. God is not a secret to be kept. We're going public with this, as public as a city on a hill. If I make you light-bearers, you don't think I'm going to hide you under a bucket, do you? I'm putting you on a light stand. Now that I've put you there on a hilltop, on a light stand—shine! Keep open house; be generous with your lives. By opening up to others, you'll prompt people to open up with God, this generous Father in heaven."

Matthew 5:16 (MSG)

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CHAPTER 1: INTRODUCTION

Approximately one quarter of American adults have at least one disability that influences their ability to participate in activities of daily life (Okoro et al., 2018). Some disabilities originate in childhood and are lifelong while others are acquired due to injury or disease after the person reaches adulthood. Children with disabilities may have fewer social opportunities than those without disabilities due to marginalization associated with special education, differences in communication or social behaviors, or exclusion from common childhood activities and experiences (e.g., sports, clubs, etc.). Children with lifelong disabilities may experience reduced social opportunities as they age and may experience effects in other areas of their lives.

1. Definitions

1.1 Developmental disability

Disabilities beginning in childhood and lasting throughout life are developmental disabilities (Developmental Disabilities Assistance and Bill of Rights Act 2000). Developmental disability is an umbrella term encompassing a variety of diagnoses and a range of needs and abilities. Developmental disability diagnoses include intellectual disability, autism spectrum disorder, attention deficit/hyperactivity disorder (ADHD), learning disability, cerebral palsy, problem hearing or seeing, speech or language disorder, seizure disorder, and developmental delay (Zablotsky et al., 2019). Although personal experiences differ, individuals whose disabilities begin in the developmental period (prior to age 22) share the unique experience of advancing through most life stages with a disability.

Researchers, policy makers, and service providers use different understandings of developmental disability, depending on the purpose of their work. This difference in definition can affect prevalence estimates. For example, as many as 18% of American children have a developmental disability based on diagnosis alone (Zablotsky et al., 2019); this figure is reduced to approximately 8-10% when the definition requires evidence of lifelong impact (Hoyle et al., 2020; J. Laditka et al., 2022). Estimates of developmental disability prevalence in adulthood are limited due to surveillance challenges and lack of data (Anderson et al., 2019).

1.2 Intellectual disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD, 2021), intellectual disability is a developmental disability characterized by "significant limitations in both intellectual functioning and adaptive behavior," beginning before age 22 years. Intellectual functioning includes the abilities to learn, reason, and solve problems, and is often measured by intelligence quotient (IQ). Adaptive behaviors include conceptual skills (e.g., language and literacy, number concepts and self-direction), social skills (e.g., interpersonal skills, self-esteem, social problem solving) and practical skills (e.g., occupational skills and activities of daily living such as bathing or walking) (AAIDD, 2021). An estimated 1-2% of American children have an intellectual disability (Anderson et al., 2019).

1.3 Social capital

Social capital, the resources exchanged among individuals through the relationships they have with each other, is a key component to understanding how people experience the world around them. I take a network approach to understanding social capital, consistent with the work of Bourdieu (1986) and Lin (1999, 2001). This approach considers how individuals access resources from and contribute resources to their social networks. An individual's social capital is dependent on the size, density, and composition of their social network. An individual's ability to access their social capital resources is dependent on their location within the network, their knowledge of the resources, and their capability to request or obtain the resources they need (Bourdieu, 1986; Lin, 1999). Social capital also refers to the total value of people's relationships with each other.

2. Historical perspective

A historical context is useful to understand the social structures currently experienced by people with developmental disabilities. The provision of care for people with developmental disabilities in the United States changed dramatically in the 20th century. In the early to mid-20th century, medical professionals commonly advised parents to place children with disabilities in institutions. Many of these facilities were over capacity and understaffed, with little oversight; these characteristics resulted in widespread abuse and mistreatment (Wehmeyer, 2003). As a result of the American eugenics movement, more than 50,000 Americans in 33 states were labeled "inferior" due to disability, intellectual performance, mental illness, or criminal behavior and were sterilized without consent (Wehmeyer, 2003). For generations, many people with developmental disabilities lived away from the general population and had few to no civil rights.

Individuals with and without developmental disabilities began to advocate for civil rights in the mid-1960s. This movement led to many positive changes in social acceptance for and treatment of individuals with developmental disabilities and landmark legislation that would influence the lives of millions of Americans (e.g., Rehabilitation Act of 1973, Developmental Disabilities Assistance and Bill of Rights Act of 2000, and Individuals with Disabilities Education Act; Krahn & Bersani, 2016).

Since the early 2000s, national and international governing bodies have noted and addressed the human rights of individuals with disabilities. In 2005, The US Surgeon General released a “Call to Action to Improve the Health and Wellness of Persons with Disabilities” (United States Department of Health and Human Services; USDHHS, 2005), bringing attention to health and wellness challenges faced by people with disabilities. The Call to Action established goals related to public awareness, knowledge of health care providers and dignity, empowerment, accessibility, and independence for people with disabilities.

In 2006, The United Nations’ Convention on the Rights of Persons with Disabilities (United Nations General Assembly; UNGA, 2006) called for the recognition of individuals with disabilities as people with autonomy and the right to make decisions. The Convention promoted the expectation that individuals with disability should receive the highest available standard of healthcare, including care for medical needs resulting from disability, without discrimination and with “free and informed consent”. Nations are responsible for providing accessible health programming within one’s community (UNGA, 2006). Healthy People 2030 identifies objectives related to the education, mental health, preventive care, and health surveillance of people with disabilities as well as the mental health of their family caregivers (Office of Disease Prevention and Health Promotion, n.d.).

3. Models of disability

Two prevailing models of disability, the individual model and the social model, reflect the history of disability rights in the United States. In the 20th century, a notable shift occurred as we transitioned from a belief that disability is purely medical in nature to a greater understanding of the social determinants that influence health of people with disabilities.

3.1 Individual model of disability

Sometimes referred to as the medical model, the individual model of disability views disability as a “problem” in need of solution. From that perspective, individuals with disabilities are considered “other” and outside of the “norm.” Individuals are diagnosed by professionals. Therapies, treatments, and other services are designed to treat individual issues (Oliver, 1996). Within the individual model, professionals are considered experts responsible for providing care for people with disabilities (Oliver, 1996). This paternalistic approach has long been the pervasive model for viewing developmental and other disabilities. As a social construct, researchers use the label or diagnosis of disability to identify individuals with a variety of health conditions or functional limitations who experience a common set of social, psychological, or health effects. Physical, mental, medical, social, or sensory needs can contribute to an individual’s disability status (USDHHS, 2005). The ultimate aim of the individual model is to “normalize” the *person* as much as possible (Oliver, 1996). Thus, the individual model seeks to fit people within a certain mold of social acceptability.

3.2 Social model of disability

In contrast, the social model of disability suggests that disability is socially constructed to describe a lack of fit between the person and the environment. This lack of fit leads to “inclusion, exclusion, and discrimination” (Halfon et al., 2012, p. 16). The social model recognizes the lived experiences of people with disabilities and the social, physical, intellectual, and institutional barriers that most often preclude people with disabilities from full participation as community members and decision makers (Oliver, 1996). Advocates of the social model believe that people with disabilities should be accepted as they are and not forced to conform to social standards (Oliver, 1996).

The social model of disability calls for changes in the built environment and social structure to meet the needs of people with disabilities. Legislation like the Americans with Disabilities Act (ADA) of 1990 established expectations of nondiscrimination of people with disabilities in public spaces and public services, and provided standards enforceable by the federal government (ADA, 1990). Preventing discrimination does not ensure accessibility, or how easy something is to acquire, obtain, access, use, or understand. The ADA brought an initial national awareness to the accessibility needs of people with disabilities. However, many places, activities, and environments continue to be inaccessible to people with the broad spectrum of disabilities. The burden is typically on people with disabilities to advocate for access. Proponents of the social model of disability assert there is more work to do to remove barriers and increase inclusion of people with disabilities.

I subscribe to the social model of disability as a philosophical model used to guide the view of disability within my dissertation research. I recognize that individuals with developmental disabilities may have individual needs that can be addressed through targeted treatments and therapies. However, in many cases, barriers imposed by others contribute to the historical and contemporary disparities people with developmental disabilities experience. One way to remove social and physical barriers is through universal design.

4. Universal design

Universal design is “the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Connell et al., 1997). Though initially used to describe the built environment, elements of universal design may be used to increase participation of people with disabilities in research (Rios et al., 2016). Conducting research with universal design in mind may include strategies such as reading materials in large, sans serif fonts on a white background, including closed captioning, or ensuring all meeting spaces are near accessible transportation. Researchers can also ensure the research design is flexible enough to allow for accommodations such as assisted or alternative communication. I employ principles of universal design (Rios et al., 2016) in the design of the photovoice study (e.g., providing study materials in plain language, use of captions and technologies to increase accessibility; see Chapter 4 for more details).

5. Disparities

5.1 Health disparities

Although we have made great strides in increasing inclusion, recognizing the mistreatment of people with developmental disabilities in the last century and addressing the current needs of people with developmental disabilities, much work remains to address the challenges facing many people with developmental disabilities. People with developmental disabilities experience preventable health conditions at rates higher than those of people without developmental disabilities (Havercamp et al., 2004; Hoyle et al., 2020; Krahn et al., 2006; Li et al., 2018; Lunsky et al., 2011; Ouellette-Kuntz, 2005). Krahn and colleagues (2006) describe a "cascade of disparities" in which individuals with developmental disabilities have an increased risk of associated, comorbid, and secondary health conditions. "Associated conditions" are medical conditions that contribute to the developmental disability (e.g., Down syndrome, cerebral palsy). "Comorbid conditions" occur alongside the developmental disability but have a separate pathology (e.g., cancer, hypertension). "Secondary conditions" are potentially preventable conditions occurring at generally higher rates in individuals with developmental disabilities compared to the general population (e.g., obesity, complications of diabetes, decubitus ulcers, depression) (Havercamp et al., 2004; Hoyle et al., 2020; Krahn et al., 2006; Li et al., 2018; Lunsky et al., 2011; Ouellette-Kuntz, 2005).

Adults with intellectual and developmental disabilities have significantly higher rates of obesity (39.2%; 95% confidence interval [CI] 28.6-39.9), diabetes (9.1%; CI 2.6-15.6), hypertension (18.0%; CI 8.7-12.1), and smoking (30.8%; CI 21.9-39.7) compared to those without these disabilities (respectively 23.4%, CI 20.9-26.0; 2.1%, CI 1.4-2.8; 10.4%, CI 8.7-12.1; 12.8%, CI 11.4-14.3) (Hoyle et al., 2020). People with intellectual and developmental disabilities report ever having had fair or poor health, or ever having had fair or poor mental health, at six times the rate of people without developmental disabilities (Li, et al., 2018).

Inadequate primary health care, preventive care, health promotion, treatment, and overall access to health care compound the effects of these conditions in people with developmental disabilities. Approximately 60% of adults with intellectual disabilities have at least some communication difficulty (Smith et al., 2020). Communication difficulties and cognitive impairments may increase challenges in recognizing and communicating with care providers and understanding and following recommendations of health care and social service providers (Ward et al., 2010). Sedentary behavior, poor diet, lack of access to care, medication side effects, and inadequate access to emotional support contribute to the development of avoidable chronic health conditions, with greater impact on individuals with developmental disabilities (Havercamp et al., 2004; Hoyle et al., 2020; Krahn et al., 2006; Ouellette-Kuntz, 2005). People with developmental disabilities who belong to minority ethnic or racial groups have less access to health care services and experience greater health disparities compared to white individuals with developmental disabilities (Scott & Havercamp, 2014).

People with developmental disabilities are much more likely than those without disabilities to be diagnosed with a mental health condition (Hoyle et al., 2020; Hughes-McCormack et al., 2017; Lunsky et al., 2019). Correctly detecting and diagnosing mental illness in individuals with developmental disabilities can be difficult due to the reliance in most diagnosis protocols on verbal communication (Paschos & Bouras, 2007). The higher prevalence of mental illness among people with developmental disabilities results in more use of psychotropic medications, which have been historically linked to overuse associated with efforts to control behaviors (Paschos & Bouras, 2007).

Individuals with lifelong developmental disabilities may need assistance from caregivers throughout their lives (Hoyle et al., 2021; Laditka et al., 2021). This assistance is often provided by unpaid family members. Family caregivers of people with disabilities can experience increased stress and mental and physical health disparities, as well (e.g., Hoyle et al., 2021; Seltzer et al, 2011). Mothers of children with disabilities ages 13-17 have 84% (odds ratio [OR] 1.84; CI 1.58-2.15) higher odds of developing anxiety or depression compared to mothers of children without disabilities; among mothers of children with developmental disabilities living in their own homes, the odds of developing anxiety or depression are 189% (CI 2.33-3.59) higher (Hoyle et al., 2021). Fathers of children with developmental disabilities and challenging behaviors had more than seven times larger odds (OR 7.18, CI 5.37-9.61) of developing psychological distress compared to parents of children without developmental disabilities (Hoyle et al., 2021).

The life expectancy of people with developmental disabilities has steadily increased since the beginning of the twentieth century, consistent with trends in the general population (Emerson et al., 2014). In the 1930s, most individuals with what we would now call intellectual and developmental disabilities were not expected to live into their 20s (Braddock, 1999). The estimated life expectancy of individuals with intellectual and developmental disabilities is now 40-62 years, depending on diagnosis and other conditions (Stevens, 2019). Many people with developmental disabilities now outlive their parents (primary caregivers), a shift from the early-mid twentieth century. Therefore, the service needs of people with developmental disabilities are compounded as parents are caring for children with developmental disabilities at older ages. In some cases, siblings without disabilities are responsible for the care of both aging parents and siblings with developmental disabilities. Although overall life expectancy has increased, individuals with developmental disabilities continue to live shorter lives and are more dependent on others throughout their lives compared to people without developmental disabilities (Balogh et al., 2016; Coppus, 2013; Laditka et al., 2021). Planning future care of people with developmental disabilities presents a challenge to families and is complicated by a variety of factors including individual needs, smaller family sizes, community accessibility and resources, and financial resources (Lee & Burke, 2020).

The cost of care for individuals with developmental disability varies notably among persons, based on specific disability and severity. The financial burden of caring for a child with special health care needs varies by state and disproportionately affects families with low incomes (Shattuck & Parish, 2008). In 2013-2015, the cost of intellectual and developmental disability services in the United States totaled $65.21 billion (Braddock et al., 2017). It is difficult to estimate the true financial impact of developmental disabilities due to variation in definition and use of terms. Researchers caution that actual costs may be more than reported due to inadequate access to care, unpaid care provided by family members, and the exclusion of supportive and residential care expenses from cost estimates (Fujiura, Li, & Magaña, 2018).

5.2 Social Disparities

Educationally, people with developmental disabilities are less likely than people without disabilities to earn a high school diploma or General Equivalency Diploma and much less likely to attend a four-year college or university (Hoyle et al., 2020; Lipscomb, et al., 2017; Newman, et al., 2011). Of adults with intellectual and developmental disabilities surveyed in 2015-2016, only 19% reported having a job in the community (National Core Indicators, 2019). Despite policies requiring transition planning for adolescents (e.g., Individuals with Disabilities Education Act; IDEA, 1997) and workplace accommodations for people with intellectual and developmental disabilities (Public Law 106-402), people with developmental disabilities earn more than $10,000 per year less than others (Hoyle et al., 2020; Queirós et al., 2015). Individuals with developmental disabilities are also more likely to report physical or sexual assault (Harrell, 2017) and criminal arrest compared to others without developmental disability (Hoyle et al., 2020).

Compared to people without developmental disabilities, a smaller percentage of people with developmental disabilities live on their own. Approximately 60% of Americans with developmental disabilities lived with a family member, 23% lived in a group setting, 12% lived in their own home, and 5% lived with a foster family in 2017 (Larson et al., 2020). The living situation of individuals with developmental disabilities (e.g., institutions, community-based group residence, independent home or apartment, or parent/relative home) affects access to annual health exams and preventive care (e.g., screenings and vaccinations) (Bershadsky, et al., 2012; Scott & Havercamp, 2014). Individuals with developmental disabilities living in the home of a parent or other relative had the least consistent preventive care, while individuals living in institutional settings received the most consistent care (Bershadsky, et al., 2012). Living situation disproportionately affects individuals in minority and racial ethnic groups; for example, among people with intellectual disability (ID), those who are racial or ethnic minorities are more likely to live in the home of a parent or other relative than white individuals (Scott & Havercamp, 2014).

6. Theoretical Foundations

6.1 Life course perspective

I will focus on understanding how people with developmental disabilities experience social capital using the life course perspective (Alwin, 2012; Elder, 1998). The life course perspective aims to understand an individual's development throughout their lives and recognizes that experiences, events, and other people can influence an individual's life trajectory (Elder, 1998). Developmental disabilities are unique compared to disabilities acquired later in life as individuals with developmental disabilities often experience a lifetime of disability and adaptation. Individuals with developmental disabilities are a diverse group of people with a wide range of abilities and needs. Despite these differences, many people with developmental disabilities share experiences that would be unfamiliar to most people who do not have developmental disability (e.g., participation in special education).

Individuals with developmental disabilities often receive special education services and may have distinctly different developmental opportunities compared to those without disabilities. Federal legislation (IDEA, 1997; Rehabilitation Act of 1973) provides for free and appropriate education for all students, including those with disabilities. Students receiving special education services may have individualized instruction either with or apart from students without disabilities. Students receiving special education have an educational team consisting of the student, their parents or guardians, educators, therapists and other individuals deemed necessary for the student's educational success. The educational team is responsible for setting goals for the student and tracking their progress toward those goals. A student can transition out of special education if their educational team determines the services are no longer educationally necessary (IDEA, 1997). With the educational team, students who remain in special education develop a transition plan to aid in their transition to the community after they complete or age out of school (IDEA, 1997).

In this dissertation research, I focus on the period of life from childhood to the transition to adulthood (ages 5-29 years old). This period of life is critical to an individual's development and life trajectory (Elder, 1998). As people move from childhood into adulthood, they typically move from dependent roles into more independent ones influenced by social institutions such as education (student), employment (employee) and marriage (spouse) (Bardo & Vowels, 2021). However, people with developmental disabilities are more likely to remain in dependent roles in young adulthood compared to people without disabilities (Giesbers et al., 2020a,b; Walmsley, 1993).

Having a disability in childhood can substantially impact key elements of the transition to adulthood (e.g., education, employment, income, independent living, social and family status) (Janus, 2009; Bardo & Vowels, 2021). Disability in childhood is associated with an accumulation of disadvantage over time (Bardo & Vowels, 2021) and may affect individuals as they age into later life and contribute to health disparities (e.g., Havercamp et al., 2004; Hoyle et al., 2020; Krahn et al., 2006; Latham, 2015; Latham-Mintus & Aman, 2019; Laditka, et al., 2022; Li et al., 2018; Lunsky et al., 2011; Ouellette-Kuntz, 2005; West & Kamis, 2022).

6.2 Social capital theory

Humans need relationships with other humans; our health is inextricably linked to our social networks (Holt-Lunstad et al., 2017). Notably, the World Health Organization (WHO) lists “social support networks” as a determinant of health (WHO, 2019). Social networks refer to the connections between individuals. These connections serve a function for individuals in the network and may result in social support (Heany & Israel, 2002). Social support refers to the provision of aid or assistance by the social network with the intention to provide benefit to the recipient (Cohen, 2004). Social support may be instrumental (provision of material aid), informational (provision of advice or guidance), or emotional (provision of empathy, trust, and opportunities for expression of emotions). Social support can increase one’s health and perceived well-being by functioning as a “stress buffer” (Cohen, 2004; Leahy-Warren, 2014). Social support can mitigate the effects of stressors by promoting effective coping strategies and reframing the perceived intensity of the stressor (Cohen, 2004). Social support in its various forms are examples of social capital.

Once associated primarily with finances, Bourdieu (1986) made the case that capital includes all tangible and intangible benefits and that “social capital” describes resources derived from our relationships with other people. A person’s position (e.g., as a student, employee, community leader, supervisor) within their social network or group influences their interactions with others and access to resources within the network (Lin, 2001). Individuals in positions of greater power may have access to more resources. When people access the resources available within their social networks, they benefit through improved health, well-being, safety, and ability to cope (Kawachi & Berkman, 2014; Lin, 2001). Rooted in economics (Fukuyama, 2002), the concept of social capital appears primarily in sociology (Bourdieu, 1986; Gelderblom, 2018; Julien, 2015; Portes, 1998) but has been applied to population health (Ehsan et al., 2019; Kawachi & Berkman, 2014).

Social capital theory focuses on the resources and benefits provided by one's social network (Bourdieu, 1986; Lin, 2001). This theory has foundations in the classical Marxian theory of capital in which capital is the result of a cyclical social exchange of resources among people (Lin, 2001). According to Lin (2001), all people have access to ascribed and acquired resources. Resources an individual is born with (e.g., gender and race) are ascribed resources. Acquired resources include education and employment (Lin, 2001). When individuals within social networks exchange resources, those individuals receive and may accumulate social capital (Lin, 2001). At the microstructure (individual) level, Lin (2001) makes two main assumptions regarding the interactions of people within social networks. The first assumption is that individuals engage in homophily, the interaction of individuals with similar status and position. Homophily results in expressive action (e.g., personal interaction such as sharing one's feelings). The second assumption is that the main driving forces behind social interaction are the maintenance or gain of valued resources. This interaction results in instrumental action (i.e., interaction to achieve a certain goal) (Lin, 2001).

Figure 1.1 depicts how individuals build, access, and use social capital (Lin, 2001). The first block of the model contains variables that are antecedent to the accumulation of social capital. Collective assets are resources accessible to an individual found within a social network. Structural position describes an individual's personal status within the social network. The second block refers to the elements of social capital: accessibility and mobilization of social capital. Each person has a unique set of resources available that they can use in instrumental or expressive action to obtain returns. Instrumental actions result in economic, political, or social returns. Expressive actions result in physical health, mental health, and life satisfaction.

There are three widely recognized types of social capital found in an individual's social network: bonding, bridging, and linking (see Figure 1.2; Neves et al., 2019). We form bonding social capital through personal relationships among people who often share similar characteristics (Neves et al., 2019). These may be familial relationships or relationships formed because of shared interests or proximity. Bonding is often associated with reciprocal relationships, two or more individuals contributing to and benefitting from the relationship (Lin, 1999). We create bridging social capital by linking with people and resources outside our personal social networks (Neves, et al., 2019), allowing us to use our social connections to obtain resources (Kramer & Heller, 2013). Linking social capital extends bridging and connects people with those who have institutional authority or power (Hoyle et al., 2022; Szreter & Woolcock, 2003).

The amount of a person's available social capital, or the resources embedded in an individual's social network (Lin, 1999), depends on the amount of resources each individual in a person's resource network has and contributes. The individual must also contribute resources to their social networks (social capital investment) to maintain and grow their networks and social capital resources (Lin, 1999). This give and take is interdependence.

Individuals with developmental disabilities are likely to have smaller social networks (Clement & Bigby, 2009) and are more likely to have less connected social networks compared to individuals without developmental disabilities (Widmer et al., 2008). The size and fragmentation of and individual's social network may impact their access to social capital. Where people with developmental disabilities live (e.g., in home in the community or a residential facility) also influences their social network configurations and related social capital access (Widmer et al., 2013).

6.3 Convoy Model

The convoy model posits that individuals are surrounded by other people who support them throughout their lives; these relationships vary in closeness, quality, and structure and may change over time based on an individual's needs (Antonucci et al., 2014). The guiding theories of my dissertation research are the life course perspective and social capital. However, there are elements of the convoy model that I will include in the photovoice study (Chapter 4), specifically by using the hierarchical mapping technique (described below). Gerontologists developed the convoy model (Antonucci et al., 2014; Fuller et al., 2020) to represent the way an individual's convoy, or the people surrounding them, influence their well-being, health, and quality of life. Researchers primarily use the convoy model to study older adults, the way their social relationships change over time, and how social relationships contribute to well-being, health, and quality of life (Antonucci et al., 2014; Fuller et al., 2020). In many ways, the convoy model mirrors the concepts of social capital. For example, in the convoy model, an individual's personal characteristics and situational characteristics contribute to the structure and composition of their convoy. Similarly, social capital theory identifies structural position and personal characteristics as concepts influencing social capital resources (Lin, 1999, 2001).

Figure 1.2 overlays the three types of social capital on the hierarchical mapping technique described by Fuller and colleagues (2020) in which respondents use concentric circles to outline the people who are in their convoy. In the hierarchical mapping technique, the center circle represents the individual, the inner circle contains people who are closest to the individual, the middle circle contains people who are important to the individual, and the outer circle contains people with whom the individual has a relationship but are not as close as the people in the first two circles (Fuller et al., 2020). In Figure 1.2, I overlay the concepts of bonding, bridging, and linking social capital onto the hierarchical mapping technique.

7. Problem Statement

In many ways, people with intellectual and developmental disabilities were historically segregated from the greater community and viewed as a group in need of care and protection (Wehmeyer, 2003). As a result of this social segregation, persistent discrimination, and continuing social and environmental barriers, people with developmental disabilities often have smaller social support networks resulting in limited social capital. People with developmental disabilities often require support from others to meet physical, social, or cognitive needs (Thompson, et al., 2009). These supports can be implemented in ways that promote interdependence of people with developmental disabilities instead of dependence (Thompson, et al., 2009).

I theorize that people with developmental disabilities have abilities and assets they can contribute to their communities and social networks. Because of limited social networks and opportunities, people with developmental disabilities are often precluded from sharing their abilities and assets with their networks and communities. Therefore, it is useful to explore the experience of social capital by people with developmental disabilities and the relationship of social capital with the disparities experienced by people with developmental disabilities. Better understanding how people with intellectual and developmental disabilities can contribute resources to, as well as access resources within, their social networks can allow for more effective integration efforts.

7.1 Limitations and Gaps in the Literature

Researchers from many fields have incorporated social capital into their work. We find social capital literature specific to people with developmental disabilities in education, sociology, public health, disability studies, economics, etc. (e.g., Kramer & Heller, 2013; McClimens & Gordon, 2009; Waterfield & Whelan, Widmer et al., 2013). This diversity is beneficial in that each discipline brings a unique viewpoint to the utilization and conceptualization of social capital and its applicability to people with developmental disabilities. Unfortunately, this dispersion of knowledge may limit our ability to integrate perspectives across fields: for example, researchers in education may not be aware of relevant work in public health.

Individuals with developmental disabilities are often excluded or “hidden” in population-level research (Krahn & Havercamp, 2019; Havercamp et al., 2019). Few national surveys include people with developmental disabilities or have adequate information to identify them, leading to incomplete prevalence estimates, and little knowledge about the population as a whole (Anderson et al., 2019). Most studies of people with developmental disabilities based on larger samples use cross-sectional research (e.g., Bershadsky et al., 2012; Fujiura et al., 2018; Havercamp et al., 2004), which does not provide adequate information to allow researchers to assess if a disability begun in childhood has lasting implications for the individual's life. There are many factors to consider when examining outcomes for people with developmental disabilities, and cross-section research only allows us to see a brief moment in someone's life.

Much of developmental disability literature relies on parent or other proxy reports (Scott & Havercamp, 2018). A small, but increasing, proportion of the developmental disability literature includes people with developmental disabilities as primary informants (Beail & Williams, 2014). The reliance on reports from parents or proxies may be caused by inaccessible research methods, institutional review board restrictions, social hesitancy, or concerns about exploitation (Scott & Havercamp, 2018). However, individuals with developmental disabilities have unique experiences, and these may not be accurately represented by proxy reports. We need more research including people with developmental disabilities as primary respondents using research methods that emphasize universal design (Rios et al., 2016).

8. Dissertation Research

In this dissertation, I present three studies examining the research question: "how do people with developmental disabilities experience social capital from childhood to young adulthood?" Each study uses different methods to examine unique aspects of this question.

8.1 Chapter 2: Developmental disability and social capital from childhood to emerging adulthood: A scoping review

Following PRISMA standards (Tricco et al., 2018), I conducted a scoping review of literature to investigate the ways social capital is currently conceptualized and applied to developmental disability research during the period from childhood to the transition to adulthood (ages 5-29 years). I conducted an in-depth search using the online databases PubMed, PsychInfo, Social Services Abstracts, and Educational Resource Information Center (ERIC). I examined literature from all relevant fields to assess how researchers define, measure and apply social capital within developmental disability research.

This review helps us understand the current conceptualization of social capital for people with developmental disabilities. This study addresses the gap in our knowledge caused by the dispersion of the social capital and developmental disability literatures across many disciplines. This review also identifies measurements and proxies for social capital in extant literature, which informed the conceptualization and application of social capital in my other two dissertation studies.

8.2 Chapter 3: Childhood extracurricular involvement and mental health of young adults with developmental disabilities

In Chapter 3, I present the results of a longitudinal analysis of children with and without developmental disabilities. I studied the associations of childhood-adolescent extracurricular participation with mental health outcomes in young adulthood and compared extracurricular participation rates between children with and without developmental disabilities. I used the Panel Study of Income Dynamics (1968-2017), its Child Development Supplement (CDS, 1997, 2002, 2007), and its Transition into

Adulthood Supplement (TAS, every-other year, 2005-2019). Using the TAS, I looked at the relationship of childhood extracurricular involvement with young adult mental health indicators: psychological distress and flourishing. I used the CDS time diaries to identify the amount of time children were involved in extracurricular activities.

8.3 Chapter 4: “Not a one-way street”: Using photovoice to understand how young adults with intellectual and developmental disabilities experience interdependence

I conducted a photovoice study to address the research question, “for young adults with intellectual and developmental disabilities, what does it mean to be interdependent?” This study contributes to the existing literature by helping us better understand the experience of young adults with intellectual disabilities and how they contribute to and benefit from their social networks.

Much of the relevant literature includes information from proxy informants (e.g., parents, teachers). This study amplifies the voice of people with intellectual disabilities as primary respondents. Using photovoice provides participants the opportunity to tell their own story and “show” others how they experience social capital as college students. Listening to the stories of people with intellectual and developmental disabilities helps us understand how they experience interdependence and what they need to increase their access to and use of social capital. Results of this study can inform colleges how to support students with intellectual disabilities in accessing social capital resources and contributing to, or investing in, their social networks.

8.4 Significance

This research is significant in three specific ways. First, the systematic review increases our understanding of social capital for people with developmental disabilities during the critical period from childhood to young adulthood. This study maps the current definition, measurement, and application of social capital within the developmental disability literature and reveals key gaps in the literature.

The secondary analysis of the PSID uses a nationally representative, longitudinal dataset. This dataset includes people with and without developmental disabilities and has measures that allow researchers to identify individuals with developmental disabilities using a definition that is consistent with federal guidelines (e.g., Developmental Disabilities Assistance and Bill of Rights Act of 2000), and uses information collected from individuals with disabilities, their parents, teachers, and others. Using the PSID allows us to shine light on a population that is often hidden in nationally representative data. The longitudinal nature of the PSID allows us to follow individuals throughout the life course. I use this longitudinal data to contribute a better understanding of how people with developmental disabilities experience social capital and its relationship with mental health throughout childhood, adolescence, and young adulthood.

Finally, the photovoice study is significant in that it includes people with developmental disabilities as primary respondents. People with disabilities are often excluded from participating in research. My research gives voice to people with disabilities by providing information from their lived experiences in their own words. The use of photos and intentional incorporation of universal design principles increases the accessibility of the research, providing additional ways for individuals to express themselves.

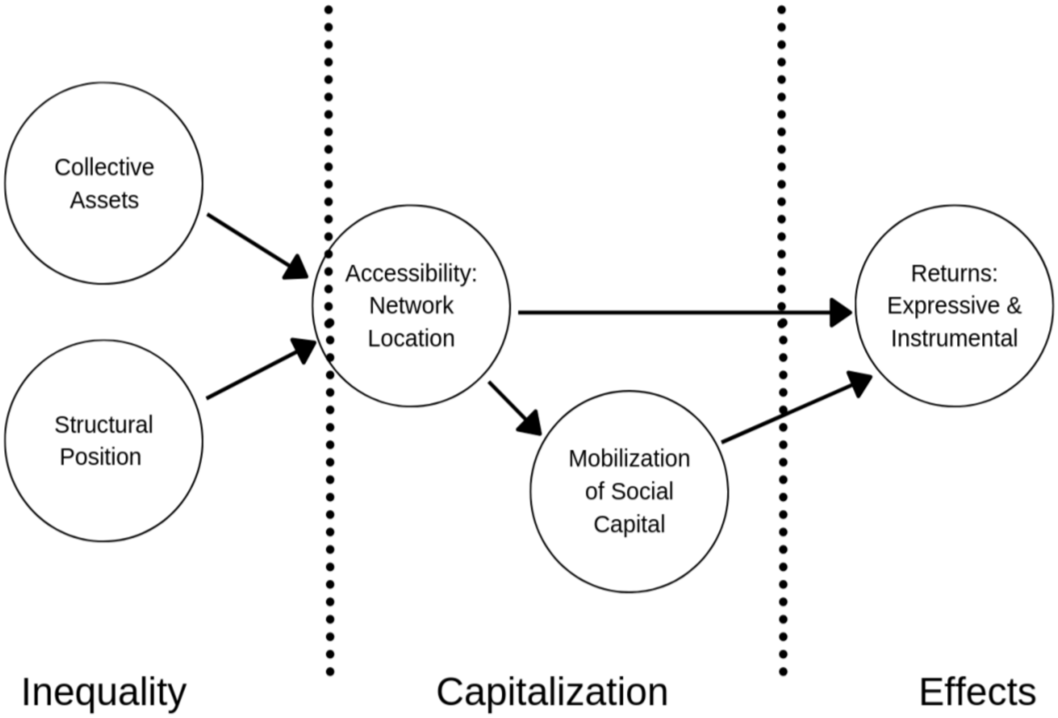
Each of these three studies uses a different methodology to address the question, “how do people with developmental disabilities experience social capital from childhood to young adulthood?" Using multiple methodologies allows me to address gaps in the literature and add useful knowledge to our understanding of this area of research.

9. Researcher Statement

I am a 39-year-old, White, doctoral candidate in public health sciences. I have over a decade of clinical experience working with adults and older adults with a range of intellectual and developmental disabilities. In my work with adults with developmental disabilities, I observed that many had limited social networks. For people requiring lifelong supports, their social networks were limited to the people they lived and worked with. I also have three years' experience as a university instructor teaching students with and without disabilities in a large urban university. As an instructor, I designed my in-person and online courses using principles of universal design for learning (e.g., use of captions for videos and live captions for lectures, contrasting colors for web-based materials) to increase the accessibility of the coursework for all students.

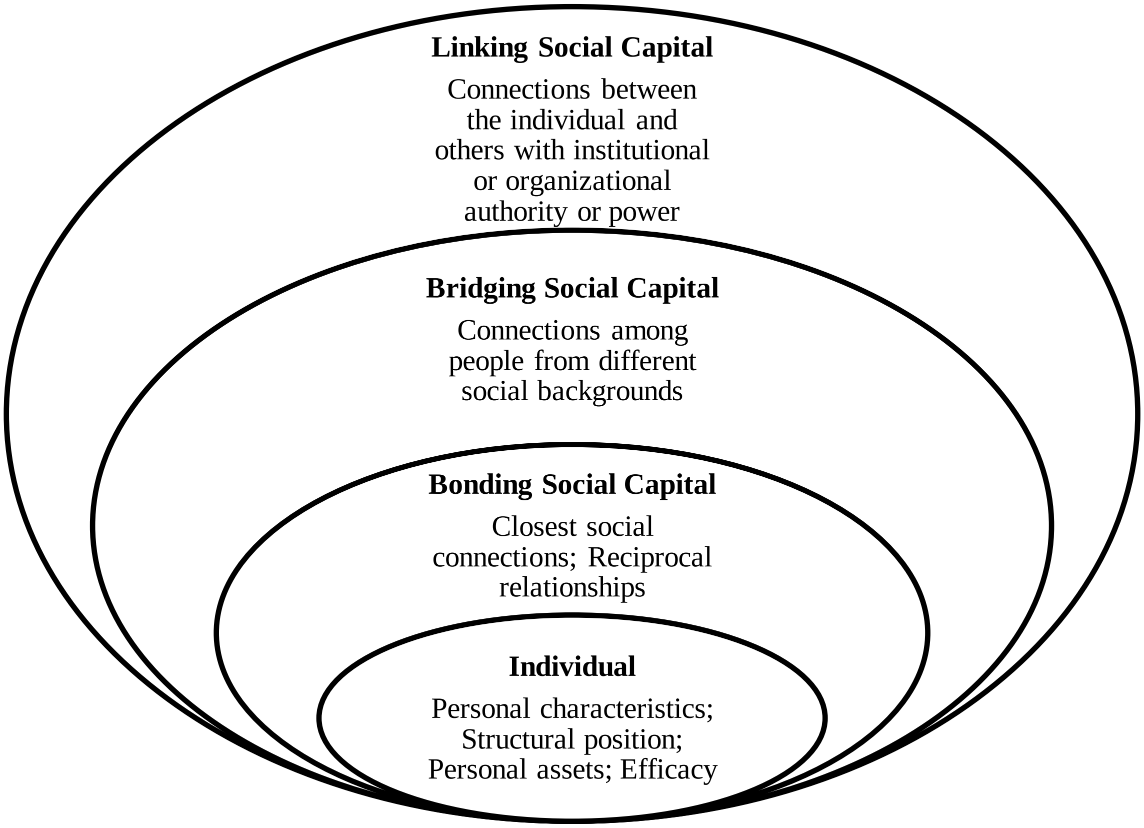
As an educated individual who is well-connected in my community, I see the benefits of the social capital I can access. I have used my social connections, for example to find people to perform needed home repairs, help with school projects, and provide support during difficult times. I am able to do so because of the number of my connections and knowing how to access the resources inherent in them. I want to know how individuals with developmental disabilities experience social capital. That knowledge may contribute to the design of interventions to increase the social capital of people with intellectual and developmental disabilities.

Figure 1.1 Modeling a theory of social capital.



Adapted from: Lin, N. (2001). Social Capital: A Theory of Social Structure and Action. New York: Cambridge University Press.

Figure 1.2. Individual social network in relation to types of social capital



Adapted from: Fuller et al., 2020 and University of Minnesota Extension, 2021

CHAPTER 2: DEVELOPMENTAL DISABILITY AND SOCIAL CAPITAL FROM CHILDHOOD TO EMERGING ADULTHOOD: A SCOPING REVIEW

1. Introduction

Relationships among people are important and closely tied to health (Ehsan, 2019). One benefit of relationships is social capital, resources from connections in our social networks (Bourdieu, 1986; Coleman, 1988; Lin, 1999; Putnam, 2000). Social capital is cumulative; people who begin with more social capital tend to continue accumulating social capital throughout their lives (Volker, 2020).

People with developmental disabilities, disabilities beginning in childhood and lasting throughout life, may have few or limited social connections, thereby limiting their social capital and ability to benefit from knowledge and opportunities that others may take for granted (Giesbers et al., 2020a; Mithen et al, 2015; Presnell & Keesler, 2021). Their social connections are also often shaped or limited by external systems and influences (Hall & Kramer, 2009; Hamilton et al., 2017; Kramer et al., 2013; Riddel et al., 2001a). For example, individuals with developmental disabilities may have difficulty finding employment and may rely on government support. These external factors may limit their access to other people and organizations.

1.1 Developmental Disabilities: Definition and Prevalence

Approximately 18% of American children have a developmental disability diagnosis (Zablotsky et al., 2019). Developmental disability is an umbrella term encompassing a variety of diagnoses and a range of needs and abilities. Developmental disability diagnoses include intellectual disability, autism spectrum disorder, attention deficit/hyperactivity disorder (ADHD), learning disability, cerebral palsy, significant problems hearing or seeing, speech or language disorder, seizure disorder, and developmental delay (Zablotsky et al., 2019). Although personal experiences differ, individuals whose disabilities begin in the developmental period (prior to age 22) share the unique experience of advancing through most life stages with a disability.

Some children with disabilities make developmental gains or acquire coping mechanisms that minimize their need for external supports due to their disability. However, a recent study using the federal definition of the Developmental Disabilities Assistance and Bill of Rights Act (2000) found that about 10% of young adults have a developmental disability requiring lifelong support (Hoyle et al., 2020). The federal definition combines diagnosis with evidence of functional limitation and likelihood of lifelong disability (Developmental Disabilities Assistance and Bill of Rights Act 2000). To meet this definition, individuals must have a “severe chronic disability” that manifests before age 22, is likely to last throughout the individual’s life, and is accompanied by functional limitations in three or more domains (self-care, language, learning, mobility, self-direction, capacity for independent living or economic self-sufficiency) resulting in need for lifelong individualized support (Developmental Disabilities Assistance and Bill of Rights Act 2000).

Estimates of developmental disability prevalence in adulthood are limited due to surveillance challenges and lack of data (Anderson et al., 2019). People with developmental disabilities experience preventable physical, mental, social, and economic disparities (e.g., Erickson & Macmillan, 2018; Hoyle et al., 2020; Krahn et al., 2006). Researchers, policy makers, and service providers use different operational definitions of developmental disability, depending on the purpose of their work.

I studied individuals who had any of the nine disability diagnoses outlined in US developmental disability surveillance literature (listed above; Zablotsky et al., 2019). This approach does not require evidence of lifelong impairment and recognizes that some individuals may develop coping mechanisms or experience changes in symptoms that limit the functional impact of their disability as they age. Substantial percentages of these individuals attend college and can be found in most occupations, although they may nonetheless have difficulty succeeding in traditional adult roles. Others have lifelong disabilities that greatly limit the individual's functional status.

1.2 Childhood to emerging adulthood

Within life course theory, the period from childhood to emerging adulthood is critical to an individual's development and life trajectory (Elder, 1998). The delineation between childhood and adulthood is socially constructed of expected roles and influenced by social institutions such as education, employment and marriage (Bardo & Vowels, 2021). As people age into adulthood, they often leave the care and support of their families and transition into traditional adult roles like student, employee, spouse, or parent. People with developmental disabilities are more likely to remain in dependent roles in young adulthood compared to people without disabilities (Giesbers et al., 2020; Walmsley, 1993).

Having a disability in childhood can substantially impact key elements of the transition to adulthood (e.g., education, employment, income, independent living, social and family status) (Janus, 2009; Bardo & Vowels, 2021). Disability in childhood can result in a "path of cumulative disadvantage" (Bardo & Vowels, 2021) that may affect individuals as they age into later life. Individuals who experience disability in childhood and adolescence are more likely to exhibit lasting disparities throughout their lives: depression (Latham, 2015; West & Kamis, 2022), difficulty recovering from mobility limitations in later life (Latham-Mintus & Aman, 2019), and shorter lives (Laditka, et al., 2022).

Researchers use various age ranges for emerging adulthood, generally 18-25 years (Arnett, 2000; Norona et al., 2015) or 18-29 years (Jensen & Arnett, 2012). For the purpose of this paper, I chose to use the 18-29 year range to be more inclusive of potentially relevant research.

1.3 Social Capital

The social model of disability is built on the notion that people exist, operate in, and are thus a product of their relationships with others (Reindal, 1999). Disability results from a lack of fit between the person and their environment (Halfon et al., 2012).

Social capital, defined as the resources exchanged among individuals through the relationships they have with each other, is a key component to understanding how people experience the world around them. There are several theorists associated with social capital. The works of Bourdieu (1986) and Lin (1999, 2001) take an individual network approach to understanding social capital. The individual network approach considers how individuals access resources from and contribute resources to their social networks. In their view, social capital is property of an individual and comes from individual position and status within the network. Coleman (1988), while recognizing the importance of individual position and status, saw social capital as a both a private and collective resource. While Coleman acknowledged both individual and collective roles in the formation of social capital, Putnam (2000) described social capital as a collective resource built on norms of trust, cohesion and reciprocity within groups of people.

Social capital was initially theorized and discussed as developed and held by adults and subsequently transferred to their children (Bourdieu, 1986; Lin, 1999; Putnam 2000). However, scholars have challenged the notion that building social capital is reserved for adulthood and have explored how social capital operates in childhood and the transition to adulthood, as well (e.g., Leonard, 2005; Bessell, 2017; Stjernqvist et al., 2018). Sociologists have noted that social capital can and does change throughout the life course and can impact an individual's life trajectory (McDonald & Mair, 2010). The presence of multiple conceptualizations of social capital can affect the measurement of social capital, and make it difficult to compare work of authors using different theoretical orientations (Rotenberg et al., 2020; De Silva et al., 2005). For the purpose of this work, I consider both the individual and collective approaches. An individual's social capital is dependent on the size, density, and composition of their social network. An individual's ability to access their social capital resources is dependent on their location within the network, their knowledge of the resources, and their capability to request or obtain the resources (Bourdieu, 1986; Lin, 1999). The amount of a person's available social capital, or the resources embedded in an individual's social network (Lin, 1999), depends on the amount of resources each individual in a person's resource network has and contributes. The individual must also contribute resources to their social networks (social capital investment) to maintain and grow their networks and social capital resources (Lin, 1999). Social capital access may also be dependent on the levels of trust, cohesion, and reciprocity within a social network or community (Coleman, 1988; Putnam, 2000). Social capital refers to the total value of people's relationships with each other.

Types of social capital include bonding, bridging and linking (Neves et al., 2019). People form bonding social capital with others who share similar characteristics (e.g., family or close friends) (Hoyle et al., 2022; Neves et al., 2019; Szreter & Woolcock, 2004). Bonding social capital encourages reciprocity and collaboration and fosters emotional support (Hoyle et al., 2022; Riddel et al., 2001a). Bridging social capital is formed through links outside one's close social network (Hoyle et al., 2022; Lin, 2001; Neves et al., 2019; Szreter & Woolcock, 2004) and can be used to access resources outside the individual's personal connections (Riddel et al., 2001a). Bonding allows people to function in their current situation whereas bridging allows people to move ahead or in a different direction. Linking is an extension of bridging and connects individuals with others who are in a position of power (Szreter & Woolcock, 2004; Widmer et al., 2013). For example, in a college, people in power include faculty members and administrators who can connect students to resources in the campus community (Hoyle et al., 2022).

Social capital is a multidimensional construct. There are no existing measures that capture the full extent of an individual's social capital. Therefore, researchers often measure limited dimensions of social capital. The qualities of individuals' communities, neighborhoods, or other social groupings can influence their access to social capital (Coleman, 1988; Putnam, 2000). For example, an individual living in a community with few public resources is at a disadvantage compared to a similar individual living in a community with plentiful public resources. An individual's available social capital is also affected by their relationships with others and their position within their community (Bourdieu, 1986; Lin, 1999). Social capital has both structural and cognitive dimensions (De Silva, 2005; Uphoff, 1996). Structural dimensions refer to how an individual participates in social relationships (De Silva, 2005; Uphoff, 1996). Cognitive dimensions refer to how people perceive qualities of their social interactions (e.g., trust, reciprocity, feelings of belonging) (De Silva, 2005; Uphoff, 1996).

Social capital is associated with positive physical and mental health outcomes (Ehsan et al., 2019; Mithen et al., 2015). People in an individual's social network may provide emotional, informational, or material resources through a period of poor health, or support healthy behaviors (Bolin et al., 2003). However, others in a social network could also provide health misinformation or promote unhealthy behaviors, which could lead to poorer health outcomes. Higher levels of cognitive dimensions of social capital may decrease the risk of mental illness (De Silva et al., 2005).

1.4 Social Capital, Developmental Disabilities, and the Life Course

How a person develops and accesses their social capital changes throughout their lives. Most people transition from family-centered networks to friend-centered networks as they age into adulthood and begin to establish themselves as individuals (Kramer et al., 2013). This change in network structure means that their social capital shifts from being primarily family-based to resources within their own established social networks, which often extend beyond familial ties.

Individuals with developmental disabilities are likely to have smaller social networks than those without developmental disabilities (Clement & Bigby, 2009; Giesbers et al., 2020; Mithen et al., 2015; Presnell & Keesler, 2021). People with developmental disabilities consistently had lower odds of having access to informal or formal networks and social support compared to people with other types of disability or no disability (Mithen et al., 2015). Where people with intellectual and developmental disabilities live (e.g., in home in the community, a residential facility) influences their social network configurations and access to social capital (Widmer et al., 2013). For some people with intellectual and developmental disabilities, their social networks are mostly comprised of family, paid caregivers, or other people with developmental disabilities. Without successful integration enabling people with developmental disabilities to fully participate in all aspects of community life (e.g., work, leisure, religious practice, etc.), people with developmental disabilities may have less access to community-based social capital.

Emerging adults with developmental disabilities are more likely to have smaller close family-based networks and fewer peer-centered relationships compared to those without disabilities (Giesbers et al., 2020). Families may be an important source of bonding social capital (Kramer et al., 2013). However, some research suggests that strong family ties can inhibit the formation of bridging social capital when families or caregivers try to protect an individual by controlling access to activities associated with developing social capital (Hall & Kramer, 2009; Hamilton et al., 2017; Kramer et al., 2013; Riddell et al., 2001a).

Researchers have conducted reviews of social capital and deaf adolescents (Byatt et al., 2019), people with psychosis (Rotenberg et al., 2020), and people with mental illness (De Silva et al., 2005). However, there are no systematic reviews examining the use of social capital in the literature on developmental disability.

1.5 Purpose of this study

Researchers from many fields incorporate social capital into their work. We find social capital literature specific to people with developmental disabilities in education, sociology, public health, disability studies, and economics (e.g., Kramer et al., 2013; McClimens & Gordon, 2009; Waterfield & Whelan, Widmer et al., 2013). This diversity is beneficial in that each discipline brings a unique viewpoint to the conceptualization and operationalization of social capital and its applicability to people with developmental disabilities. However, the variety of ways that researchers in these fields view social capital may limit our ability to integrate perspectives across fields: for example, researchers in education may not be aware of relevant work in public health. The purpose of this study is to review how social capital is defined, measured and applied to developmental disability literature across disciplines.

This review helps us understand the current conceptualization of social capital for people with developmental, how researchers apply the concept of social capital to developmental disability research and helps to identify opportunities to develop social capital among people with developmental disabilities. This review assesses the definition and measurement of social capital during the critical time from childhood to emerging adulthood. This study identifies gaps in our knowledge caused in part by the variety of ways that researchers in various disciplines view social capital and developmental disability. This knowledge will help researchers further advance our understanding of these topics and identify areas for future research and intervention.

2. Method

I conducted a scoping review following the 5-stage methodological framework developed by Arksey and O’Malley (2005): 1) identify the research question; 2) identify relevant studies; 3) select studies; 4) chart the data; and 5) collate, summarize, and report the results. Scoping reviews are a systematic way of surveying a broad swath of relevant literature within a particular field or topic (Arksey & O’Malley, 2005; Tricco et al., 2018). Scoping reviews allow us to identify similarities and differences among the concepts, theories, and methods used to address a particular topic, help us identify knowledge gaps, and allow us to survey relevant literature using a variety of research designs within a particular field (Arksey & O’Malley, 2005). Scoping reviews do not compare the effectiveness of methodologies or interventions (Arksey & O’Malley, 2005; Tricco et al., 2018).

2.1 Identify the research question

In this study, I address the research question, “How is social capital conceptualized, measured, and applied to developmental disability research from childhood through the transition to adulthood?”

2.2 Identify relevant studies

I conducted an in-depth search using the online databases PubMed, APA PsychInfo, CINAHL Complete, Sociological Abstracts and Educational Resource Information Center (ERIC). I used index terms and key words for all databases. See Appendix A for search strategies and search terms.

I included English-language, peer-reviewed, qualitative and quantitative empirical research articles of people with developmental disabilities ages 5-29 years old, published between January 2000 and February 2022. I did not limit the country of origin. The concept of social capital had to be included and defined or used as a variable. I excluded review articles, commentaries, book chapters, theses, dissertations, and studies of people outside the specified age range, or people described as having general “disabilities.” I excluded articles about people with general “disabilities” to capture the unique experience of people who have a lifelong disability begun in childhood.

I limited the literature to participants with developmental disability ages 5-29 to address the life course stages of childhood through emerging adulthood. I begin at age 5 as this is typically the age a child begins school, and may also start to engage in other activities in which they can develop relationships with others. Developmentally, children at age 5 may also be able to reflect on their own experiences and provide responses to researchers. I closed the age range at the theorized end of the stage known as “emerging adulthood” (ages 18-29 years old; Jensen & Arnett, 2012).

In cases where the age range of participants overlaps my inclusion age range (5-29), I included the study. Some studies included a large range of ages (e.g., Elias & Cook, 2016; 18-82 years old). I determined it was important to explore articles using a large age range and to consider why the authors chose to do so.

I excluded studies that did not include outcomes for individuals with developmental disabilities. This criterion excludes studies that describe parents of children with developmental disabilities but do not include any measures of child outcomes. I included studies that may use parents or others as proxy informants for specific outcomes of individuals with developmental disabilities.

2.3 Select studies

I used EndNote 20 (The Endnote Team, 2013) to collect and manage the search results. I removed duplicate results. I reviewed the titles and abstracts of the search results and removed those that were irrelevant or met exclusion criteria. I then obtained the remaining studies of interest and reviewed the full papers. I included in the review only those studies that met the inclusion criteria.

2.4 Chart the data

Once I identified the final sample, I used tools in NVivo (QSR International Pty Ltd., 2020) to organize the data. I abstracted key information from each study including the definition of social capital, theory and/or theorists identified (if applicable), research methods, sample size, sample characteristics, social capital measurement, unit of analysis, source of data, evidence of intervention, associated concepts, main findings, limitations and recommendations.

2.5 Collate, summarize, and report the results

In response to the research question, I present the following results: descriptive summary and limitations of the included studies, conception of social capital, measurement of social capital, and application of social capital in developmental disability research from childhood to emerging adulthood.

3. Results

3.1 Descriptive information and summary of the studies

The initial search returned 673 results. After removing duplicates and screening article records (e.g., titles, abstracts, citation information), I assessed 281 full-text articles. Of these, 36 met the criteria for inclusion in the study. Through the full-text review, I identified two additional articles from references. Thus, the final sample for this study was 38 articles (see Figure 2.1 for more details). My coauthors and I conducted interrater reliability checks at the screening and eligibility stages. We resolved disagreements through discussion until we reached consensus.

Table 2.1 displays key elements of the studies included. The studies included a total of 8,214 individuals with developmental disabilities described in the studies as intellectual disability; intellectual impairment (used as a proxy for intellectual disability); autism spectrum disorder; deaf and hard of hearing; visual impairment; special educational needs; developmental disorder; learning disability; developmental, physical, cognitive and/or mental health needs; reading difficulties; ADHD; physical disability; Down syndrome; cerebral palsy; and special health care needs. Of the 38 studies, 27 solely focused on outcomes of individuals with developmental disabilities (e.g., Duncan et al., 2021; Emerson & Hatton, 2007; Kvalsund & Bele, 2010). Others included outcomes associated with family members, service providers, and organizations in addition to individuals' outcomes (e.g., Kramer et al., 2013; McConkey et al., 2013; Patterson & Loomis, 2016).

The studies represented work from many countries: United States (n=11, 28.9%); United Kingdom (n=9, 23.7%); Australia (n=4, 10.5%); Canada (n=3, 7.9%); Switzerland (n=2, 5.3%); and one study (2.6%) each for the following: Egypt, Israel, Norway, South Korea. One study (McConkey et al., 2013) employed a multinational approach and included participants from Serbia, Poland, Ukraine, Germany, and Hungary. Only half (n=19) reported participants' race or ethnicity. The studies reporting race or ethnicity were from the United States (n=9), United Kingdom (n=4), the Netherlands (n=4), Australia (n=1), and Norway (n=1).

All but 7 reported gender. Of the 5,765 individuals with developmental disabilities for whom gender was reported, 64% were male, 36% were female. Two studies reported a third gender, represented by only 3 people (Hassrick et al., 2020; Waterfield & Whelan, 2017).

Although the age cut-off for emerging adulthood was 29 years old, 21 studies included ranges that went beyond that age (e.g., Chadwick & Fullwood, 2018; Elias & Cook, 2016; Haider et al., 2014; Kramer et al., 2013; Papasotiriou & Windle, 2012). Five articles did not report participant age ranges; these studies were focused on particular life events or stages (e.g., childhood, adolescence, attending college; Azad et al., 2019; Duncan et al., 2019; Kvalsund & Bele, 2010; Waterfield & Whelan, 2017; Whitney et al., 2012).

Most studies were limited to people formally served by provider organizations or healthcare centers, participants in disability-specific social groups, or included in disability-specific registries. Only four studies used nationally representative samples; three of these were from the United Kingdom (Emerson & Hatton, 2007; Emerson et al., 2016; Emerson et al., 2015; Hock & Ahmedani, 2012), and the fourth was from the United States (Hock & Ahmedani, 2012). Researchers used a wide range of study methods (quantitative n=21, 55.3%; qualitative n=14, 36.8%; mixed method n=3, 7.9%).

The quantitative studies used primarily cross-sectional methods (n=14; e.g., Emerson & Hatton, 2007; Giesbers et al., 2020b; Looman & Farrag, 2009; Widmer et al., 2013). Other study designs included longitudinal (Kvalsund & Bele, 2010), pre- and post-test (Duncan et al., 2019; Duncan et al., 2021), prospective cohort (Wong et al., 2018), matched controls (Giesbers et al., 2020a), and pre-experimental designs (Webber et al., 2019). Qualitative approaches identified in the studies included case study (Baker et al., 2020; Riddel et al., 2001a; Riddel et al., 2001b), grounded theory (Hall & Kramer, 2009; Papasotiriou & Windle, 2012; Waterfield & Whelan, 2017), phenomenological (Shpigelman, 2018), and critical realist (Hamilton et al., 2017).

In more than half of the studies (n=21, 54%), the number of people with developmental disabilities was less than 50 participants (e.g., Chadwick & Fulwood, 2018; Hall & Kramer, 2009; Kramer, et al., 2013; Shpigelman, 2018; Waterfield & Whelan, 2017; Whitney, et al., 2012; Widmer, et al., 2013) or unspecified (Patterson & Loomis, 2016). Looman & Farrag (2009) did not report the number of people with developmental disability represented by their parent sample; however, they reported parent-reported outcomes for their children with developmental disabilities. Analyses of registry and national survey data had larger sample sizes of people with developmental disabilities (299-1430 participants; Azad et al., 2019; Emerson & Hatton, 2007; Emerson et al., 2016; Emerson et al., 2015; Haider, et al., 2014; Hock & Ahmedani, 2012; Kvalsund & Bele, 2010). The qualitative studies had, on average, many fewer participants than the quantitative studies. The incorporation of social capital in developmental disability literature steadily increased since 2000 (years 2000-2005, n=2; 2006-2010, n=5; 2011-2015, n=10; 2016-2011, n=21).

3.2 Concepts and Definitions of Social Capital

Consistent with the inclusion criteria, all studies included a definition of social capital or used the concept as a working variable in the study. Concepts mentioned often in social capital definitions included *social networks, resources, exchange,* and *relationships.* Using these concepts, a common definition of social capital in the studies is *resources and support exchanged by people who have relationships with each other*. The authors most often cited Bourdieu (n=17), Putnam (n=15), Coleman (n=12), and Lin (n=8), when defining and describing social capital; many studies cited multiple social capital theorists (e.g., Duncan et al., 2019; Hassrick et al., 2020; Papasotiriou & Windle, 2012; Patterson & Loomis, 2016; Wong et al., 2018).

Researchers in several of the articles categorized social capital into specific types: bonding, bridging, and linking. Bonding social capital is formed through close ties (Kramer, et al., 2013). The researchers observed these ties most often in familial relationships and close friendships (e.g., Giesbers et al., 2021; Hall & Kramer, 2009; Kramer, et al., 2013; Shpigelman, 2018; Widmer, et al., 2013; Wong et al., 2016). Bridging social capital allows people to use their social connections to obtain resources to which they do not have direct access (Kramer, et al., 2013). Researchers found that individuals with intellectual and developmental disabilities can use bridging social capital to obtain resources to which their family members or other social ties have access (e.g., Giesbers et al., 2021; Hall & Kramer, 2009; Kramer, et al., 2013; Shpigelman, 2018; Whitney, 2012; Widmer, et al., 2008; Widmer, et al., 2013).

Internet use may also provide avenues for individuals with developmental disabilities to build their bridging social capital (Duncan et al., 2019; Wong et al., 2016). Widmer and colleagues (2013) added to this body of literature the concept of linking social capital, or the resources to which one has access through professional channels (e.g., social workers, nurses, etc.). Wong and colleagues (2018) were the only others to mention linking social capital, but only in their introduction.

3.3 Measurement of Social Capital

In the qualitative studies, researchers used mostly observations and semi-structured interviews with individuals with developmental disabilities, their families, and support staff to collect data, including measures of social capital. Authors of one qualitative study conducted focus groups (Hamilton et al., 2017). Authors of mixed methods studies also used interviews and observations (Elias & Cook, 2016) and surveys (Stack-Cutler et al., 2015; Whitney et al., 2012).

Most studies examined social capital at the individual level, analyzing interpersonal relationships (e.g., Kramer et al., 2013) and personal social network structures (e.g., Widmer et al., 2013). Several took an ecological perspective, considering social capital at the neighborhood (e.g., Emerson et al., 2015) or organizational level (e.g., Patterson & Loomis, 2016). Within the qualitative literature, there was some overlap among studies that included descriptions of social capital at both the individual and ecological levels (e.g., Elias & Cook, 2016; Hall & Kramer, 2009; Riddel et al., 2001a, Riddel et al., 2001b).

The studies used a variety of approaches to measure social capital. I categorized these measures as “existing measures,” “researcher-created scales,” “quantitative proxies,” and “qualitative proxies” (see Table 2.2). Existing measures (n=6) included instruments that were used, published, or validated in previous studies. The validated social capital scales used included: Looman Social Capital Scale (Duncan et al., 2021; Looman & Farrag, 2009; Wong et al., 2018), Internet Social Capital Scale (Duncan et al., 2019; Wong et al., 2016), Family Empowerment Scale (Wong et al., 2018), and Resource Generator-UK (Webber et al., 2019). Looman & Farrag (2009) reported the development of the Arabic Social Capital Scale, which was translated and adapted from the Looman Social Capital Scale.

Researcher-created scales (n=4) were scale scores of existing items within a dataset, combined by the researchers and described in the study as a measure of social capital. Most of the researcher-created scales included scale scores of items related to perceived neighborhood quality (Emerson et al., 2015; Emerson et al., 2016; Hock & Ahmedani, 2012). Azad and colleagues (2019) used a scale score of parental education and insurance status as a proxy for social capital.

Quantitative proxies (n=12) were numerical variables used as indicators of social capital. Of the 12 studies using quantitative proxies, 6 used measures that summarized or identified resources mobilized within personal or professional relationships (e.g., emotional support, reciprocity, or employment services), 5 used measures of structural aspects of social networks (e.g., social network size and density), and 1 used a measure of neighborhood perception (e.g., satisfaction with local area).

All qualitative studies used qualitative proxies (n=16), descriptions representing dimensions of social capital. Qualitative studies described structural social capital in terms of types of relationships. Some described multiple types of relationships, and are counted more than once: of the 16 qualitative studies, 9 described organizational relationships (e.g., participation in academic or residential groups), 7 investigated peer relationships (e.g., friends, classmates, work colleagues), 4 explored family relationships (e.g., parents, siblings caregivers), 3 described relationships supported by online social networks (e.g., Facebook) and 2 examined relationships outside the individual with developmental disabilities (e.g., parental social ties that were mobilized to support the individual with developmental disability).

3.4 Application of Social Capital

Most of the studies included social capital as either an outcome of another concept or as a precursor to other outcomes. In some studies, the relationships between social capital and other concepts were speculative, while others were directly measured. I describe these as potential relationships and do not evaluate the strength of the association. Three studies were descriptive in nature and did not describe any potential relationships between social capital and other concepts (Giesbers et al., 2021; Hassrick et al., 2020; Kvalsund & Bele, 2010).

Figure 2.2 shows the potential predictors and outcomes of social capital in the reviewed studies. Potential predictors of social capital included: individual disability status (n=6, 15.8%); online social network engagement (n=4, 10.5%); individual or family/parent characteristics (e.g., educational attainment and socioeconomic status; n=3, 7.9%), social relationships (n=2, 5.3%); educational setting (n=2, 5.3%); short-term residential situation (e.g., camp; n=2, 5.3%); work placement (n=1, 2.6%); long-term residential situation (n=1, 2.6%); social care (n=1, 2.6%). Researchers investigated the following potential outcomes of social capital: psychosocial outcomes (e.g., loneliness, mental well-being, behavioral and emotional problems; n=6, 15.8%), reported health (e.g., parent-report and self-report; n=4, 10.5%), academic achievement (e.g., grade point average, literacy; n=3, 7.9%), educational navigation/accommodations (n=3, 7.9%), parent perception and response to child developmental disability diagnosis (n=2, 5.3%), inclusion (n=1, 2.6%), physical health measures (n=1, 2.6%), and polypharmacy (n=1, 2.6%).

4. Discussion

This review is the first to map the extant literature examining the use of social capital concepts and theory in developmental disability literature. Researchers using qualitative methods provide a rich foundation of lived experience of people with intellectual and developmental disabilities. The interviews and focus groups produced valuable information such as the possibilities and potential importance for people with intellectual and developmental disabilities to engage in online social connections (e.g., Chadwick & Fulwood, 2018; Shpigelman, 2018); the value of familial relationships to provide support and resources (e.g., Kramer, et al., 2013); and the need to consider the intersection of socioeconomic status and stigma in inhibiting the opportunities for adults with intellectual and developmental disabilities to build and access social capital (Waterfield & Whelan, 2017).

The researchers using quantitative methods provide measurable understanding of social capital of people with developmental disabilities through the use of validated scales (Duncan et al., 2021; Looman & Farrag, 2009; Webber et al., 2019; Wong et al., 2016; Wong et al., 2018), researcher-created scales (Azad et al., 2019; Emerson et al., 2015; Emerson et al., 2016; Hock & Ahmedani, 2012), and use of quantitative proxies (Giesbers et al., 2020a; Giesbers et al., 2020b; Giesbers et al., 2021; Emerson & Hatton, 2017; Haider et al., 2014; Hassrick et al., 2020; Kvalsund & Bele, 2010; Stack-Cutler et al., 2015; Trainor et al., 2013; Tournier et al., 2021; Widmer et al., 2008; Widmer et al., 2013). Comparing network maps with reported social capital (in the form of quantitative proxy) expands our understanding of how people with developmental disabilities experience and use social capital (Giesbers et al., 2020a; Giesbers et al., 2020b; Giesbers et al., 2021; Tournier et al., 2021; Widmer et al., 2013).

Researchers note the lack of a single definition of social capital as a challenge in reviewing social capital literature (De Silva et al., 2005; Rotenberg et al., 2020). While there was some variation, the social capital definitions used in the reviewed studies had common threads, most notably the exchange of resources within social network relationships. Operationally, the variation in definition manifested in a variety of measurements used for social capital.

4.1 Limitations of the reviewed studies

A clear limitation seen throughout the reviewed studies is the lack of a validated, standardized measure of social capital. The majority of studies used quantitative or qualitative proxy measures for social capital. These measures addressed only certain aspects of social capital, limiting their functionality (Ehsan et al., 2019). Social capital is not a single item that can be measured; therefore, instruments measuring multiple aspects of an individual's social capital should be considered given the depth, breadth, and multidimensional nature of social capital (Uphoff, 1996; De Silva, 2005). There was some use of validated scales which measured multiple aspects of social capital (Duncan et al., 2019; Duncan et al., 2021; Looman & Farrag, 2019; Webber et al., 2019; Wong et al., 2016; Wong et al., 2018). Researchers should consider the feasibility of using such standardized measures in the future. While the wide range of social capital measurement makes it challenging to compare the applications of social capital, this range offers us a broad look at the expansive opportunities for social capital formation and its potential effects.

Other limitations are recruitment and inclusion criteria of participants. For example, Emerson and colleagues (2015) relied on a proxy measure for intellectual disability and used a dataset that excluded institutionalized individuals (e.g., people who live in group homes or congregate care facilities) and those not able to respond to the questionnaire due to communication impairment or other disability. The authors acknowledge that these limitations may have affected their results, but the impact is unclear (Emerson, et al., 2015). In some cases, parents, caregivers, or service providers (e.g., Haider et al., 2014; Hall & Kramer, 2009; Hock & Ahmedani, 2012) served as proxy respondents or provided supplemental information for children or people with more complex needs. However, most of the studies included only people who could communicate verbally and were receiving services from developmental disability service providers (e.g., Chadwick & Fulwood, 2018; Giesbers et al., 2020a; Papasotiriou & Windle, 2012). Therefore, we have little direct information from individuals with more complex needs and those who do not receive services.

The wide age ranges in several of the reviewed studies (e.g., Haider et al., 2014; Hamilton et al., 2017; Riddel et al., 2001a; Riddel et al., 2001b; Stack-Cutler et al., 2015) is a potential limitation to understanding social capital in the lives of people with developmental disabilities within the life course stages that were the focus of the present study. The wide range of ages suggests we may need refinement in subsequent research that specifically considers the experiences of individuals with developmental disabilities at certain stages of life. However, it may also indicate that people with developmental disabilities experience life stages differently than people without developmental disabilities.

In most developed countries, individuals often enter higher education or the workforce following completion of their secondary education. This transition is often accompanied by greater financial, social, and residential independence and decreased reliance on families. People with developmental disabilities are more likely than those without disabilities to remain in dependent roles in young adulthood (Giesbers et al., 2020; Walmsley, 1993). One study with a wide age range suggested an innovative residential housing similar to housing for older adults with integrated services such as activities of daily living assistance and programs promoting social and life skills (Elias and Cook, 2016). Within this structure, emerging adults with developmental disabilities are experiencing residential housing in the ways we might typically associate with older adults. However, the services and structure provided may enable these emerging adults to gain greater safety, freedom and interdependence than traditional independent housing options. Therefore, the role of social capital at certain life stages (McDonald & Mair, 2010) may be different for people with developmental disabilities compared to those without.

The diversity of methods and approaches to applying social capital to developmental disabilities creates substantial challenges for comparison among studies, and would thus make a systematic review or meta-analysis difficult given the current literature. However, this diversity also gives us an idea of the wide range of possible applications for people with developmental disabilities.

4.2 Limitations and strengths of the current study

I did not assess “risk of bias” or conduct a systematic “critical appraisal of individual sources of evidence” (Tricco et al., 2018). In scoping reviews, a "risk of bias" analysis is usually considered not applicable as researchers are not comparing interventions or methodologies (Tricco et al., 2018). Given my research question, a critical appraisal would not contribute much to the analysis, particularly since there is a wide range of information (e.g., methodologies, study aims, etc.) represented in my review (Tricco et al., 2018).

This review was limited, in part, by the exclusion criteria. I did not include dissertations, books, book chapters or theses, or any materials not published in English. This review was bounded by time and only included studies published between January 2000 and February 2022. It is possible that additional sources could add to our knowledge.

The age criterion is also a potential limitation. Not all articles contained specific reports of participant age (e.g., Waterfield & Whelan, 2017). I used information from the article (e.g., descriptors like “university student”) to assign the study to the most reasonable life course stage group. As stated earlier, people with developmental disabilities may not experience life course stages in the same way as people without developmental disabilities, and such differences may vary among individuals with various developmental disability diagnoses.

I did not control for cultural context. All of the studies were from developed countries. Access to services, supports, and social networks among people with developmental disability is affected by governments, organizations, and societal expectations. It is likely that findings from one country may not be transferable to another. However, this diversity may also be a strength in that examining the experience of social capital among people in different cultural contexts gives a broader perspective of what is possible for people with developmental disabilities.

This review had several notable strengths. First, I used comprehensive search terms and five databases to capture as many studies as possible (see Appendix A). Second, I maximized the strength of my search by Medical Subject Heading (MeSH) terms. MeSH terms group articles by topic, thus providing a more comprehensive search. Third, I captured over 20 years of data in an emerging field. The number of articles steadily increased in each five-year period from 2 (years 2000-2005) to 21 (years 2016-2021). Fourth, this review focuses on the period of childhood through emerging adulthood. These years are critical to the life course, providing a foundation upon which the remainder of a person's life is built. Fifth, I conducted a comprehensive analysis of the studies, providing a clear snapshot of the current state of the research. Finally, I included qualitative studies, which are often excluded from systematic reviews.

4.3 Future Research

Only two studies (Patterson & Loomis, 2016; Webber et al., 2019) described interventions targeted at building social capital for people with developmental disabilities. The lack of intervention studies is a critical gap in the literature, and a key area for further study. Interventions that promote social inclusion and community participation will help people with developmental disabilities expand their social networks and reservoir of social capital resources. Interventions that teach people how to recognize and access these resources will enable them to benefit from these resources. Researchers can use the results of this review to inform intervention research.

While researchers employed some validated measures of social capital, the use of these measures is limited to people who understand and can respond to written or verbal prompts. Some people with developmental disabilities have cognitive and communication limitations that prevent them from completing such measures. To increase our understanding of social capital among people with more complex communication and cognitive needs, we need a comprehensive, low burden social capital measurement tool that allows flexibility in administration and can be adapted to a range of communication needs.

Conducting research using universal design principles could increase the representation of people with significant communication or complex needs. Universal design is "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (Connell et al., 1997). Though initially used to describe the built environment, elements of universal design may be used to increase participation of people with disabilities in research (Rios et al., 2016; Vinoski Thomas et al., 2019).

Researchers should also consider how to expand recruitment for people with developmental disabilities who are not receiving services. It is possible that people with developmental disabilities are included in research and not identified as having developmental disabilities because researchers do not know how to identify them. One potential approach is to ask about special education history. Asking if an individual has a history of special education presents low burden on the researcher and the participant. A history of special education is a likely indicator of developmental disability and can help us identify people with developmental disabilities who are not receiving formal support services (Laditka et al., 2022).

4.4 Conclusions

People with developmental disabilities need and can develop social capital. We need more research including larger samples to create a more comprehensive understanding of how people with developmental disabilities build and access social capital and the benefits they receive from their social capital. Standardized measures of social capital will allow us to better compare studies and outcomes. We also need to evaluate methods for developing and maximizing social capital for adults with developmental disabilities. Increasing the social capital of people with developmental disabilities can help us address the health and social disparities that persist for this group of people.

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APPENDIX A. Search strategies to identify social capital and developmental disability research

Database	Search Strategy
PubMed	((special need*[Title/Abstract] OR epilepsy[Title/Abstract] OR learning dis*[Title/Abstract] OR vis* imp*[Title/Abstract] OR blind*[Title/Abstract] OR deaf*[Title/Abstract] OR development* delay[Title/Abstract] OR speech disorder[Title/Abstract] OR intellectual* disab*[Title/Abstract] OR asperger*[Title/Abstract] OR cerebral palsy[Title/Abstract] OR autis*[Title/Abstract] OR developmental disab*[Title/Abstract] OR retard*[Title/Abstract]) OR ("Attention Deficit and Disruptive Behavior Disorders"[Mesh] OR "Child Behavior Disorders"[Mesh] OR "Child Development Disorders, Pervasive"[Mesh] OR "Communication Disorders"[Mesh] OR "Developmental Disabilities"[Mesh] OR "Intellectual Disability"[Mesh] OR "Learning Disabilities"[Mesh] OR "Motor Skills Disorders"[Mesh] OR "Mutism"[Mesh] OR "Stereotypic Movement Disorder"[Mesh] OR "Tourette Syndrome"[Mesh] OR "Cerebral Palsy"[Mesh] OR "Seizures"[Mesh] OR "Epilepsy"[Mesh])) AND ("social capital"[Title/Abstract] OR "Social Capital"[Mesh]) Filters applied: English, from 2000/1/1
APA PsychInfo	(TI "special need*" OR AB "special need*" OR TI epilepsy OR AB epilepsy OR TI “learning dis*” OR AB “learning dis*” OR TI “vis* imp*” OR AB “vis* imp*” OR TI blind* OR AB blind* OR TI “hearing imp*” OR AB “hearing imp*” OR TI deaf* OR AB deaf* OR TI “development* delay*” OR AB “development* delay*” OR TI “speech disorder*” OR AB “speech disorder*” OR TI “intellectual* disab*” OR AB “intellectual* disab*” OR TI asperger* OR AB asperger* OR TI “cerebral palsy” OR AB “cerebral palsy” OR TI autis* OR AB autis* OR TI “developmental disab*” OR AB “developmental disab*” OR TI retard* OR AB retard* OR DE "Neurodevelopmental Disorders" OR DE "Attention Deficit Disorder" OR DE "Autism Spectrum Disorders" OR DE "Developmental Disabilities" OR DE "Emotional and Behavioral Disorders" OR DE "Intellectual Development Disorder" OR DE "Learning Disorders" OR DE "Specific Language Impairment" OR DE "Deaf Blind" OR DE "Learning Disorders" OR DE "Dyslexia" OR DE "Acalculia" OR DE "Agraphia" OR DE "Down's Syndrome" OR DE "Klinefelters Syndrome" OR DE "Microcephaly" OR DE "Phenylketonuria" OR DE "Prader Willi Syndrome" OR DE "Rett Syndrome" OR DE "Savants" OR DE "Williams Syndrome" OR DE "Intellectual Development Disorder" OR DE "Anencephaly" OR DE "Crying Cat Syndrome" OR DE "Down's Syndrome" OR DE "Tay Sachs Disease" OR DE "Attention Deficit Disorder with Hyperactivity") AND (DE "Social Capital" OR TI "Social Capital" OR AB "Social Capital") Limits: 2000-2022; English Language
CINAHL Complete	(TI "special need*" OR AB "special need*" OR TI epilepsy OR AB epilepsy OR TI “learning dis*” OR AB “learning dis*” OR TI “vis* imp*” OR AB “vis* imp*” OR TI blind* OR AB blind* OR TI “hearing imp*” OR AB “hearing imp*” OR TI deaf* OR AB deaf* OR TI “development* delay*” OR AB “development* delay*” OR TI “speech disorder*” OR AB “speech disorder*” OR TI “intellectual* disab*” OR AB “intellectual* disab*” OR TI asperger* OR AB asperger* OR TI “cerebral palsy” OR AB “cerebral palsy” OR TI autis* OR AB autis* OR TI “developmental disab*” OR AB “developmental disab*” OR TI retard* OR AB retard* OR MH "Developmental Disabilities" OR MH "Mutism" OR MH "Motor Skills Disorders" OR MH "Learning Disorders" OR MH "Dyslexia" OR MH "Dyscalculia" OR MH "Intellectual Disability" OR MH "Communicative Disorders" OR MH "Asperger Syndrome" OR MH "Autistic Disorder" OR MH "Pervasive Developmental Disorder-Not Otherwise Specified" OR MH "Child Development Disorders, Pervasive" OR MH "Child Development Disorders" OR MH "Child Behavior Disorders" OR MH "Attention Deficit Hyperactivity Disorder" OR MH "Mental Disorders Diagnosed in Childhood" OR MH "Social Anxiety Disorders") AND ((MH "Social Capital") OR TX "social capital" OR AB "social capital") Limits: 2000-2022; English Language

Sociological Abstracts	(ti(“special need*) OR ab(“special need*) OR ti(epilepsy) OR ab(epilepsy) OR ti(“learning dis*”) OR ab(“learning dis*”) OR ti(“vis* imp*”) OR ab(“vis* imp*”) OR ti(blind*) OR ab(blind*) OR ti(“hearing imp*”) OR ab(“hearing imp*”) OR ti(deaf*) OR ab(deaf*) OR ti(“development* delay*”) OR ab(“development* delay*”) OR ti(“speech disorder*”) OR ab(“speech disorder*”) OR ti(“intellectual* disab*”) OR ab(“intellectual* disab*”) OR ti(asperger*) OR ab(asperger*) OR ti(“cerebral palsy”) OR ab(“cerebral palsy”) OR ti(autis*) OR ab(autis*) OR ti(“developmental disab*”) OR ab(“developmental disab*”) OR ti(retard*) OR ab(retard*) OR MAINSUBJECT.EXACT("Developmental Disabilities") OR MAINSUBJECT.EXACT("Autism") OR MAINSUBJECT.EXACT("Blind") OR MAINSUBJECT.EXACT("Deaf") OR MAINSUBJECT.EXACT("Learning Disabilities") OR MAINSUBJECT.EXACT("Attention Deficit Disorder") OR MAINSUBJECT.EXACT("Downs Syndrome")) AND (ab("social capital") OR ti("social capital")) Limits - Date: After December 31, 1999; Language: English
ERIC	(TI "special need*" OR AB "special need*" OR TI epilepsy OR AB epilepsy OR TI “learning dis*” OR AB “learning dis*” OR TI “vis* imp*” OR AB “vis* imp*” OR TI blind* OR AB blind* OR TI “hearing imp*” OR AB “hearing imp*” OR TI deaf* OR AB deaf* OR TI “development* delay*” OR AB “development* delay*” OR TI “speech disorder*” OR AB “speech disorder*” OR TI “intellectual* disab*” OR AB “intellectual* disab*” OR TI asperger* OR AB asperger* OR TI “cerebral palsy” OR AB “cerebral palsy” OR TI autis* OR AB autis* OR TI “developmental disab*” OR AB “developmental disab*” OR TI retard* OR AB retard* OR DE "Developmental Disabilities" OR DE "Asperger Syndrome" OR DE "Autism" OR DE "Cerebral Palsy" OR DE "Communication Disorders" OR DE "Developmental Delays" OR DE "Epilepsy" OR DE "Intellectual Disability" OR DE "Learning Disabilities" OR DE "Neurological Impairments" OR DE "Pervasive Developmental Disorders" OR DE "Attention Deficit Disorders" OR DE "Behavior Disorders" OR DE "Communication Disorders" OR DE "Developmental Disabilities" OR DE "Hearing Impairments" OR DE "Intellectual Disability" OR DE "Language Impairments" OR DE "Learning Disabilities" OR DE "Mild Disabilities" OR DE "Multiple Disabilities" OR DE "Perceptual Impairments" OR DE "Physical Disabilities" OR DE "Severe Disabilities" OR DE "Special Health Problems" OR DE "Speech Impairments" OR DE "Visual Impairments" OR DE "Emotional Disturbances") AND (DE "Social Capital" OR TI "Social Capital" OR AB "Social Capital") Limits: 2000-2022; English Language

Figure 2.1. PRISMA Diagram

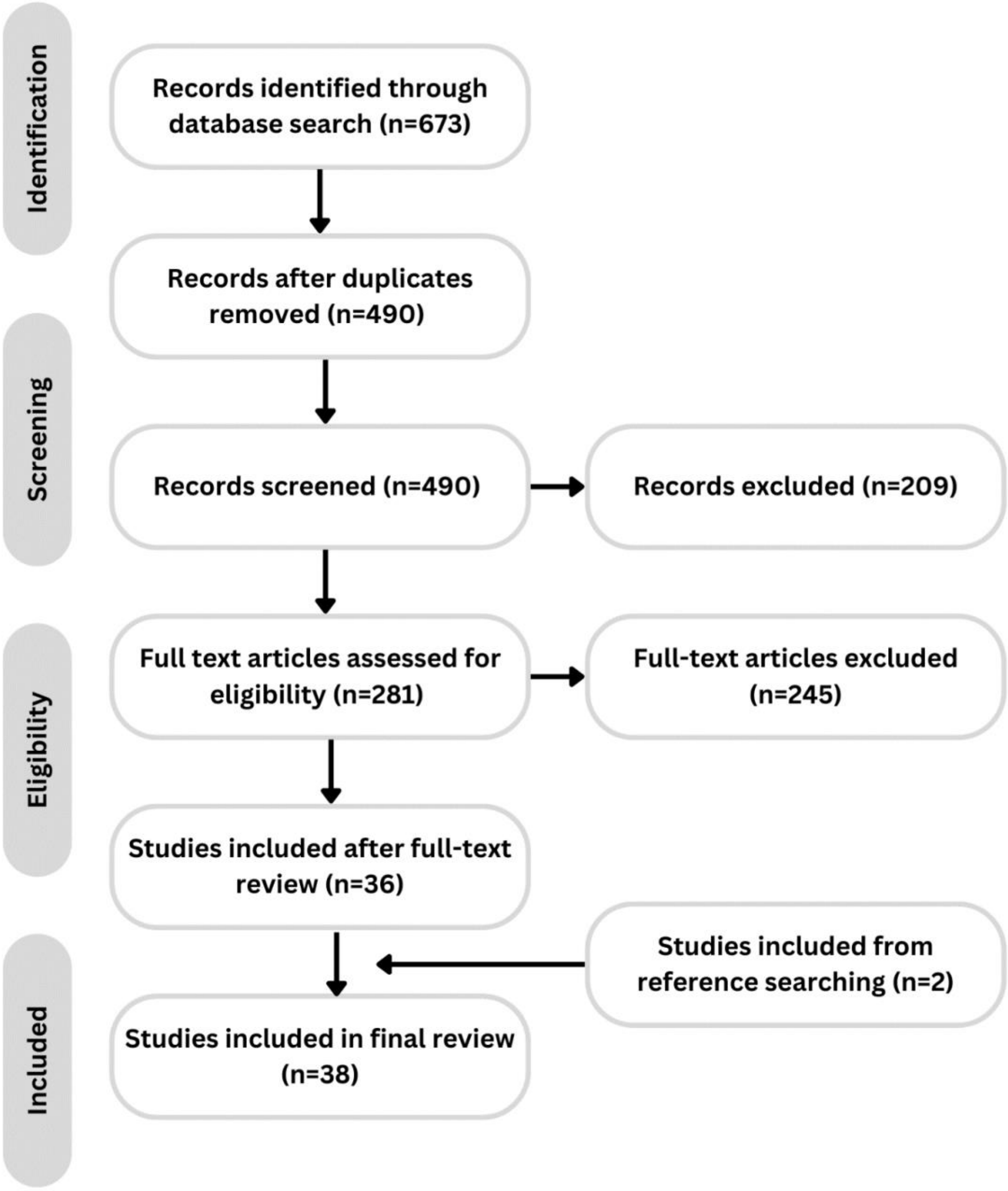


Table 2.1. Data extraction table of included studies (n=38)

Author, year (country)	**Design**	**Study purpose**	**Sample^**	**Source of data**	**Unit of Analysis**	**Main Findings & Limitations**
Azad et al., 2019 (US)	Quantitative Prospective cohort	To examine factors associated with initial appointment attendance, parental diagnostic agreement, and commitment to follow-up visits	n=6558 children at intake; n=1430 children diagnosed with ASD (mean age 7; 53% Caucasian; 22% Black/AA; 25% Other) receiving services from an urban ASD specialty clinic; n=1353 children who returned for physician follow-up	Research registry electronic medical records, including parent-completed questionnaires, Child Behavior Checklist	Child with DD & their parents	Parents with high SC less likely to agree with ASD clinical diagnosis; SC not significantly associated with follow-up attendance; Limitations include urban context only, no comparison group, no information on families who did not consent to research registry
Baker et al., 2020 (US)	Qualitative Multiple case study	To examine collaboration between US special educators and Somali American families of boys with ASD using capital theory	n=3 Somali American boys with ASD (ages 2-17) and their mothers	Qualitative interviews, observations, field notes, educational documents	Child with DD & their parents	Family immigration history and parent education may affect access to economic, social, & cultural capital; Parents who effectively use SC may be more involved in their child's education; Children of families with greater access to capital may have better educational opportunities; Limitations include use of interpreter with one of the mothers
Chadwick & Fulwood, 2018 (UK)	Qualitative Phenomeno-logical	To explore how adults with ID use the internet and social media, as well as how this affects their self-	n=11 adults (55% male, 45% female; ages 20-43) with mild to moderate ID who used the Internet and Facebook	Online and face-to-face interviews, structure adjusted as	Individual with DD	Use of online social networks helped maintain existing SC and enabled people with ID to support others; Limited to people with ID with good communication skills and who primarily use Facebook

		concept and relationships		needed by participants		
Duncan et al., 2019 (US)	Quantitative Pre and post-test	To measure baseline of on- and offline SC of adolescents who are DHH; To examine possible link between attending a disability-specific residential camp and SC	n=29 DHH adolescents (38% male, 62% female)	Online survey	Individual with DD	Little change in pre- and post-camp bridging SC; Decrease in online bonding SC post-camp; Mixed reports of offline bridging SC pre- and post-camp; Overall increase in offline bonding SC post-camp; Limitations include small sample size, selection bias and non-response bias, timing of survey may have influenced completion
Duncan et al., 2021 (US)	Quantitative Pre and post-test with follow-up	To compare pre- and post-camp measures of general SC and perceptions of loneliness and peer relations, and associations between SC and measures of loneliness and peer relations	n=36 DHH adolescents (ages 15-17 years, mean 16; 31% males, 69% females)	Online survey	Individual with DD	Little change in reported SC across the 4 timepoints; No significant association between SC, loneliness and social dissatisfaction; Higher levels of common good associated with less loneliness; Limitations include small sample size, selection bias and non-response bias, timing of repeated measures
Elias & Cook, 2016 (Canada)	Mixed Method Case Study	To examine unique housing model combining service provision, social participation and SC development for people with developmental,	n=65 adults with developmental, physical, cognitive, and/or mental health needs (65% male, 35% females; ages 18-82 years) who recently moved to an “intentional	Semi-structured interviews, observations	Individual with DD	Findings from a subsample of the respondents (7 people aged 20-35) indicate that they felt more independent, safe, included, and interested in pursuing individual goals such as attending college since moving into the community; Of the 12 who moved out of the community within the first 2 years, all but 2 were under age 35 years; Limitations include

		physical, cognitive, or mental health needs	community" with integrated services			wide age range, non-replicable results, small sample size
Emerson & Hatton, 2007 (UK)	Quantitative Cross-sectional secondary data analysis	To estimate the impact of socioeconomic position on health disparities of children and adolescents with ID	Nationally representative sample of British children (n=12160, ages 0-17 years); subsample (n=593) with ID	Department of Work and Pensions' Families and Children Study	Individual with DD	Children with ID more likely to have poorer health than children without ID; 31% of elevated risk explained by differences in socioeconomic position and SC; Limitations include use of an operational definition of ID, parent report of child health, cross-sectional design
Emerson, et al. 2015 (UK)	Quantitative Cross-sectional secondary data analysis	To examine health of parents with and without intellectual impairment and determine relationship between health status and exposure to social determinants of poor health	n=14371 parents with and without intellectual impairment (used as a proxy for ID; ages 16-49 years) n=299 with intellectual impairment	Understanding Society panel survey	Individual with DD	Parents with intellectual impairment had poorer mental and physical health and less neighborhood SC or intergenerational support; Limitations include use of ID proxy, general household sampling frame, consent and interview procedures which may exclude people with greater needs, survey not adapted for people with intellectual impairment, cross-sectional design
Emerson et al., 2016 (UK)	Quantitative Cross-sectional secondary data analysis	To estimate physical health status of British adults with and without ID while controlling for confounding effects of gender, age, socioeconomic	n=22927 adults with and without ID (ages 16-49 years) n=299 with ID	Understanding Society panel survey	Individual with DD	Adults with mild ID have worse health than those without ID; Poorer health was associated with gender, age, socioeconomic disadvantage and neighborhood SC; Limitations include use of ID proxy, general household sampling frame and consent and interview procedures may exclude people with greater needs, survey was not adapted for people with intellectual impairment, participants with ID underrepresented in

		disadvantage and neighborhood SC				nurse measurement sample; not possible to include other confounders; cross-sectional design
Giesbers et al., 2020a (NL)	Quantitative Matched control descriptive comparison	To describe differences in self-reported family network characteristics and family support experiences reported by emerging adults with and without mild ID	n=106 emerging adults (ages 18-25 years); n=53 with ID (32% male, 18% female, 94% Dutch cultural background); n=53 without ID (32 male, 21 female, 89% Dutch cultural background)	Researcher-administered survey	Individual with DD & matched controls	People with ID reported fewer significant family members, peers, and siblings, had fewer reciprocal support relationships and a less central position in their family network compared to students without ID; Limitations include potential non-response bias, matched controls were all university students, comparisons matched only by age and sex, limited evidence of validity of network mapping method, ambiguity of the “family” construct for some participants
Giesbers et al., 2020b (NL)	Quantitative Cross-sectional primary data analysis	To examine how people with mild ID define and perceive their family, the emotional support they receive from family members, and how they perceive reciprocity of emotional support	n=138 people with mild ID (ages 18-40 years, mean 28; 57% male, 43% female; 92% Dutch cultural background; 44% reported additional diagnoses)	Structured interviews	Individual with DD	Participants reported “significant” family members beyond the nuclear family, with parents seen as main provider of support; 50% reported support from siblings, 13% reported partners, about 30% of support was reciprocal; Limitations include risk of non-response bias, sample included only people with mild ID who lived apart from family and received support from a service provider, no comparison group, cross-sectional design

Giesbers et al., 2021 (NL)	Quantitative Cross-sectional primary data analysis	To examine support within family networks of people with mild ID and factors associated with differences in perception among people with mild ID and their family members	n=333 individuals; n=111 with mild ID (ages 18-40 years, mean 28; 56% male, 44% female; 95% Dutch); n=111 family members (mean age 56 years; 33% male, 67% female; 94% Dutch); n=111 key support workers (mean age 41 years; 19% male, 81% female)	Researcher-administered survey, structured interview, proxy report	Individual with DD, family member, key support worker	People with mild ID reported denser family networks, more bonding and bridging SC, and more reciprocity in relationships compared to family members; Both groups reported similar levels of support from the family to the person with ID; Limitations include risk of non-response bias, sample included only people with mild ID who lived apart from family and received support from a service provider, data based on perceptions of people with mild ID and their family member, models included few confounding variables
Haider et al., 2014 (AUS)	Quantitative Cross-sectional secondary data analysis	To describe prevalence of medicine use and polypharmacy (≥ 5 drugs) and examine role of factors associated with polypharmacy of people with ID in Victoria, Australia	n=897 adults with ID (ages 18-82 years; mean 42; 56% male; 44% female; 91% born in Australia; 54% ages 18-39 years)	Victorian Population Health Survey of people with an Intellectual Disability 20090 (VPHS-ID 2009), proxy report	Individual with DD	People with ID who were older, unemployed, and lacked social support were more likely to experience polypharmacy; Polypharmacy was associated with poorer health and more common among people with greater impairment; Limitations include low response rate and reliance on an administrative database to identify participants with ID

Hall & Kramer, 2009 (US)	Qualitative Grounded theory	To compare experiences of people with ID in sheltered workshops and community employment and how employment affects opportunities for SC creation	n=81 total individuals; n=29 adults with ID (ages 22-64 years; mean 42; 41% male, 59% female; 83% non-Hispanic white, 10% non-Hispanic black, 7% Hispanic white); n=23 family members; n=29 community rehabilitation provider staff	Semistructured interviews, observation field notes	Individual with DD	Connections at workplace helped create SC; Community employment produced added opportunities; Family members were critical in supporting community employment and helping develop SC; Limitations include wide age range and focus only on people served by a community rehabilitation provider
Hamilton et al., 2017 (UK)	Qualitative Critical realist	To explore how personalization and social care budget cuts impact daily experiences of people with mild/moderate ID at risk of losing care due to service eligibility and their support workers	n=39 total individuals ages 23-60 years, 97% white British, 3% black British; n=26 adults with ID (73% male, 27% female;); n=13 support workers (46% male, 54% female)	Focus groups	Individual with DD & Support workers	Many, but not all, participants expressed a desire for independence; Managing support workers was an unexpected burden on some participants; Educational and employment opportunities limited for some; Social networks and relationships were important to their well-being; Changes in formal care can disrupt social networks; Some participants reported limited SC and connection to their communities; Limitations included small sample on only people with mild-moderate ID from one area with access to support

Hassrick et al., 2020 (US)	Quantitative Cross-sectional feasibility study	To test the feasibility of a social network measure among autistic adults	n=20 individuals; n=17 autistic young adults (ages 18-29 years, mean 23; 59% male, 29% female, 12 % gender nonconforming; 67% white); n=3 parents from matched youth-parent pairs	Online social network measurement survey	Individual with DD; Parent-child dyads	Social network measurement survey captured data on the size and density of social networks of autistic adults, and the different types of support they provide; Limitations include feasibility study design - does not result in generalizable results, the measure only allows participants to identify 5 people in their social networks
Hock & Ahmedani, 2012 (US)	Quantitative Cross-sectional secondary data analysis	To examine how the social ecological contexts of parents differ for those with and without children with ASD, and how these contexts influence parents' perception of severity of their child's ASD	n=81923 children ages 2-17 years; n=1427 children with ASD (78% male, 22% female; 71% white non-Hispanic, 9% black non-Hispanic, 10% Hispanic, 10% other); n=80496 children without ASD (52% male, 48% female, 69% white non-Hispanic, 10% black non-Hispanic, 12% Hispanic, 9% other)	National Survey on Children's Health (2007-2008)	Parent, child with DD	Parents of children with reported poorer neighborhood SC, greater aggravation, more difficulty coping, and lower levels of relationship satisfaction and mental health; Severity of parent-reported ASD was associated with aspects of the physical environment (e.g., rundown housing and garbage on the street), the social environment (e.g., parent relationship satisfaction) and individual parent characteristics (e.g., parent aggravation and mental health); Limitations include cross sectional design, reliance on parent reports, use of mostly landline telephone surveys, inability to control for comorbid conditions (e.g., ID)
Johnson et al., 2020 (US)	Qualitative	To describe the aspects of Deaf community cultural wealth experienced by Deaf students in mainstreamed	n=18 Deaf students (ages 18-44 years, mean 27; 44% Latinx, 33% Black or AA, 11% White, 5% mixed race or other)	Semi-structured interviews	Individual with DD	SC is an aspect of Deaf community cultural wealth that provides information and resource-sharing; Participants that having Deaf peers helped them navigate the community college environment, but the presence of Deaf peers could be distracting in academic settings;

		community college				Limitations include small sample recruited from one community college
Kim & Qian, 2021 (South Korea)	Qualitative	To understand how people with IDD in South Korea use social media, and to identify benefits and challenges of using social networking sites	n=20 individuals with IDD with less intensive support needs (ages 20-49 years; 45% male, 55% female)	Semi-structured interviews	Individual with DD	Participants reported benefits of using social networking sites including SC, self-confidence, and positive self-image; Participants used sites to maintain friendships, initiate new relationships, find new information, and engage in self and community advocacy; Some participants reported safety concerns; Limitations include narrow age range (most participants were young adults), exclusion of family members or support staff as respondents, exclusion of individuals with IDD who were nonverbal or needed communication support
Kramer, et al., 2013 (US)	Qualitative open-ended	To explore the role of reciprocity within sibling relationships to create SC, how sibling relationships create SC, and how siblings use their SC to support siblings with IDD	n=16 adults (50% Caucasian, 25% African American, 25% Hispanic); n=8 adults with ID, DD, ASD, DS, and MI (ages 25-59 years, mean 45; 88% male, 12% female); n=8 siblings (ages 32-59 years, mean 54; 12% male, 88% female)	3 qualitative interviews per sibling pair; each sibling interviewed individually and then jointly	Sibling dyads	Siblings create reciprocity through family roles; Siblings without ID use bonding and bridging SC to help siblings with ID; Limitations include reliance on reports by siblings with positive relationships, only included siblings with DD with good communication skills, lack of socioeconomic status measurement

Kvalsund & Bele, 2010 (Norway)	Quantitative Longitudinal secondary data analysis	To identify social adaptation patterns in early adulthood and understand social marginalization of students with special educational needs as they enter adulthood	Project I: original cohort (n=760 students with special educational needs, 61% male, 39% female); Project II: follow up 65% response (n=494, 62% male, 39% female)	Project I: Reform 94 - Special education needs; Project II: Adult life on special terms?	Individual with DD	Small, less dense networks were socially isolating and mostly consisted of family relationships; Almost half of the sample reported large, highly dense networks most often characterized by mixed relationships with family and friends or primarily friends which provide greatest opportunity for SC development; Limitations include proxy measurement of SC, unclear how data from Project I was incorporated into the analysis
Looman & Farrag, 2009 (Egypt)	Quantitative Cross-sectional primary data analysis	To evaluate the validity and reliability of the Arabic translation of the SC Scale among	n=117 parents of children with special health care needs (children ages 1-18 years, mean 10; 59% male, 41% female)	Researcher-administered psychometric tool	Parent, Child with DD	Parents rating their child's health as "very good" or "excellent" had significantly higher SC than those rating their child's health as "good," "fair," or "poor;" The translated tool demonstrated good reliability and validity using four internally consistent factors; Limitations include the tool's inability to compare cultural groups
McConkey et al., 2013 (Serbia, Poland, Ukraine, Germany, & Hungary)	Qualitative	To identify and describe aspects of Unified Sports® that contribute to social inclusion according to key stakeholders in five European countries	n=156 athletes with ID (ages 12-25 years); n=106 partners; n=65 coaches; also included community representatives and parents (n not reported)	Face to face semi-structured interviews	Country-based Unified Sports® teams	Unified Sports® promoted social inclusion for athletes with ID through developing bonds with their teams, coaches, and friends, learning sports and personal skills, gaining access to new and different places, and experiencing positive perception as athletes; Social inclusion was promoted through alliances among families, schools, teams, and organizations; Limitations include a non-random sample of active members of Unified Sports® teams

Papasotiriou & Windle, 2012 (AUS)	Qualitative Grounded theory	To explore factors shaping self-concept of disabled university students and how attending university may influence their SC development	n=4 physically disabled university students (ages 23-52 years, mean 33; 50% male, 50% female)	Semi-structured interviews	Individual with DD	Students were more strongly connected with other people outside of the university; The university was not a rich source of SC for the participants; Limitations include small sample size, data collected only at one point in time, inclusion only of students with physical disabilities, potential reluctance among participants to disclose information
Patterson & Loomis, 2016* (England)	Qualitative	To evaluate the effectiveness of the 12-month reverse inclusion SIGNAL project in schools for students who are blind and visually impaired	Two schools for students with visual impairments aged 4-19 years, a university, a police department, and local businesses and organizations	Participant observations; aggregated student outcomes; two student case studies	Participating organizations, including individuals with DD	Using the SIGNAL model increased equality and helped students with visual impairments be more engaged in their communities; The SIGNAL approach helped generate specialized curriculum focused on local issues and fostered social entrepreneurship; Limitations include potential bias because the lead researcher had used the SIGNAL model previously and was involved in one of the participating schools, no objective measures to assess the effectiveness of the model.
Riddel et al., 2001a (UK)	Qualitative Case Studies	To explore the lifelong learning experiences of people with learning difficulties through the lens of SC, gender, and social class	n=40 adults with learning difficulties, ID, ASD, MD, DS, CP, (ages 17-67 years, mean 33, 53% male, 47% female)	Observations, semi-structured interviews with the individual, their parents, caregivers, employers, and support staff	Individual with DD	People with learning difficulties experience social and economic challenges not related to their social class or gender; Social class and gender may worsen some of these challenges and impact the SC available to them; Limitations include small sample size, lack of measurement of SC

Riddel et al., 2001b (UK)	Qualitative Case Studies	To explore how gender affects SC of individuals with learning difficulties and to identify any negative consequences of SC	n=40 adults with learning difficulties, ID, ASD, MD, DS, CP, (ages 17-67 years, mean 33, 53% male, 47% female)	Observations, semi-structured interviews with the individual, their parents, caregivers, employers, and support staff	Individual with DD	Women reported stronger social networks, characterized mostly by bonding SC; Excluding people based on disability, gender or race may have negative consequences, even in societies otherwise high in SC; Limitations include small sample size, lack of measurement of SC
Shpigelman 2018 (Israel)	Qualitative Phenomen-ological	To examine how people with ID use Facebook to access SC	n=20 adults with mild-moderate ID, ASD, and cerebral palsy (ages 21-43 years, mean 30, 50% men, 50% women)	Qualitative observation of participants using Facebook followed by a semi-structured interview	Individual with DD	Online engagement enhanced bonding SC and improved psychological well-being; Difficulties in using Facebook inhibited users' bridging SC; Limitations included nonrepresentative sample of people with ID, small sample size, no quantitative measure of the relationship between Facebook use and SC, missing perspectives of family members and care professionals
Stack-Cutler et al., 2015 (CAN)	Mixed method exploratory	To explore how university students with reading difficulties SC to achieve their personal goals	n=107 university students with a history of reading difficulties (ages 18-55 years, mean 25; 27% male, 73% female)	On-campus and online surveys	Individual with DD	Most participants discussed goals and important matters with friends, parents, and significant, while only 28% listed institutional ties; Outlets for personal SC included social media networking sites, family and friends; Outlets for institutional SC included university supports and services, community organizations, online networks, and other professional not associated with the university; Employment status was positively related to student GPA as a measure of SC; Limitations include use of self-reported disability; lack of assessment of the quality of social ties; no comparison group; inclusion of only native English speakers

Tournier et al., 2021 (NL)	Quantitative Cross-sectional latent class analysis	To examine family networks of people with ID based on perceived emotional support and to identify relationships between family network types and psychosocial outcomes	n=137 adults with mild ID (ages 18-40 years, mean 28; 56% male, 44% female; 92% Dutch cultural background, 8% identified as another cultural background, not specified)	Face to face structured interviews	Individual with DD	Four classes of family networks varied in the level of support provided to the person with DD; Most supportive family networks were those in which the person with ID engaged in reciprocal support with their family members; Limitations include use of emotional support as the only SC proxy, no qualitative measure of emotional support, potential non-response bias, sample only included people living apart from family and supported by staff in long term care
Trainor, et al., 2013 (US)	Quantitative Cross-sectional secondary data analysis	To explore the relationship between social networks and transition to adult outcomes for young adults with high incidence disabilities	n=1250 individuals with learning disability, ADHD, or emotional behavioral disorder (ages 19-23 years; weighted demographics: 67% male, 33% female; 70% white, 16% African American, 13% Hispanic)	National Longitudinal Transition Study-2 (NLTS2)	Individual with DD	Up to 5 years post high school, most of the young adults with high incidence disabilities reported employment or post-secondary education enrollment, living with parents, being single, and engaged in individual and social activities; Limitations include no comparison group, cross sectional design, absence of a clear SC measure
Waterfield & Whelan, 2017 (CAN)	Qualitative Grounded theory	To explore how socioeconomic status and stigma affect accommodation access and management of stigma for students with learning disabilities	n=10 university students self-identified as having a learning disability or ADHD (80% women, 10% men, 10% nonbinary)	Semi-structured interviews	Individual with DD	Students with learning disabilities and lower socioeconomic status had less SC to use in obtaining accommodations or supports at university; Mothers were instrumental in providing connections to SC; Limitations include small sample size, subjective socioeconomic grouping

Webber, et al., 2019* (UK)	Quantitative Prospective one group pretest-posttest pre-experimental design	To evaluate the effect of the Connecting People Intervention (CPI) on access to SC, social inclusion, and mental well-being	n=155 adults with mental health problems (n=130) or learning disability (n=25) (ages 16-87 years, mean age 42; 55% male, 45% female; 80.6% white British, 9.7% Asian, 3.1% black, 6.2% other ethnic origin)	Face to face structured interviews	Individual with DD	After CPI, all groups improved their ability to access resources within networks; No difference between mental health and learning disability groups implies that both groups have opportunity and need to enhance their SC; Limitations include small group of people with learning disability, potential Type 1 errors, low representation of ethnic minority groups, absence of control group, diagnoses were not verified, short follow-up period
Whitney, et al., 2012 (US)	Mixed methods	To explore ways in which participation in a STEM learning community contributes to the SC of participants	n=43 university students with disabilities (ADHD, learning disability, MI, ASD, other physical disability, DHH, TBI; 74% male, 26% female; 95% Caucasian, 4% AA, 1% Native American	Pre- and post-seminar survey results complimented with results from a focus group of current students including online discussion forum	Individual with DD	Students with disabilities reported improvement in accessing resources, social support, skills, and knowledge important to social capital after joining the STEM learning community; Limitations include small sample size, group specifically for students with disabilities, insufficient data to determine relationship between the program and academic outcomes

Widmer et al., 2008 (Switzerland)	Quantitative Cross-sectional primary data analysis with matched control	To explore how people with ID define their family contexts and how they perceive the relationships within those contexts	n=72 individuals (ages 18-35 years), 3 groups: n=24 participants with ID and MI (mean age 33); n=24 participants with ID only (mean age 27; 50% male, 50% female); n=24 university students (mean age 31; 54% male, 46% female)	Face to face structured interviews using the Family Network Method	Individual with DD & matched controls	People with ID had smaller, less dense family networks, considered themselves less of a resource for their families, and did not benefit from the same bridging or bonding SC compared to the non-clinical (control) group; Limitations include matched controls were all university students, groups were matched only by age and sex
Widmer et al., 2013 (Switzerland)	Quantitative Cross-sectional primary data analysis	To understand how families of people with intellectual disabilities are structured and how social support is provided within those structures.	n=40 individuals with ID (ages 28-35 years; mean age 27; 45% male, 55% female) receiving services from public facilities providing support and work to people with ID	Face to face structured interviews using the Family Network Method	Individual with DD	Identified 4 types of family structures, which were closely related to residential situation; People with Kinship and Professional configurations had less SC than Nuclear or Friendship; People with ID may consider care professionals and friends as family members who play familial roles; Limitations include a small purposive sample of individuals with no comorbidities
Wong et al., 2016 (AUS)	Quantitative Cross-sectional primary data analysis	To assess the feasibility of using an online survey to examine internet and social media use of DHH adolescents, and to explore the relationship between online behavior with online and offline	n=29 Australian DHH adolescents (ages 11-18 years, mean age 15; 45% male, 55% female)	Online survey	Individual with DD	The online survey reliably collected data on online participation and SC but was not reliable for measuring literacy skills; DHH adolescents reported high internet use; There was a positive relationship between internet use and bridging social connections online, but no relationship between internet use and bonding social connections; Limitations include small sample size, low response rate, missing data in literacy scores, the online survey may not be completely accurate or easy to understand for all respondents, especially

		SC and literacy skills				given the wide range of ages of the adolescents studied
Wong et al., 2018 (AUS)	Quantitative Prospective cohort	To explore the relationship between adolescent-reported and parent-reported SC, characteristics associated with reported SC, relationship between reported SC and adolescents' language and literacy and psychosocial outcomes	n=40 Australian DHH adolescents and their parents enrolled in the Longitudinal Outcomes of Children with Hearing Impairment study; n=16 DHH adolescents (ages 11-14 years, mean age 12; 50% male, 50% female); n=24 parents (4% male, 96% female); 14 parent-child dyads	Online surveys completed by parents and adolescents	Parent, Individual with DD, Dyads	Parent-rated and adolescent-rated SC were positively related; Adolescent-reported SC was significantly related to adolescents' language and literacy skills, but not psychosocial outcomes; Limitations include small sample size of adolescents who primarily used spoken English for communication, used adapted scales which were originally parent-report scales and were not validated for use with adolescents, language and literacy outcome measures were from 2-5 years before the SC data collection

*Intervention study

^Demographics include age, gender/sex, and race/ethnicity, if reported

Abbreviations. AUS = Australia. CAN = Canada. NL = The Netherlands. UK = United Kingdom. US = United States. SC = social capital. DHH = deaf or hard of hearing. ID = intellectual disability. ASD = autism spectrum disorder. MI = mental illness. TBI = traumatic brain injury. MD = muscular dystrophy. AA = African American

Table 2.2. Measurement & application of social capital in reviewed studies (n=38)

	Study	Measure(s)
Established measures	Duncan et al., 2019[a] Wong et al., 2016[a]	Internet Social Capital Scale (Williams, 2006)*
	Duncan et al., 2021[a] Wong et al., 2018[a]	Looman Social Capital Scale (Looman, 2006)*
	Looman & Farrag, 2009[b]	Arabic Social Capital Scale,* translated and adapted from the Looman Social Capital Scale (Looman, 2006)*
	Webber et al., 2019[a]	Resource Generator-UK (Webber & Huxley, 2007)*
	Wong et al., 2018[a]	Family Empowerment Scale (Koren et al., 1992)*
Researcher-created scale	Azad et al., 2019[a]	Parent social capital: scale score of parental education and insurance
	Emerson et al., 2015[b]	Neighborhood social capital: scale score of 12 items related to “perceptions of neighborhood quality and civic and social participation”*
	Emerson et al., 2016[b]	Neighborhood social capital: scale score of 13 items related to “perceptions of neighborhood quality and civic and social participation”*
	Hock & Ahmedani, 2012[a]	Neighborhood social capital: sum totaled scale of four items related to perceptions of neighborhood cohesion and support
Quantitative proxy	Giesbers et al., 2020b Haider et al., 2014 Stack-Cutler et al., 2015 Tournier et al., 2021 Trainor et al., 2013 Widmer et al., 2008	Resources mobilized within personal or professional relationships (e.g., reciprocity and emotional support within families; reported ability to get help from others, care in an emergency, or access to community resources)[a]
	Giesbers et al., 2020a Giesbers et al., 2021 Hassrick et al., 2020 Kvalsund & Bele, 2010 Widmer et al., 2013	Structural aspects of social networks (e.g., family or social network size and density)[a]
	Emerson & Hatton, 2017	Neighborhood perception (e.g., satisfaction with local area)[b]

Qualitative proxy	Elias & Cook, 2016 Hall & Kramer, 2009 Hamilton et al., 2017 McConkey et al., 2013 Papasotiriou & Loomis, 2016 Patterson & Loomis, 2016 Riddel et al., 2001a Riddel et al., 2001b Whitney et al., 2012	Organizational relationships (e.g., relationships formed through work, educational institutions, service providers)[b]
	Elias & Cook, 2016 Hall & Kramer, 2009 Hamilton et al., 2017 Johnson et al., 2020 Papasotiriou & Loomis, 2016 Riddel et al., 2001a Riddel et al., 2001b	Peer relationships (e.g., friends, coworkers, people not identified as family or service providers)[a]
	Hamilton et al., 2017 Kramer et al., 2013 Riddel et al., 2001a Riddel et al., 2001b	Family relationships (e.g., biological or chosen family)[a]
	Chadwick & Fullwood, 2018 Kim & Qian, 2021 Shpigelman, 2018	Relationships supported by online social networks (e.g., Facebook and other social networking sites)[a]
	Baker et al., 2020 Waterfield & Whelan, 2017	Relationships outside the individual with developmental disability (e.g., parental social connections that benefit the individual with developmental disability)[a]

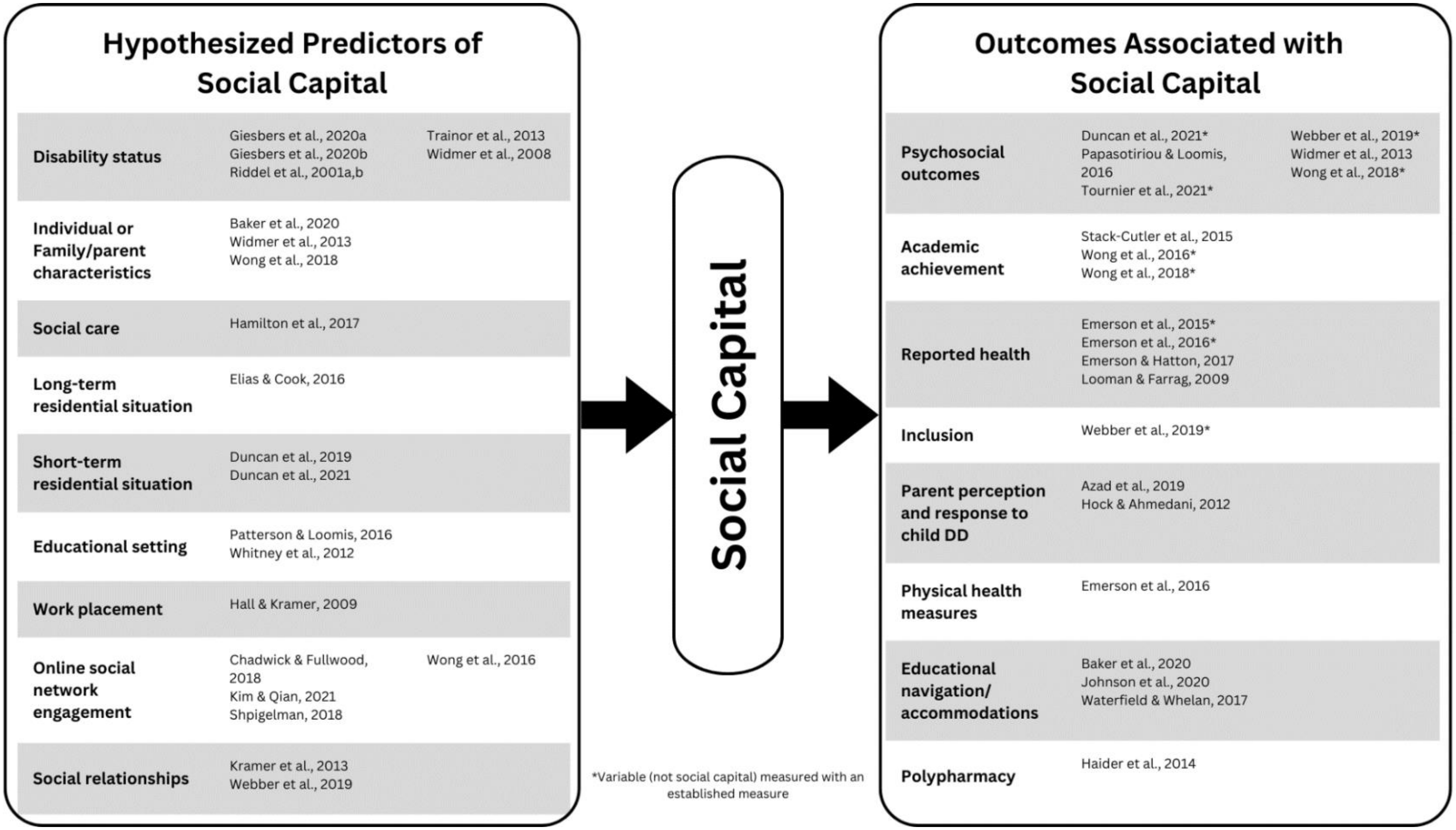
FNM-ID = Family Network Method – Intellectual Disability

Level of analysis of social capital: [a]Individual [b]Ecological

*Validity and/or reliability reported (applies only to Established Measures and Researcher-Created Scales)

^Variable (not social capital) measured with an established measure

Figure 2.2. Predictors and outcomes associated with social capital among people with developmental disabilities



Hypothesized Predictors of Social Capital

Disability status	Giesbers et al., 2020a Giesbers et al., 2020b Riddel et al., 2001a,b	Trainor et al., 2013 Widmer et al., 2008
Individual or Family/parent characteristics	Baker et al., 2020 Widmer et al., 2013 Wong et al., 2018	
Social care	Hamilton et al., 2017	
Long-term residential situation	Elias & Cook, 2016	
Short-term residential situation	Duncan et al., 2019 Duncan et al., 2021	
Educational setting	Patterson & Loomis, 2016 Whitney et al., 2012	
Work placement	Hall & Kramer, 2009	
Online social network engagement	Chadwick & Fullwood, 2018 Kim & Qian, 2021 Shpigelman, 2018	Wong et al., 2016
Social relationships	Kramer et al., 2013 Webber et al., 2019	

Outcomes Associated with Social Capital

Psychosocial outcomes	Duncan et al., 2021* Papasotiriou & Loomis, 2016 Tournier et al., 2021*	Webber et al., 2019* Widmer et al., 2013 Wong et al., 2018*
Academic achievement	Stack-Cutler et al., 2015 Wong et al., 2016* Wong et al., 2018*	
Reported health	Emerson et al., 2015* Emerson et al., 2016* Emerson & Hatton, 2017 Looman & Farrag, 2009	
Inclusion	Webber et al., 2019*	
Parent perception and response to child DD	Azad et al., 2019 Hock & Ahmedani, 2012	
Physical health measures	Emerson et al., 2016	
Educational navigation/ accommodations	Baker et al., 2020 Johnson et al., 2020 Waterfield & Whelan, 2017	
Polypharmacy	Haider et al., 2014	

*Variable (not social capital) measured with an established measure

CHAPTER 3: CHILDHOOD EXTRACURRICULAR INVOLVEMENT AND MENTAL HEALTH OF YOUNG ADULTS WITH DEVELOPMENTAL DISABILITIES

1. Introduction

Mental health problems among children, adolescents, and young adults are a growing public health concern (Bitsko et al., 2022; Mojtabai & Olfson, 2020). Poor mental health in childhood can impact an individual's life trajectory and may result in lower life satisfaction and poorer health-related quality of life in adulthood (Schlack et al., 2021).

Volunteering with local organizations, playing sports, taking lessons in music and art, and other extracurricular activities give many children opportunities to develop socially, connect with peers and adults, and learn about the value of relationships. Extracurricular activities are often among children's first opportunities to independently connect with others outside their family and homes which may contribute to building social capital, resources available to individuals through the relationships they have with other people. Participating in extracurricular activities is associated with positive mental health outcomes for children and adolescents as the resources people gain from social connections can promote healthy behaviors, provide benefits linked with social interaction, and deepen supportive networks and relationships (Boelens et al., 2022; Bohnert et al., 2010; Mahoney et al., 2005; Oberle et al., 2019).

Children with developmental disabilities—such as intellectual disability, learning disabilities, emotional disorders, and other conditions that begin in childhood and are expected to last throughout life (Developmental Disabilities Assistance and Bill of Rights

Act 2000)—may be less likely to participate in extracurricular activities than other children due to social, physical, or intellectual barriers (Agran et al., 2017). These barriers may prevent children with developmental disabilities from expanding their social connections in the same ways as children without developmental disabilities. Many such barriers may be due to the views, expectations, or actions of others, including individuals, social groups, organizations, schools, and governments, rather than the characteristics of the individuals with developmental disabilities.

1.1 Developmental disability

Developmental disabilities are a group of disabilities that begin in the developmental period (prior to age 22) and result in functional limitations that affect a person throughout life (Developmental Disabilities Assistance and Bill of Rights Act 2000). Developmental disability diagnoses include intellectual disability, autism spectrum disorder, attention deficit/hyperactivity disorder (ADD/ADHD), learning disability, cerebral palsy, problem hearing or seeing, speech or language disorder, seizure disorder, and developmental delay (Zablotsky et al., 2019).

As many as 18% of American children have a developmental disability diagnosis (Zablotsky et al., 2019). Many of them will be enrolled in special education in childhood, and will benefit from special services in adulthood, such as help provided by disability services at a college or university that addresses a learning disability. However, not all individuals with a developmental disability diagnosis have impairments that meaningfully affect functional capacities such as self-care, mobility, self-direction, or independent living. Approximately 8-10% of young adults have a diagnosis of a developmental disability and also evidence of such impairments that are likely to have lifelong impact (Hoyle et al., 2020; Laditka et al., 2022).

1.2 Social capital

When children are young, their families and the people they live with make up the majority of their social connections. As children start school, they begin to develop relationships with people outside of their homes. Schools provide a structure to nurture relationships, although that structure is typically limited to the school day and to activities at school. Children who are homeschooled may also have the opportunity to develop relationships beyond family if they participate in homeschool cooperatives, groups of homeschool families who meet together regularly to pursue similar academic goals. Homeschooled children, like those in traditional schools, may participate in community organizations and activities outside academic time. The activities children participate in beyond home and school provide an opportunity for children to expand their social networks.

Social capital is commonly defined as the benefits and resources provided through the connections in a person’s social network (Bourdieu, 1986; Kawachi & Berkman, 2014; Lin, 2001; Gelderblom, 2018). The size, density, composition, and frequency of contact within an individual’s social network affects the amount of social capital the individual may access. A person’s position within their social network or group influences their interactions with others and access to resources within the network (Lin, 2001). When people leverage their position and access the resources available within their social networks, they benefit through improved health, well-being, safety, and ability to cope (Ehsan et al., 2019; Kawachi & Berkman, 2014; Lin, 2001).

There are three widely recognized types of social capital found in individuals' social networks: bonding, bridging, and linking (Neves et al., 2019). We form bonding social capital through personal relationships among people who often share similar characteristics (Neves et al., 2019). These may be familial relationships or relationships formed because of shared interests or proximity. Bonding is often associated with reciprocal relationships, two or more individuals contributing to and benefitting from the relationship (Lin, 1999). We create bridging social capital by connecting with people and resources outside our personal social networks (Neves, et al., 2019), thus allowing us to use our social connections to obtain resources (Kramer et al., 2013). Linking social capital extends bridging. It connects people with those who have institutional authority or power (Szreter & Woolcock, 2003).

1.3 Mental health, social capital, and the transition to adulthood

Psychological distress is an indicator of mental health consisting of feelings of depression and anxiety as evidenced by an individual's mood and physical state (Mirowsky & Ross, 2003; Payton, 2009). Most people will experience distress during their lives (Payton, 2009). Psychological distress can be measured on a continuum with cut-off points indicating levels of mental health, including clinically significant levels that are consistent with diagnosable disorders (Kessler et al., 2002).

Social capital is grounded in the relationships people have with each other. Having more social capital is associated with lower levels of psychological distress among adults (Laurence & Kim, 2021; Song, 2011). Disparities in social capital access may explain the link between structural factors (e.g., age, gender, race-ethnicity, socioeconomic status) with psychological distress (Song, 2011). However, relationships are not always beneficial; conflict within relationships may cause stressors and problems that lead to greater psychological distress (Song et al., 2021), and potentially a loss of social capital.

Flourishing is another indicator of mental health, characterized by three dimensions: positive feelings, positive psychological functioning and positive functioning in community life (Keyes, 2002; Lamers et al., 2010). An individual's experience of flourishing can be measured using indicators of subjective emotional, social, and psychological well-being (Keyes, 2002). Studies examining the specific relationship between flourishing and social capital are few and limited (e.g., Guo & Qu, 2021). However, research indicates that individuals with more social capital typically have better mental health (Ehsan, 2019; Kawachi & Berkman, 2014).

1.4 Extracurricular activities

We commonly believe that extracurricular activities are useful for child development. Extracurricular activities are organized and structured activities that typically involve adult supervision and often take place outside of school hours (Bohnert et al., 2010; Mahoney et al., 2005). Participating in extracurricular activities is linked to educational attainment and achievement, reduced problem behaviors, positive psychosocial outcomes, and community involvement (Christison, 2013; Mahoney et al., 2005; Mahoney & Vest, 2012). Research suggests that extracurricular activities provide opportunities for children to learn and practice social skills and learning-related skills (e.g., following directions, problem solving), connect to their communities (Christison, 2013), and develop relationships with adult mentors outside their families (Ashtiani & Feliciano, 2018).

Our understanding of extracurricular activities as a way for children to develop social capital is limited. Researchers have examined the relationship between social capital developed through extracurricular activity and educational attainment (Ashtiani & Feliciano, 2018; Glanville et al., 2008; Long, 2020). Studying adolescent suicidal ideation, Langille and colleagues (2012) used extracurricular activity participation as a measure of social capital. They found no relationship between participation rates and suicidal ideation or attempt. However, other relational measures of social capital (e.g., trust in others) were associated with a reduction in the likelihood of suicidal ideation (Langille et al., 2012).

No studies have specifically examined the relationship between social capital developed through extracurricular activity and mental health outcomes among individuals with developmental disabilities. However, research has suggested that sports programs for individuals with and without disabilities provide opportunities to build social by promoting socially inclusive relationships, learn new skills, gain access to new and different places and experience positive perception as athletes (McConkey et al., 2013).

Group extracurricular activities (e.g., participating in organizations, religious groups, team sports) may provide opportunities for children to develop social relationships with peers and to build bonding or bridging social capital (Christison, 2013). Individual extracurricular activities (e.g., music/art lessons, individual sports) provide focused time and training devoted to individual skill acquisition and development and may provide ways for children to develop stronger relationships with coaches or mentors, which could provide linking social capital (Ashtiani & Feliciano, 2018). Because of the potential for bridging and linking social capital in group and individual activities, this study posits that social capital is one of the pathways involved in the association of extracurricular activities and mental health outcomes.

Few studies differentiate between the effects of individual and group activities (e.g., Metsäpelto & Pulkkinen, 2012). Most studies group all extracurricular activities together (e.g., Mahoney & Vest, 2012), are limited to specific activities such as sport or religious involvement (e.g., Glanville et al., 2008; Long, 2020), or focus on the comparison of structured and unstructured activities (e.g., Brooks et al., 2015).

A concern about child development is that too much participation in extracurricular activities may be detrimental for children and adolescents due to external pressures to participate and excessive time requirements (“over-scheduling”) (Mahoney et al., 2008). Threshold effects have been observed for high-achieving adolescents, with positive mental health effects dropping off for those involved in 10 or more hours per week of extracurricular activity (Randall & Bohnert, 2012). However, other studies found a positive relationship between extracurricular activity and mental health even at higher levels of participation (Boelens et al., 2022; Mahoney & Vest, 2012).

Children with disabilities may have fewer opportunities to participate in extracurricular activities with peers who do not have disabilities (Wagner et al., 2003). Although children with developmental disabilities typically have individualized education plans that support inclusion in school (Individuals with Disabilities Education Improvement Act 2004), these supports usually do not extend beyond state-mandated instructional time, even for school-sponsored activities (Agran et al., 2017; Agran et al., 2020). Researchers have identified a number of barriers that may prevent children with disabilities from participating in extracurricular activities including lack of accessible activities or transportation; lack of school professional or parent support; students' challenges with social or communication skills; or attending school geographically far from the child's home (Agran et al., 2017; Carter et al., 2010). Outside of school, community sports leagues may not offer sensory, physical, or cognitive accommodations that some children with developmental disabilities need to be successful. Researchers examining the participation of children with disabilities in extracurricular activities have linked this involvement with postsecondary educational outcomes (Palmer et al., 2017).

For children with disabilities, participating in extracurricular activities may provide additional opportunity to learn and practice social skills with peers and adults outside their homes (Brooks et al., 2015). Participating in inclusive activities (i.e., activities designed to involve students with and without disabilities) may increase social interaction between students with disabilities and their peers without disabilities (Siperstein et al., 2019).

There is little information about the relationship between extracurricular activity involvement and mental health outcomes for children with developmental disabilities when they enter young adulthood (Coster et al., 2012; Palmer et al., 2017). This study aims to describe the time children with and without disabilities spend in extracurricular activities and examine the relationship between the time spent in extracurricular activities in childhood and mental health outcomes in young adulthood using a longitudinal panel study.

1.5 Objectives and hypotheses

There is little information about the relationship between extracurricular activity involvement and young adulthood mental health outcomes for children with developmental disabilities (Coster et al., 2012; Palmer et al., 2017). I use longitudinal data from a nationally representative household panel survey to describe the time children with and without disabilities spend in extracurricular activities, and to examine the relationship between children's involvement with extracurricular activities and their mental health outcomes in young adulthood. I hypothesize that: (1) children with developmental disabilities will have less involvement in extracurricular activities than children without developmental disabilities; and (2) childhood extracurricular involvement will be associated with better mental health in young adulthood for people with and without developmental disabilities. This study is the first to examine the relationship between childhood extracurricular activities and mental health in young adulthood with results specific to people with developmental disabilities. Results can contribute to a better understanding of how people with developmental disabilities experience social capital and its relationship with mental health throughout childhood, adolescence, and young adulthood.

2. Method

2.1 Data source and study sample

I used data from the Panel Study of Income Dynamics (PSID, 1968-2017), its first Child Development Supplement (CDS, 1997, 2002, 2007), and its Transition into Adulthood Supplement (TAS, every-other year, 2005-2019). The PSID is the longest running nationally representative household panel study in the world. The PSID has followed individuals and their descendants for over 50 years (Duffy & Sastry, 2012; Johnson et al., 2018).

The first CDS followed up to two children per household (ages birth-12 years old in 1997, n=3,563). The CDS collected time diaries for 82% of these children (n=2,904). The time diaries include detailed records for children's time use on one entire random weekday (i.e., Monday-Friday) and one entire random weekend day (i.e., Saturday or Sunday; Hofferth et al., 2018). I used the CDS time diaries to calculate the amount of time children were involved in group and individual extracurricular activities.

The TAS began in 2005 and followed CDS participants from age 18-28 years. Using the CDS and TAS, I examined the relationship of childhood extracurricular involvement with psychological distress and flourishing as indicators of young adult mental health. Data within the CDS, TAS, and PSID are linked at the individual and family levels.

The data are nationally representative of noninstitutionalized individuals in the United States, with oversampling of African Americans and immigrants (Duffy & Sastry, 2012; Johnson et al., 2018). The item-specific non-response rate of the PSID is less than 2% (Duffy & Sastry, 2012). The PSID provides sampling weights to account for non-response. I use the sampling weights provided for the 1997 CDS to account for the original sample design.

2.2 Outcome variables

I used two measures of mental health as outcome variables: psychological distress and flourishing.

2.2.1 Psychological distress

The TAS used the Kessler K-6 scale (Kessler et al., 2002) to measure psychological distress among young adults aged 18-28. The scale is validated for use with adults with disabilities, excepting individuals with psychosis (Cronbach's alpha 0.88; Cornelius et al., 2013). The K-6 uses questions that ask: "how often in the past month did you feel:" "nervous," "hopeless," "restless or fidgety," "everything was an effort," "so sad nothing could cheer you up," and "worthless." Possible responses ranged from "1. All the time" to "5. None of the time." Responses are reverse scored from 0 to 4 (e.g., 0=None of the time).

The total scale score ranged from 0-24. A score of 13 or higher indicates clinically significant non-specific distress (Kessler et al., 2002). A score of 5 or greater indicates moderate levels of distress (Prochaska et al., 2005). I calculated the continuous psychological distress variable by averaging each individual's scores across all reported waves; I report weighted descriptive statistics and regression results using the continuous variable. I report weighted descriptive statistics for dichotomous psychological distress scores ("clinically significant psychological distress" [K-6 scale score >13] and "moderate psychological distress" [K-6 scale score >5]).

2.2.2 Flourishing

The TAS used the Mental Health Continuum-Short Form (MHC-SF) to measure flourishing. This scale is validated for adolescents and adults (Cronbach's alpha >0.70; Keyes, 2005; Lamers et al., 2011). The MHC-SF is comprised of 14 items across three subscales measuring emotional well-being, social well-being, and psychological well-being. Responses for each item ranged from "1. Never" to "6. Every day." The emotional well-being subscale is based on participants' responses to three questions, "In the last month, how often did you feel:" "happy," "interested in life," "satisfied?" The social well-being subscale is based on participants' responses to five questions, "In the last month, how often did you feel:" "that you had something to contribute to society," "that you belonged to a community like a social group, your school, or your neighborhood," "that our society is becoming a better place," "that people are basically good," and "that the way our society works made sense to you?" The psychological well-being subscale is based on participants' responses to six questions, "In the last month, how often did you feel:" "good at managing the responsibilities of your daily life," "that you have warm and trusting relationships with other people," "that you have experiences that challenged you to grow or become a better person," "confident to think or express your own ideas and opinions," "that you liked your personality," and "that your life had a direction or purpose?" Responses included a range of "1. Never" to "6. Every day."

The overall flourishing scale score was calculated by adding the mean scores from each of the three domains. The flourishing scale values range from 4-18. I calculated the flourishing variable by averaging each individual's scores across all reported waves. I use average flourishing scores as a continuous variable for the weighted descriptive statistics and in the regression models.

2.3 Exposure variables

I drew the main exposure variables from the CDS time diaries (Hofferth et al., 2018). I used the aggregate activity measures, which calculated the total time for an activity for each day, as proxies for extracurricular involvement. I created separate variables for the amount of time each child spent in individual and group extracurricular activities. I use extracurricular activity involvement as an operationalization of social concepts bridging and linking. Group extracurricular activities may provide opportunities for the development of bridging social capital as children have opportunities to develop relationships with peers outside their main social network (Christison, 2013); individual extracurricular activities may provide opportunities for the development of linking social capital as children have opportunities to develop relationships with mentors or coaches that may give them access to institutional resources (Ashtiani & Feliciano, 2018).

2.3.1 Group extracurricular activities

The CDS time diary aggregate files report all time spent in a particular activity, totaled for each child. Group extracurricular activities include involvement in after-school academic clubs, performing arts groups, school sports, volunteer/civic organizations, religious groups, sports groups outside of school, and child/youth/family organizations. These are coded in the CDS as "Organizational Activities:" "Volunteer, Helping Organizations," "Religious Groups," "Before/after school" and "Child/Youth/Family Organizations," "Miscellaneous Organizational Activities," "Special Interest Organizations," and "Sports/Active:" "Games/Practices – Team." I created one variable based on the mean frequency of that child's responses for all waves for which they completed a time diary. In univariate analysis, the mean of the average group activity variable was 30.3 minutes (SD 48.8). Almost half (47.2%) of the participants reported no time (0 minutes) in group activities in the time diaries. Using average activity as a continuous variable would have resulted in skewed results. Using only those with positive time reports would limit the sample and the statistical power of the analysis. Therefore, I created a 3-level variable for "group extracurricular activities." I used "no time in group activity" as the reference (0 minutes, coded as "1"). I used the 90th percentile (135 minutes) as a cut-off between "some" (> 0 < 135 minutes, coded "2") and "high" group activity (greater than or equal to 135 minutes, coded "3"). In the regression analyses, the 90th percentile cut-off provided the best fit of the model to the empirical data.

2.3.2 Individual extracurricular activities

Individual extracurricular activities include formal leisure activities outside the home, including individual sports, arts lessons, and individual religious practice. These are coded in the CDS as “Sports/Active: Classes/lessons,” “Religious Practice” and “Games/practices – Individual.” Over half (58.2%) of the participants reported no time (0 minutes) in individual activities in the time diaries. I created a 3-level variable for “individual extracurricular activities.” I used “no time in group activity” as the reference (0 minutes, coded as “1”). To parallel the group activity variable, I used the 90th percentile (91 minutes) as a cut-off between “some” (> 0 < 91 minutes, coded “2”) and “high” group activity (greater than or equal to 91 minutes, coded “3”).

2.3.3 Developmental disability

I stratified the analysis by the child’s developmental disability status (yes/no). I used a measure of developmental disability based on the *Developmental Disabilities Assistance and Bill of Rights Act* (2000). Hoyle and colleagues (2020) used this definition with CDS and TAS data. This definition requires the child to have one or more developmental disability diagnoses (ADD/ADHD, autism spectrum disorder, developmental delay, epilepsy, intellectual disability, learning disability, and severe problems with hearing, speech or vision). The CDS asks parents to report any of those diagnoses. In addition to the diagnosis, to fulfill the definition of developmental disability the child must have evidence of impairment in at least 3 of 7 functional categories: self-care, learning, language, mobility, self-direction, independent living, or economic self-sufficiency (DD Act 2000; Hoyle et al., 2020; Hoyle et al., 2021; J. Laditka et al., 2022). I measured functional impairment using CDS reports. Examples of functional measures include: self-care (e.g., “picks up after self” “never” or “almost never”, ages 6+), receptive and expressive language (e.g., “uses speech therapy” or special education for “speech & language”), learning (e.g., “physical or mental condition limits or prevents ability to do regular school work”), mobility (e.g., “activity limitation playing games/sports or attending school”), self-direction (e.g., Behavioral Problem Index ≥ 95th percentile for externalizing or internalizing behavior), independent living (e.g., “low responsibility” managing daily life), and economic self-sufficiency (e.g., “low financial responsibility”). Details of this measure are published (Hoyle et al., 2020).

2.4 Confounders

I controlled for network characteristics related to a person’s ability to access social capital resources (Lin, 2001) using proxies for network density (closeness to friends), environmental factors (support from parents), and an individual’s valuation of their self (self-esteem) are related to a person’s ability to access their social capital resources (Lin, 2001). Because individuals with developmental disabilities are more likely to experience emotional problems in childhood and having emotional problems can affect both participation in extracurricular activities and mental health outcomes, I also controlled for evidence of emotional problems in childhood. Full descriptions of the confounding variables are included in Figure 3.1.

Survey and sampling weights are provided by the PSID. Using these weights controls for sample selection, non-response, age, sex, race, immigrant status, family income, region, metropolitan statistical area, educational attainment, and employment status. The analytic procedures used for this analysis also used additional survey variables that account for the complex survey design, such as the shared characteristics and data clustering among descendants of the two national surveys that were combined to form the original PSID sample in the late 1960s, one of which primarily represented households with incomes below the poverty threshold (Hill, 1991).

2.5 Data analysis plan

To assess the sample needed to provide enough power for the analysis, I used a power calculator from Qualtrics.com (Qualtrics, 2021) to estimate the sample needed to generalize results to US children (population 74.2 million). I calculated the ideal sample size for this study would be 385 children (95% confidence interval; 5% margin of error). The CDS time diaries include information for randomly selected CDS respondents, about 2,900 children.

I used SAS 9.4 (Cary, NC) for all data cleaning and analysis. I included all CDS Time Diary participants who responded to at least one TAS wave and had positive sampling weights. The CDS includes information for individuals ages 3-17; the TAS includes information for individuals ages 18-28.

To provide a better understanding of children represented by the developmental disability variable, I include results of disability diagnosis/disorder by category. I report the percentage of all children with each diagnosis/disorder, the percentage of those represented in the developmental disability category based on the federal definition requiring evidence of lasting impairment, and the percentage of those not represented in the developmental disability category.

For the first hypothesis, “children with developmental disabilities would have less participation in extracurricular activities than children without developmental disabilities.” I compared how much time children reported being involved in extracurricular activities based on disability status using the SAS SURVEYMEANS procedure. I report means, confidence intervals, and p-values for each group. Consistent with recommendations from the American Statistical Association I report p-values for all comparisons and models as continuous values (Wasserstein et al., 2019).

I used psychological distress and flourishing as two measures of mental health for the second hypothesis, “childhood extracurricular involvement will be associated with better mental health in young adulthood for people with and without developmental disabilities.” I conducted weighted unadjusted and adjusted linear regressions using the SAS SURVEYREG procedure to assess the relationship between each primary exposure and each outcome. For the unadjusted analyses, I conducted separate analyses for each activity variable: group extracurricular activities and individual extracurricular activities. I conducted separate analyses for individuals with and without developmental disabilities to compare the relationship of extracurricular activities with mental health. I tested the validity of the regressions using four assumptions: the residuals follow a symmetric unimodal bell-shaped curve (Gaussian distribution), the scatterplot of residuals shows no patterns (independence assumption), the variability of the residuals remains constant (homoscedasticity), and error distribution remains normal. I used the PSID-provided survey weights in the adjusted analyses. I report the estimated β coefficient, 95% confidence interval and p-value for each model.

3. Results

The final sample for this analysis included CDS time diary participants with positive sampling weights and no missing values for the outcome variables (n=2,801). The sample for the regression analysis was 2,416 due to missing values for predictor variables, most notably “closeness to friends” (327 missing). “Closeness to friends” was only assessed in 2002 and 2007. Therefore, missing values are likely due to children who aged out after the first CDS wave. Results with and without “closeness to friends” were not meaningfully different from the results for the full model (not shown).

3.1 Developmental disability

Table 3.1 shows the distribution of developmental disabilities among the sample. Because I used the federal definition requiring evidence of lasting impairment, not all individuals with diagnoses were identified as having a developmental disability. Therefore, there are some individuals with diagnoses who were coded as having no developmental disability. For example, within the total sample, 11.1% (95% confidence interval (CI) 9.2-13.1) of children had a diagnosis of ADD/ADHD. However, 7.6% with ADD/ADHD had no lasting impairment, thus they are coded as having no developmental disability. Within the sample of children coded as having a developmental disability, 44.9% (CI 37.5-52.2) had ADD/ADHD. Among children with a diagnosis of ADD/ADHD, 38.7% had lasting impairments and met the federal definition of developmental disability. Overall, 9.6% (CI 7.8-11.4) of participants had a developmental disability (see Table 3.2).

3.2 Bivariate results

Table 3.2 shows the weighted demographics of the full sample and stratified by developmental disability. In univariate analysis, the mean of the average individual activity variable was 24.0 minutes (SD 40.4), the mean psychological distress score was 5.1 (standard deviation, SD 3.2), and the mean average flourishing score was 13.6 (SD 2.0) (univariate results not shown in tables). Individuals with and without developmental disabilities significantly differed in all mental health measures. On average, individuals with developmental disabilities had higher K-6 scores indicating greater psychological distress (6.0, CI 5.4-6.6) compared to children without developmental disabilities (5.0, CI 4.9-5.1). Children with developmental disabilities also had lower average flourishing scale scores (12.7, CI 12.4-13.1) compared to children without developmental disabilities (13.6, 13.5-13.7).

Children involved in any group activity spent an average of 60.4 minutes (CI 55.7-65.2) in those activities. Children without developmental disabilities spent an average of 10 minutes more (61.4 minutes, CI 56.3-66.4) in group activities compared to children without developmental disabilities (50.9 minutes, CI 30.4-71.4). Significantly more children without developmental disabilities (11.1%, CI 9.4-12.8) were involved in a high level of group activity (≥135 minutes) compared to those with developmental disabilities (5.1%, CI 1.5-8.8).

Children involved in any individual activity spent an average of 52.5 minutes (CI 48.4-56.6) in those activities. Children with developmental disabilities, on average, spent more time (58.0 minutes, CI 46.4-69.7) in individual activities compared to children without developmental disabilities (51.9 minutes, CI 47.5-56.3). Children with and without developmental disabilities had similar rates of participation in the three levels of individual activities.

Turning to parent reported extracurricular activities, most of children (90.7%, CI 89.0-92.3) participated in some activity. More children without developmental disabilities participated in volunteering (45.7% vs. 31.3%; p=0.001), unspecified extracurricular activities (72.5% vs. 55.1%; 0.008), and sports (60.2% vs. 52.0%; p=0.061). There were minimal differences in the proportions of children with and without developmental disabilities involved in lessons or religious activities.

3.3 Psychological distress and activity participation

Table 3.3 shows the psychological distress results of the unadjusted models for group extracurricular activities and individual extracurricular activities and the adjusted model (including both activity variables, disability status, sex, race, closeness to friends, self-esteem, support from parents, and emotional problems in childhood) for the full sample and stratified by developmental disability.

In unadjusted models, compared to no group activity, participating in “some” or “high” levels of activity was associated with lower psychological distress scores for all participants, “some” group activity was associated with lower psychological distress for individuals without developmental disabilities (β -0.49; CI -0.86- -0.12), and “high” group activity was associated with lower psychological distress for individuals with developmental disabilities (β -2.16; CI -3.95- -0.36). The results for individual activity were mixed and not significant in any of the models.

After controlling for confounders, “high” group activity remained significantly associated with lower psychological distress for individuals with developmental disabilities (β -2.00; CI -3.95- -0.05). All other significant group activity relationships from the unadjusted models were no longer significant.

Self-esteem and support from parents were significantly negatively associated with psychological distress for the full sample and for individuals without developmental disabilities. Emotional problems in childhood was a significant predictor of psychological distress for all groups.

3.4 Flourishing and activity participation

Table 3.4 shows the flourishing results of the unadjusted models for group extracurricular activities and individual extracurricular activities and the adjusted model (including both activity variables, disability status, sex, race, closeness to friends, self-esteem, support from parents, and emotional problems in childhood) for the full sample and stratified by developmental disability.

In unadjusted models, participating in some or high levels of activity was associated with higher flourishing scores in the full sample and for individuals without developmental disabilities. Only high levels of activity were significantly associated with higher flourishing scores for individuals with developmental disabilities (β 1.23, CI 0.12-2.35). After controlling for confounders, only “some” group activity remained modestly associated (p=0.091) with higher flourishing for the full sample (β 0.22; CI -0.04-0.47). All other significant group activity relationships from the unadjusted models were no longer significant.

In the unadjusted models only, “some” individual extracurricular activity was associated with higher flourishing scores for the full sample (β 0.32; CI 0.07-0.57). For individuals without developmental disability, there was a modest association between “some” individual activity and higher flourishing scores (β 0.26; CI -0.003-0.52; p=0.053). The results for individual activity were mixed in the adjusted models.

Being very close to friends in childhood was associated with higher level flourishing scores for all participants (β 0.72, CI 0.39-1.05). The effect size for closeness to friends was larger for individuals with developmental disabilities (β 1.43, CI 0.67-2.21) than for individuals without developmental disabilities. Self-esteem was associated with higher level flourishing scores in the full sample and for individuals without developmental disabilities. Having emotional problems in childhood was associated with lower average levels of flourishing for all groups.

4. Discussion

This study followed children for as long as 20 years to examine the relationships between childhood activities and young adult mental health. The results add to our understanding of the extracurricular activity experiences of children with and without developmental disabilities and how participating in these activities may influence their mental health in young adulthood. This study is the first to examine the potential link between childhood extracurricular involvement and mental health in young adulthood, comparing results for individuals with and without developmental disabilities.

Results partially supported the first hypothesis, that children with developmental disabilities would spend less time participating in extracurricular activities than children without disabilities. Children without developmental disabilities participated in a high level of group activities at twice the rate of children with developmental disabilities. However, the rates of children with and without disabilities participating in “some” group activity were similar. Individual activity participation was similar across groups. Previous research found that individuals with developmental disabilities were less likely to participate in extracurricular activities compared to children without disabilities (Agran et al., 2017; Agran et al., 2020; Coster et al., 2012). However, these studies only measured whether or not an individual participated in activities. I am unaware of any studies that have compared the amount of time children with and without disabilities spend in activities.

Results also partially supported the second hypothesis, that childhood extracurricular involvement would be associated with better mental health in young adulthood for people with and without developmental disabilities. Children who participated in group activities had lower levels psychological distress and higher levels of flourishing in young adulthood. These findings were similar to those of previous research (Mahoney & Vest, 2012), which found a similar relationship. Although Mahoney and Vest (2012) used the CDS and TAS data, they used only dichotomous activity variables that combined individual and group activities. In this study, individual activities were only associated with greater flourishing in the unadjusted model. The relationship between group extracurricular activities and mental health was present for both participants with and without developmental disabilities.

The results suggest a threshold level of effect for individuals with developmental disabilities. Unlike previously examined threshold effects for activity participation among high achieving students (Randall & Bohnert, 2012), these results suggest that individuals with developmental disabilities may need higher levels of group extracurricular involvement to experience positive mental health effects. I am unaware of any studies examining threshold effects for individuals with developmental disabilities. This result could alternatively indicate that individuals who have high levels of involvement in extracurricular activities share characteristics linked with better mental health. This study proposed that social capital may be a mechanism behind the extracurricular activity and mental health relationship; if so, children with developmental disabilities may require more time in groups to develop relationships and form bonds through which they can build and access social capital. Group activities may also provide space for children to develop the social skills needed to capitalize on those relationships (McDaniel et al., 2022). These results suggest that, while group activities are beneficial for both children with and without developmental disabilities, children with developmental disabilities may experience greater effects when involved in higher levels of activity. It is possible that differences between groups (e.g., duration or structure of the activity) may influence the relationship between the activity and the observed mental health outcomes. Future analyses may also look at potential differences between types of group activities.

Although the potential confounders in the models did not provide information on the relationship between the main exposures of interest and outcomes, these confounders may have implications for the development of social capital. Self-esteem and support from parents were associated with less psychological distress for those without developmental disabilities. Self-esteem also promoted flourishing for those without developmental disabilities; closeness to friends was associated with higher flourishing scores for all participants. The differences between people with and without developmental disabilities could potentially be an issue of sample size; there were fewer people with developmental disabilities compared to those without developmental disabilities. Further research is needed to better understand the relationships between these factors and mental health outcomes, specifically for people with developmental disabilities.

4.1 Limitations and strengths

The data did not allow for assessment of the quality of activities or account for factors such as the size of groups or composition of groups. These results do not tell us anything about the effects of inclusive groups comprised of children with and without developmental disabilities or groups that include only children with or without developmental disabilities.

I averaged measures for time in activities and mental health outcomes across waves. Doing so may smooth out individual variations and potentially mask fluctuations or changes over time. This approach may also oversimplify the dynamic nature of children’s activity participation and the relationship with mental health outcomes. On the other hand, this approach may provide more stable results that are less likely to be affected by random variation across time in individuals’ responses about activities and outcomes.

I did not control for parental factors including socioeconomic status, parental mental health, or available resources (e.g., cost of activities and availability of transportation). The lack of these controls may limit our understanding of how parental characteristics and resources may impact their children’s participation in extracurricular activities and subsequent mental health. Including these controls would introduce potential for overcontrolling.

This study is limited by potential selection bias due to the composition of the original CDS, which began in 1997 and only followed up to two children per family.

Therefore, it is possible that children with disabilities were disproportionately excluded. While the subsequent CDS beginning in 2014 includes all household children, the current analysis only focuses on the original cohort. Using the 1997 CDS cohort allowed me to follow a consistent group of children for up to three waves of the CDS and into young adulthood in the TAS. All children from the 1997 CDS cohort had entered into adulthood and were eligible for the TAS by 2014.

Children in the 1997 cohort had limited exposure to social media. Social media has been linked to poor mental health, prompting the US Surgeon General to issue an advisory on the social media use among adolescents (US Public Health Service, 2023). However, emerging research suggests the available social capital within online social networks may be beneficial (Hussenoeder, 2022). The CDS began asking about social media use in 2014. Extending this work using the CDS 2014 cohort would allow for further examination of online social capital.

Attrition between CDS waves and the TAS may also be a source of bias, as individuals who participated in subsequent waves may differ from those who did not. The PSID and its supplements generally have high response rates (≥80%), which is likely to have limited bias due to attrition (McGonagle & Sastry, 2015).

Using a definition limiting the developmental disability sample to those with evidence of lifelong disability was a limitation and a strength. The results may only apply to those with lifelong disability. Children with developmental disability diagnoses without evidence of lifelong disability may experience disparities in extracurricular activities and young adult mental health outcomes. However, including children with and without lifelong disabilities in the developmental disability group would create more variation within the group due to differences in support needs. Therefore, the limited definition of developmental disability within this study is also a strength as it is more likely to identity a group of people with similar needs and experiences—individuals who may experience greater barriers to extracurricular activity participation and social capital formation, and more problems with mental health.

This study has several additional strengths. I used multiple measures of activity and two outcomes. By capturing various aspects of engagement, we have a more comprehensive view of childhood activity involvement and its relationship with young adulthood mental health. Social capital is a multidimensional concept. Although the activity measures used in this study do not capture the totality of individual social capital, separating group and individual activities may provide a clearer picture of the *potential* function of social capital within the relationship between extracurricular activities and mental health. Group extracurricular activities were associated with lower distress and greater flourishing. Group extracurricular activities may foster bonding and bridging social capital (Christison, 2013) which may provide access to support and resources that support mental health. There was not a similar relationship between individual extracurricular activities and distress or flourishing. Due to their structure, individual activities may be more likely to encourage linking social capital which is associated with academic achievement and career advancement (Ashtiani & Feliciano, 2018; Szreter & Woolcock, 2004) but may not be strongly linked to mental health outcomes. This study highlights the need for further research in this area.

Population-level research often excludes or does not identify people with developmental disabilities (Anderson et al., 2019; Krahn & Havercamp, 2019;

Havercamp et al., 2019). Most large studies including people with developmental disabilities are limited to cross-sectional data (e.g., Anderson et al., 2019; Landes et al., 2019, 2020; Zablotsky et al., 2019) or rely on special registries of people with developmental disabilities (e.g., Cooper et al., 2020; Smith et al., 2020). The longitudinal design of this study followed children through multiple waves of data collection. This approach provided information for multiple timepoints, and allowed me to examine relationships between childhood activities and young adulthood outcomes. The time diaries provided a detailed account of children's activities. Previous work has established time diaries as a valid and reliable form of data collection for studying time use (e.g., Larson & Verma, 1999).

By exploring the impact of different levels of activity involvement, this study highlighted potential nonlinear relationships between activity participation and mental health, helping to identify critical thresholds at which the effects of participating in activities change. Understanding these threshold effects can provide needed information for policymakers, educators, and parents making informed decisions about children's activity involvement.

This study offers feasibility for future analysis with later waves of the CDS once the children in the study are old enough. Later waves of the CDS included a larger sample which will allow us to expand on these findings. The later waves will also permit an examination of the roles of social media in children's social capital formation. The results of this study may have relevance for a wide range of children and families across the United States.

4.2 Implications for policy and practice

These findings suggest it would be useful to increase ways for all children to participate in extracurricular activities. As children with disabilities may experience barriers to participation, our findings also support legislation and policies similar to Section 504 of the Rehabilitation Act of 1973 and the Americans with Disabilities Act, which prohibit discrimination based on disability for specific programs and services, to reduce barriers and promote participation in extracurricular activities. Families need resources (time and money) to allow/encourage their children to participate in activities. For children with developmental disabilities, finding activities that are structured to fit their needs and provide opportunities for high levels of time involvement may be important. One of the goals of Healthy People 2030 is to reduce psychological distress among people with disabilities. Promoting and supporting participation in group extracurricular activities may be a way to address this goal.

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Figure 3.1. Variable list

	Variables	Description
Main exposures	Group extracurricular activities**	Involvement in volunteer/civic organizations, religious groups, sports groups, and child/youth/family organizations (e.g., hospital volunteer, YMCA, church/synagogue, Little League, competitive sports, after-school academic club, performing arts groups, etc.)
	Individual extracurricular activities**	Involvement in formal leisure activities outside the home, including individual sports and arts lessons
Stratifying variable	Developmental disability*	One or more developmental disability diagnoses (ADD/ADHD, autism spectrum disorder, developmental delay, epilepsy, intellectual disability, learning disability, and severe problems with hearing, speech or vision), and evidence of impairment in at least 3 of 7 functional categories: self-care, learning, language, mobility, self-direction, independent living, or economic self-sufficiency
Outcomes	Clinically significant distress***	Kessler K-6 scale (Kessler et al., 2002); scale score (0-24); used to measure psychological distress. The K-6 uses asks, “how often in the past month did you feel:” “nervous,” “hopeless,” “restless or fidgety,” “everything was an effort,” “so sad nothing could cheer you up,” and “worthless” Possible responses ranged from “1. All the time” to “5. None of the time.” Responses are reverse scored from 0 to 4 (e.g., 0=None of the time). ($\alpha = 0.88$)
	Flourishing***	Mental Health Continuum-Short Form (Keyes, 2005; Lamers et al., 2011); scale score (4-18); based on three subscales: emotional well-being (“In the last month, how often did you feel:” “happy,” “interested in life,” “satisfied?”), social well-being (“In the last month, how often did you feel:” “that you had something to contribute to society,” “that you belonged to a community like a social group, your school, or your neighborhood,” “that our society is becoming a better place,” “that people are basically good,” and “that the way our society works made sense to you?”), psychological well-being (“In the last month, how often did you feel:” “good at managing the responsibilities of your daily life,” “that you have warm and trusting relationships with other people,” “that you have experiences that challenged you to grow or become a better person,” “confident to think or express your own ideas and opinions,” “that you liked your personality,” and “that your life had a direction or purpose?”). Responses included a range of “1. Never” to “6. Every day.” ($\alpha > 0.70$)

Confounders	Closeness to friends*	Child reported closeness to friends. The child was asked, “How close do you feel towards your friends? Would you say not very close, fairly close, quite close, or extremely close?” Answers were scored 1 “not very close” to 4 “extremely close”; for this analysis, I created a dichotomous variable where 1= “quite close” or “extremely close” in at least one reported wave, 0=no reports of “quite close” or “extremely close” in any wave. This question was only asked in the 2002 and 2007 waves. Used as a proxy for network density.
	Support from parents*	Home Observation for Measurement of the Environment-Short Form (Bradley & Caldwell, 1984); scale score 7-27; used to measure quality and quantity of support provided by parents; this scale was only administered in the 1997 wave. (α = 0.90). Used as a proxy for environmental factors.
	Self-esteem*	Items from the Marsh Self-Description Questionnaire (CDS 2010a,b); scale score 1-5; measured child beliefs about their self; children rated the following statements 1 “never” to 5 “always”: “Overall, I have a lot to be proud of,” “I can do things as well as most people,” “A lot of things about me are good,” “I’m as good as most other people,” “Other people think I am a good person,” “When I do something, I do it well.” This set of questions was only used in the 2002 and 2007 waves. (α = 0.82) Used as a proxy for individual’s valuation of their self.
	Emotional problems in childhood*	Presence of emotional problems in childhood as evidenced by response of yes to any CDS wave “ Has (CHILD) ever seen a psychiatrist, psychologist, doctor, or counselor about an emotional, mental, or behavioral problem?”
	Survey Weights*	Provided by the PSID; controls for sample selection, non-response, age, sex, race, immigrant status, family income, region, metropolitan statistical area, educational attainment, and employment status

Source of data: *CDS (1997, 2002, 2007) **CDS Time Diaries (1997, 2002, 2007) ***TAS (every-other year, 2005-2019)

Table 3.1. Percent distribution of diagnoses and developmental disability, United States: Results from the Panel Study of Income Dynamics and its supplements (Child Development Study and Transition into Adulthood Supplement), 2002-2019*

	Percent with Developmental Disability by Diagnosis	Percent with Diagnosis, by Developmental Disability Status					
		All (n=2801)		No Developmental Disability (n=2506)		Developmental Disability (n=295)	
Diagnosis	%	%	(95% CI)	%	(95% CI)	%	(95% CI)
Speech impairment	31.5	11.2	(9.5-12.9)	**8.5**	**(7.0-10.0)**	**36.7**	**(28.3-45.2)**
ADD/ADHD	38.7	11.1	(9.2-13.1)	**7.6**	**(6.0-9.2)**	**44.9**	**(37.5-52.2)**
Learning disability	40.2	10.0	(8.3-11.8)	**6.6**	**(5.0-8.2)**	**42.0**	**(35.8-48.2)**
Developmental delay	59.2	9.1	(7.4-10.7)	**4.1**	**(3.1-5.1)**	**55.8**	**(47.7-64.0)**
Vision impairment	20.6	8.0	(6.5-9.5)	**7.0**	**(5.4-8.6)**	**17.1**	**(12.0-22.2)**
Hearing impairment	25.6	3.8	(2.8-4.8)	**3.1**	**(2.1-4.1)**	**10.2**	**(7.0-13.3)**
Epilepsy with seizures	25.5	0.6	(2.0-4.2)	**2.6**	**(1.5-3.6)**	**8.2**	**(4.7-11.8)**
Autism spectrum disorder	68.4	0.8	(0.3-1.2)	**0.3**	**(0.2-0.4)**	**5.7**	**(1.6-9.7)**
Intellectual disability	59.7	0.5	(0.1-1.0)	**0.2**	**(0.0-0.5)**	**3.4**	**(0.8-6.1)**

*Results weighted for survey design and sampling weights; CI= 95% confidence interval; condition percentages sum to more than 100 due to some children with multiple diagnoses; speech, vision, and hearing impairments are severe, not correctable with standard equipment.

All results p<.0001

Table 3.2. Weighted sociodemographic characteristics of the sample, stratified by developmental disability. United States: Results from the Panel Study of Income Dynamics and its supplements (Child Development Study 1997-2007 and Transition into Adulthood Supplement 2005-2019)[a]

			Developmental Disability				
	All (n=2801)	(95% CI)	No (n=2506)	(95% CI)	Yes (n=295)	(95% CI)	p-value
Developmental disability (yes), %	9.6	(7.8-11.4)					
Female, %	51.0	(48.9-53.1)	**53.2**	**(51.0-55.4)**	**30.2**	**(24.4-36.2)**	**<.0001**
Race/Ethnicity, %							
Non-Hispanic White	63.1	(57.6-68.5)	63.6	(58.0-69.2)	57.8	(48.4-67.3)	0.203
Non-Hispanic Black	16.5	(12.4-20.7)	**15.5**	**(11.6-19.5)**	**25.8**	**(17.6-34.1)**	**0.0003**
Hispanic	12.6	(8.8-16.4)	12.8	(8.7-16.9)	10.6	(4.5-16.7)	0.540
Other	7.8	(5.9-9.7)	8.0	(6.1-10.0)	5.7	(1.3-10.1)	0.361
Age at time diary, mean	11.0	(10.8-11.2)	11.0	(10.9-11.2)	10.6	(10.0-11.2)	0.120
<u>Mental health outcomes</u>							
Clinically significant psychological distress (K-6 scale score >13), %	3.8	(3.1-4.5)	**3.6**	**(3.0-4.2)**	**5.7**	**(3.5-8.0)**	**0.022**
Moderate psychological distress (K-6 scale score >5), %	46.1	(43.8-48.4)	**45.0**	**(42.5-47.5)**	**56.4**	**(46.4-66.3)**	**0.038**
Psychological Distress, Kessler K-6, mean	5.1	(5.0-5.2)	**5.0**	**(4.9-5.1)**	**6.0**	**(5.4-6.6)**	**0.001**
Flourishing Scale, mean	13.5	(13.4-13.7)	**13.6**	**(13.5-13.7)**	**12.7**	**(12.4-13.1)**	**<.0001**
<u>CDS Time Diary-reported activity</u>							
Time reported in group activities[b], %							
None	45.9	(42.8-49.1)	45.5	(42.2-48.7)	50.3	(43.6-57.0)	0.150
Some (> 0 <135 minutes)	43.5	(40.7-46.4)	43.4	(40.5-46.4)	44.6	(38.1-51.1)	0.727
High (≥135 minutes)	10.5	(9.0-12.1)	**11.1**	**(9.4-12.8)**	**5.1**	**(1.5-8.8)**	**0.036**

Average time in group activities[c] (minutes) (n=1338)	60.4	(55.7-65.2)	61.4	(56.3-66.4)	50.9	(30.4-71.4)	0.333
Time reported in individual activities[b], %							
None	59.1	(55.3-63.0)	58.9	(54.9-62.9)	61.1	(54.8-67.4)	0.507
Some (> 0 <110 minutes)	33.6	(30.1-37.0)	33.9	(30.2-37.6)	30.0	(23.2-36.8)	0.321
High (≥110 minutes)	7.3	(5.8-8.9)	7.2	(5.4-8.9)	8.9	(4.9-12.9)	0.418
Average time in individual activities[c] (minutes) (n=1050)	52.5	(48.4-56.6)	51.9	(47.5-56.3)	58.0	(46.4-69.7)	0.327
Parent-reported activity							
Participated in any extracurricular activity (yes), %	90.7	(89.0-92.3)	90.9	(89.2-92.7)	88.0	(81.8-94.2)	0.321
Religious activity (yes), %	46.7	(43.1-50.3)	46.7	(43.0-50.5)	46.2	(38.1-54.3)	0.894
Sports (yes), %	59.3	(56.4-62.2)	60.2	(57.1-63.2)	52.0	(43.7-60.3)	0.061*
Volunteering (yes), %	44.2	(41.3-47.1)	**45.7**	**(42.3-49.0)**	**31.3**	**(24.9-37.7)**	**0.001**
Lessons (yes), %	43.6	(40.6-46.6)	43.9	(40.9-46.9)	41.3	(35.0-47.7)	0.391
Extracurricular activity, not specified (yes), %	71.1	(66.6-75.7)	**72.5**	**(67.7-77.3)**	**55.1**	**(42.2-68.0**	**0.008**
Confounders							
Very close to friends in childhood (yes), %	84.9	(82.4-87.3)	**86.1**	**(83.5-88.7)**	**74.7**	**(68.3-81.2)**	**0.0004**
Support from parents in childhood (HOME Scale), mean	19.6	(19.33-19.9)	**19.7**	**(19.4-20.0)**	**18.3**	**(17.7-18.9)**	**<.0001**
Self-esteem (Global Self-Concept Scale), mean	4.0	(4.0-4.1)	**4.1**	**(4.0-4.1)**	**3.8**	**(3.7-3.9)**	**<.0001**
Emotional problems in childhood (yes), %	26.7	(23.7-29.6)	**23.0**	**(20.3-25.7)**	**61.1**	**(53.1-70.2)**	**<.0001**

[a] Results account for the survey design and sampling weights; CI= 95% confidence interval.
[b] Time recorded on one weekday and one weekend day for sampled children.
[c] Among respondents reporting >0 activity time in CDS time diaries.
*p<.10

Table 3.3. Linear regression results of psychological distress for individuals with and without developmental disabilities, ages 18-28, United States, Results from the Panel Study of Income Dynamics and its supplements (Child Development Study and Transition into Adulthood Supplement), 2002-2019

	All (n=2416)			No Developmental Disability (n=2173)			Developmental Disability (n=280)		
Model	*β*	95% CI	p-value	*β*	95% CI	p-value	*β*	95% CI	p-value
Unadjusted^									
Group extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	**-0.45**	**(-0.82- -0.08)**	**0.019**	**-0.49**	**(-0.86- -0.12)**	**0.010**	-0.01	(-1.35-1.32)	0.984
High	**-0.48**	**(-0.96- -0.01)**	**0.047**	-0.33	(-0.82-0.17)	0.188	**-2.16**	**(-3.95- -0.36)**	**0.019**
Individual extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	-0.25	(-0.62-0.11)	0.168	-0.27	(-0.61-0.07)	0.118	0.13	(-1.41-1.68)	0.861
High	0.03	(-0.79-0.85)	0.948	0.04	(-0.79-0.87)	0.932	-0.11	(-2.22-1.99)	0.915
Adjusted^									
Group extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	-0.18	(-0.53-0.18)	0.328	-0.16	(-0.53-0.21)	0.392	0.12	(-1.27-1.51)	0.865
High	-0.01	(-0.57-0.55)	0.969	0.14	(-0.39-1.66)	0.604	**-2.00**	**(-3.95- -0.05)**	**0.045**
Individual extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	-0.04	(-0.44-0.37)	0.856	-0.08	(-0.43-0.27)	0.653	0.37	(-1.17-1.92)	0.630
High	0.16	(-0.66-0.97)	0.701	0.19	(-0.60-0.97)	0.636	-0.20	(-2.41-2.00)	0.854
Developmental disability, yes	0.49	(-0.15-1.12)	0.129	--	--	--	--	--	--
Female, yes	**0.69**	**(0.37-1.0)**	**0.001**	**0.61**	**(0.30-0.91)**	**0.0002**	**1.72**	**(0.52-2.93)**	**0.006**
Race									
Non-Hispanic White	ref	ref	ref	ref	ref	ref	ref	ref	ref
Non-Hispanic Black	0.12	(-0.38-0.62)	0.625	0.16	(-0.33-0.65)	0.519	0.04	(-1.34-1.42)	0.952

Hispanic	-0.13	(-0.71-0.45)	0.654	-0.09	(-0.68-0.50)	0.764	-0.47	(-2.06-1.11)	0.551
Other	-0.16	(-1.0-0.68)	0.700	-0.29	(-1.10-0.51)	0.468	1.99	(-3.99-7.97)	0.508
Very close to friends, yes	-0.36	(-0.83-0.10)	0.123	-0.22	(-0.75-0.31)	0.414	-1.11	(-2.39-0.18)	0.091*
Self-esteem	**-0.87**	**(-1.2- -0.54)**	**<.0001**	**-1.04**	**(-1.36- -0.72)**	**<.0001**	0.21	(-0.84-1.26)	0.689
Support from parents	**-0.06**	**(-0.10- -0.01)**	**0.030**	**-0.07**	**(-0.11- -0.02)**	**0.010**	0.03	(-0.12-0.17)	0.725
Emotional problems in childhood, yes	**0.96**	**(0.59-1.32)**	**<.0001**	**0.88**	**(0.49-1.28)**	**<.0001**	**1.40**	**(0.35-2.44)**	**0.010**

^Results weighted for survey design and sampling weights; CI: 95% confidence interval
*p<.10

Table 3.4. Linear regression results of flourishing for individuals with and without developmental disabilities, ages 18-28, United States, Results from the Panel Study of Income Dynamics and its supplements (Child Development Study and Transition into Adulthood Supplement), 2002-2019

	All (n=2416)			No Developmental Disability (n=2173)			Developmental Disability (n=280)		
Model	*β*	95% CI	p-value	*β*	95% CI	p-value	*β*	95% CI	p-value
Unadjusted^									
Group extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	**0.48**	**(0.22-0.74)**	**0.0004**	**0.47**	**(0.21-0.73)**	**0.001**	0.53	(-0.13-1.20)	0.114
High	**0.73**	**(0.43-1.02)**	**<.0001**	**0.63**	**(0.32-0.94)**	**0.0001**	**1.23**	**(0.12-2.35)**	**0.030**
Individual extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	**0.32**	**(0.07-0.57)**	**0.014**	0.26	(-0.003-0.52)	0.053*	0.63	(-0.24-1.49)	0.153
High	0.20	(-0.33-0.74)	0.449	0.17	(-0.42-0.75)	0.574	0.57	(-0.32-1.46)	0.204
Adjusted^									
Group extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	0.22	(-0.04-0.47)	0.091*	0.18	(-0.08-0.44)	0.172	0.29	(-0.49-1.09)	0.453
High	0.22	(-0.07-0.51)	0.130	0.17	(-0.13-0.47)	0.259	0.53	(-0.26-1.33)	0.186
Individual extracurricular activities									
None	ref	ref	ref	ref	ref	ref	ref	ref	ref
Some	0.03	(-0.19-0.25)	0.763	-0.01	(-0.24-0.22)	0.939	0.45	(-0.53-1.43)	0.363
High	0.02	(-0.44-0.47)	0.947	-0.05	(-0.55-0.44)	0.843	0.25	(-0.81-1.31)	0.634
Developmental disability, yes	**-0.41**	**(-0.80- -0.02)**	**0.039**	--	--	--	--		--
Female, yes	0.16	(-0.08-0.40)	0.199	0.16	(-0.08-0.40)	0.179	0.23	(-0.49-0.94)	0.526
Race									
Non-Hispanic White	ref	ref	ref	ref	ref	ref	ref	ref	ref
Non-Hispanic Black	-0.17	(-0.42-0.08)	0.181	-0.23	(-0.51-0.04)	0.091*	0.20	(-0.39-0.80)	0.501

Hispanic	-0.35	(-0.72-0.02)	0.061*	**-0.48**	**(-0.87- -0.09)**	**0.016**	**1.05**	**(0.28-1.82)**	**0.008**
Other	-0.25	(-0.64-0.13)	0.191	-0.29	(-0.68-0.10)	0.139	0.13	(-2.47-2.72)	0.923
Very close to friends, yes	**0.72**	**(0.39-1.05)**	**<.0001**	**0.56**	**(0.20-0.93)**	**0.003**	**1.43**	**(0.67-2.21)**	**0.0004**
Self-esteem	**0.94**	**(0.74-1.13)**	**<.0001**	**1.03**	**(0.83-1.23)**	**<.0001**	0.36	(-0.24-0.94)	0.234
Support from parents (HOME scale)	0.02	(-0.01-0.05)	0.141	0.02	(-0.01-0.05)	0.125	-0.01	(-0.09-0.08)	0.884
Emotional problems in childhood, yes	**-0.42**	**(-0.63- -0.20)**	**0.0002**	**-0.37**	**(-0.61- -0.13)**	**0.003**	**-0.71**	**(-1.18- -0.24)**	**0.004**

^Results weighted for survey design and sampling weights; CI: 95% confidence interval

*p<.10

CHAPTER 4: “NOT A ONE-WAY STREET”:

USING PHOTOVOICE TO UNDERSTAND HOW YOUNG ADULTS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES EXPERIENCE INTERDEPENDENCE

1. Introduction

Society relies on the give and take of its members. No one person has all the resources needed to thrive. People must engage with each other and exchange resources to obtain the goods, knowledge, skills, and supports needed to live the lives they want (Bourdieu, 1986; Lin, 1999, 2001; Putnam, 2000). This interpersonal “give and take,” or interdependence, is not equally shared among all people. People with intellectual or developmental disabilities often have access to fewer people with whom they can develop meaningful reciprocal social relationships (Giesbers et al., 2020; Mithen et al, 2015; Presnell & Keesler, 2021). Their social connections are also often shaped or limited by external systems and influences (Hall & Kramer, 2009; Hamilton et al., 2017; Kramer et al., 2013; Riddel et al., 2001a). For example, individuals with intellectual and developmental disabilities may not drive and are therefore dependent on others to access places outside their homes. They may also experience limited job opportunities. These external factors can influence the activities and people they can access.

1.1 Intellectual and Developmental Disabilities

Approximately 18% of American children have a developmental disability diagnosis (Zablotsky et al., 2019). Developmental disability is an umbrella term encompassing both congenital and acquired disabilities originating before age 22 years. Conditions that may cause developmental disability include intellectual disability, autism spectrum disorder, attention deficit/hyperactivity disorder (ADHD), learning disability, cerebral palsy, problems hearing or seeing, speech or language disorder, seizure disorder, and developmental delay (Zablotsky et al., 2019). Not all people with these diagnoses will require specialized support throughout life. However, a recent study using the federal definition of the Developmental Disabilities Assistance and Bill of Rights Act (2000) found that about 10% of young adults have a developmental disability that will require such support (Hoyle et al., 2020).

This study focuses on individuals with developmental disabilities that require lifelong support. Among them are the 1% to 2% of Americans with an intellectual disability (Anderson et al., 2019; Hoyle et al., 2020). Intellectual disability is a developmental disability characterized by “significant limitations in both intellectual functioning and adaptive behavior” (Schlalock et al., 2021, p.1). Intellectual functioning includes the ability to learn, reason, and solve problems, and is often measured by intelligence quotient. Adaptive behaviors include conceptual skills (e.g., language and literacy, number concepts and self-direction), social skills (e.g., interpersonal skills, social problem solving) and practical skills (e.g., occupational skills and activities of daily living such as bathing or walking) (Schlalock et al., 2021).

Intellectual disability is itself a developmental disability, and many people with intellectual disability have one or more of the other developmental disability diagnoses. For example, many people with intellectual disability also have communication impairments (Memisevic & Hadzic, 2013; Smith et al., 2020). However, effects of intellectual disability for individuals and those who care for them often differ substantially from those associated with other developmental disability diagnoses. To acknowledge that difference, I adopt the common convention of referring to the population with intellectual disability or any of the other developmental disabilities as having “intellectual and developmental disabilities.”

Although people with intellectual and developmental disabilities may share similar diagnoses or conditions, their abilities and needs vary greatly (Cooper et al., 2015; Smith et al., 2020). It is therefore often desirable to focus studies of this population on people who all have a diagnosis in common, such as autism spectrum disorder. On the other hand, people with intellectual and developmental disabilities often report experiencing similar life experiences, so it can also be useful to study this population as a group. For example, people with intellectual and developmental disabilities often share similar experiences such as participating in special education and needing additional support from others throughout their lives. In this study, all participants shared the experience of a specific educational program together, and all qualified for that program by having similar abilities. I therefore judged that it was appropriate to study the program participants as a group, while recognizing their differing abilities.

Until the mid-20th century, Americans with intellectual and developmental disabilities often received care in residential institutions where they experienced isolation from others (Wehmeyer, 2003). The work of people with disabilities and other advocates (Scott et al., 2008) led to federal legislation (e.g., Individuals with Disabilities Education Act 1997; Section 504 of the 1973 Rehabilitation Act; Developmental Disabilities and Bill of Rights Act 2000) that provided supports and services to help people with intellectual and developmental disabilities experience greater inclusion in schools and community spaces, and employment (Kleinert et al., 2012). Among people with intellectual and developmental disabilities using long term supports and services, 59% live with a family member, 25% in a group setting for people with intellectual and developmental disability, 11% in their own home, and 5% with a host or foster family (Larson et al., 2021). Despite intense efforts toward greater inclusion, people with intellectual and developmental disabilities often do not experience full community integration (Scott et al., 2008) and may experience more negative social, economic, and physical outcomes than people without disabilities (Hoyle et al., 2020).

People with intellectual and developmental disabilities often rely on a system of specialized supports to improve their functioning and overall well-being (Schlalock et al., 2021). This study considers how the interaction between young adults with intellectual and developmental disabilities and the people they are connected to contributes to a system of support in a college or university setting. I explore the roles of the individual with an intellectual or developmental disability as one who both receives support from, and gives support to, others.

1.2 Transition to adulthood

As people age into adulthood, they often leave the care and support of their families and transition into traditional adult roles like student, employee, spouse, or parent. People with intellectual and developmental disabilities are more likely to remain in dependent roles in young adulthood than people without disabilities (Giesbers et al., 2020; Walmsley, 1993). However, greater inclusion in primary and secondary education has led to increased demand for postsecondary educational opportunities for people with intellectual and developmental disabilities (Hart et al., 2006). Over 300 colleges in the United States currently provide programs developed specifically for young adults with intellectual and developmental disabilities (Think College, 2022).

Postsecondary education programs, much like traditional college and university programs, promote independence, integration into the community, and job skills needed for employment (Plotner & May, 2017; Think College, 2022). Universities began developing these programs in the late 1990s and early 2000s in response to interest in continuing education opportunities for individuals with intellectual disability after high school (Hart et al., 2006; Stodden & Whelley, 2004). For students with intellectual and developmental disabilities, their primary motivations for attending college are similar to those of their peers without disabilities: to gain knowledge and independence and improve their employment opportunities (Plotner & May, 2017).

College programs differ and may include curriculums that are separate from, parallel to, or integrated with the college experiences of traditionally matriculated students (Hart et al., 2006; Stodden & Whelley, 2004). Students may be eligible to earn a degree or certificate while completing the postsecondary program, depending on the accreditation and structure of the program (Plotner & May, 2017). Students receive the same supports and benefits of being on a college campus as traditionally matriculated students (e.g., career services, fitness centers, clubs) and additional supports including program staff, person-centered planning, and academic and social mentors (Plotner & May, 2017). Specialized postsecondary education programs may remove some of the social and educational barriers that currently exist for many people with intellectual and developmental disabilities.

1.3 Theoretical foundation

The social model of disability is built on the notion that people exist, operate in, and are thus a product of their relationships with others (Reindal, 1999). Disability results from a lack of fit between the person and their environment (Halfon et al., 2012). The social model recognizes the lived experiences of people with disabilities and the social, physical, intellectual, and institutional barriers that exclude people with disabilities from full participation as community members and decision makers (Oliver, 1996). The resources available through community integration could offer an alternative to traditional systems of support and reduce the need for some of the current systems (Hall & Kramer, 2009). The social model of disability thus lends itself to a connection with social capital, which is based on interactions and connections among people and their communities.

Social capital, defined as the resources exchanged among individuals through relationships with each other (Bourdieu, 1986; Lin, 1999, 2001; Putnam, 2000), is a key component to understanding how people experience the world around them. This study uses a network approach to understanding social capital (Bourdieu, 1986; Lin 1999, 2001), considering how individuals access resources from, and contribute resources to, their social networks. An individual's social capital is dependent on the size, density, and composition of their social network. An individual's ability to access social capital resources is dependent on their location within the network, their knowledge of the resources, and their capacity to request or obtain the resources (Bourdieu, 1986; Lin, 1999, 2001).

The concept of social capital is built on the premise of interdependence. The amount of a person's available social capital, or the resources embedded in an individual's social network (Lin, 1999, 2001), depends on the availability and quantity of resources each individual in a person’s resource network has and contributes to others within the network. People can experience interdependence and increase their social capital through reciprocal exchanges of time, information, money, emotional support, and other resources (Lin, 1999, 2001).

Families are often instrumental in helping us learn the principle of reciprocity, an expectation of giving something in return for receiving something from another person (Bubolz, 2001). However, the return of a person’s “investment” (e.g., folding your sister’s laundry) may not occur immediately or in the same form or fashion (Bubolz, 2001). In the case of siblings, where one has a disability, the reciprocity is often asymmetrical but present and important to the siblings (Kramer et al., 2013). Many people with intellectual and developmental disabilities desire to contribute to and benefit from their relationships with other people (Kramer et al., 2013).

Types of social capital include bonding, bridging and linking. People form bonding social capital with others who share similar characteristics (e.g., family or close friends) (Neves et al., 2019; Szreter & Woolcock, 2004). Bonding social capital encourages reciprocity and collaboration (Riddel et al., 2001a). Bridging social capital is formed through links outside one’s close social network (Lin, 2001; Neves et al., 2019; Szreter & Woolcock, 2004) and can be used to access resources outside the individual’s personal connections (Riddel et al., 2001a). Bonding allows people to function in their current situation whereas bridging allows people to move ahead or in a different direction. Linking is an extension of bridging and connects individuals with others who are in a position of power (Szreter & Woolcock, 2004; Widmer et al., 2013). In a college, people in power include faculty members and administrators who can connect students to resources in the campus community.

Social capital is associated with positive physical and mental health outcomes (Ehsan et al., 2019; Mithen et al., 2015). People in an individual’s social network may provide emotional, informational, or material resources through a period of poor health, or support healthy behaviors (Bolin et al., 2003). However, others in a social network could also provide health misinformation or promote unhealthy behaviors, which could lead to poorer health outcomes.

The Convoy Model of Social Relations (hereafter, “the convoy model”) posits that people are surrounded by others who move with them throughout life and play key roles in supporting their health and well-being (Antonucci et al., 2013; Fuller et al., 2020). Researchers primarily use the convoy model to study older adults, the way their social relationships change over time, and how social relationships contribute to well-being, health, and quality of life (Antonucci et al., 2014; Fuller et al., 2020). However, these concepts are applicable throughout the life course. In many ways, the convoy model mirrors the concepts of social capital. For example, in the convoy model, an individual’s personal characteristics and situational characteristics contribute to the structure and composition of their convoy. Similarly, social capital theory identifies structural position and personal characteristics as concepts influencing social capital resources.

1.4 Social capital and people with intellectual and developmental disabilities

Individuals with intellectual and developmental disabilities are likely to have smaller social networks than those without intellectual and developmental disabilities (Giesbers et al., 2020; Mithen et al., 2015; Presnell & Keesler, 2021). People with intellectual disabilities consistently had lower odds of having access to informal or formal networks and social support compared to people with other types of disability or no disability (Mithen et al., 2015). Where people with intellectual and developmental disabilities live (e.g., in home in the community, a residential facility) influences their social network configurations and access to social capital (Widmer et al., 2013). For some people with intellectual and developmental disabilities, their social networks are mostly comprised of family, paid caregivers, or other people with developmental disabilities.

Emerging adults (typically people ages 18-25 years old) with intellectual disability are more likely to have smaller close family-based networks and fewer peer-centered relationships compared to those without disabilities (Giesbers et al., 2020). Families may be an important source of bonding social capital (Kramer et al., 2013). However, some research suggests that strong family ties can inhibit the formation of bridging social capital when families or caregivers try to protect an individual by controlling access to activities associated with developing social capital (Hall & Kramer, 2009; Hamilton et al., 2017; Kramer et al., 2013; Riddell et al., 2001a).

Without successful community integration, people with developmental disabilities are at a disadvantage when it comes to accessing resources in their communities. Participation in post-secondary education programs can provide young adults with intellectual disabilities opportunities to expand their social connections and increase their access to social capital (Huang et al., 2009; Lin, 2001). Post-secondary education programs may also provide critical support in helping young adults with intellectual and disabilities learn how to build their social networks, access community supports and services, and increase their independence.

1.4 Study contributions and research question

The present study focuses on the relational aspect of how people with intellectual and developmental disabilities experience interdependence. I conducted this research in partnership with a university offering a post-secondary education program for students with intellectual and developmental disabilities, hereafter referred to as the “partner university.” I used photovoice (Sutton-Brown, 2011; Schleien et al., 2013; Wang and Burris, 1997) to address the question, “for young adults with intellectual and developmental disabilities, what does it mean to be interdependent?” This study examines the stories and lived experiences of young adults with intellectual and developmental disabilities and how they contribute to and benefit from their social networks.

By understanding how young adults with intellectual and developmental disabilities experience interdependence, we can identify what benefits they receive from their social relationships and what they feel they contribute to those relationships. This information can help us understand what is important to these young adults, identify potential areas for intervention, and discover avenues for new research.

2. Method

2.1 Photovoice

Photovoice is a research method designed to “give voice” to at-risk and vulnerable populations and those typically not represented in academic research (Sutton-Brown, 2011). Photos can also supplement communication for individuals who may have difficulty with verbal or written communication by providing a specific image for participants to discuss (Booth & Booth, 2003; Schleien et al., 2013; Williamson et al., 2020). Describing a specific image can be helpful for individuals who have difficulty with abstract thinking.

Photovoice is a method used to address a variety of public health issues (Wang & Burris, 1997). Researchers have used photovoice with individuals who have intellectual and developmental disabilities to understand participants' experiences of relationships with their communities and other people, emotions, work, beliefs, and other abstract concepts (Akkerman et al., 2014; Jurkowski & Paul-Ward, 2007; Jurkowski, 2008; Jurkowski et al., 2009; Ha & Whittaker, 2016; Povee et al., 2014; Schleien et al., 2013; Williamson et al., 2020).

Using a combination of images, individual interviews, and group discussion, photovoice gives people with intellectual and developmental disabilities an opportunity to express themselves using both visual and verbal communication (Booth & Booth, 2003). For people with intellectual and developmental disabilities who may have difficulty with abstract modes of expression, photovoice provides a concrete means of connecting with a research issue or topic (Booth & Booth, 2003). In this study, using photovoice allows individuals with intellectual and developmental disabilities the opportunity to tell their own story and "show" others how they experience social capital as college students.

2.2. Research setting & participants

I conducted this study during March through May of 2022. I used purposive sampling to recruit 5 to 9 young adults with intellectual and developmental disabilities from a four-year post-secondary education program for people with intellectual and developmental disabilities in an urban area of the Southeastern US. To be admitted to the program the student must: have a documented intellectual or developmental disability; be their own legal guardian; be at least 18 years old; have concluded secondary education with a diploma, certificate of completion, or equivalent; not meet requirements for undergraduate admissions; have basic safety skills in unsupervised settings; and have personal desire and/or support from family to gain necessary skills for self-determination, independent living, and career development. To be included in the study, participants had to be admitted to the post-secondary education program, commit to the entire project, and have access to a personal smartphone with camera and internet connection. The size of the sample is consistent with the sample size of 6-10 proposed by the creators of photovoice method (Wang & Burris, 1997) and with other photovoice studies conducted with people with intellectual and developmental disabilities (Akkerman et al., 2014; Ha & Whittaker, 2016; Jurkowski, 2008; Schleien et al., 2013; Shumba & Moodley, 2018).

2.3 Researcher’s experiences and roles

Researchers’ lived experiences may influence how they interpret and analyze qualitative data. I am a cisgender female music therapist and public health doctoral candidate in my late thirties with extensive experience working with adults with moderate to severe intellectual and developmental disabilities living in a residential facility. I conducted a previous qualitative study with college students with developmental disabilities (Hoyle et al., 2022), and used panel data to examine children and young adults with intellectual and developmental disabilities (Hoyle et al., 2020; 2021).

2.4 Procedures

The study design was comprised of four parts (see Figure 4.1):

Part 1. Recruitment & Training

Post-secondary education program coordinators at the partner university shared a recruitment video and written recruitment information with enrolled students. Participants received community service hours toward their program for participating in the study. Interested students contacted the me via a screening questionnaire or email to express their interest.

I used a web-based questionnaire to screen potential participants based on inclusion criteria (see Figure 4.2). Students who met basic inclusion criteria were directed to questions about accommodations that they would need to successfully complete the study, such as written and verbal instructions, or adapted communication). I contacted eligible individuals who completed the questionnaire. Program coordinators indicated that requiring the questionnaire prior to the group training might be a barrier for some students; thus, 2 participants completed the screening questionnaire the day of the group training meeting, including one who was initially excluded by the study due to not meeting the age requirement. I chose to make an exception for this student due to his interest in participating and the experience he shared with the other participants as a student in the program.

I conducted a 90-minute, in-person group training session at the partner university, with one participant participating through Zoom, a synchronous web-conferencing software. I provided consent forms to the participants prior to the group training meeting, told participants they could consult a trusted person to review the consent, reviewed the informed consent with participants and provided multiple opportunities for questions. I reminded participants at the group training meeting, in the individual interview, and in the group meeting that they could refuse to participate at any time. In the training session, students went through the informed consent process, learned what photovoice is, what they were asked to photograph, the "responsibilities and risks of being a photographer" (Sutton-Brown, 2011, p. 173) and how to share photos with the researchers.

In addition to the information shared in the training meeting, I provided participants with a card containing QR codes for the study website and the photo consent for people included in their photos (Figure 4.3). The study website contained instructions for the photo assignment including written and video instructions for sharing photos, a copy of the informed consent, a link to the photo consent, and contact information for the researchers.

Part 2. Photo-taking and Individual Interviews

After the training session, participants had two weeks to take photos or choose photos that represented people they help and people who help them. All participants used their personal smartphones to take and share photos. Some participants chose to share photos taken by themselves or by others before the project began. Most participants shared their photos using a web-based form that allowed them to share a photo with a title and caption. Participants who had difficulty with the web-based form sent photos directly to me via email or text.

After receiving and reviewing the submitted photographs, I conducted individual interviews with all participants via Zoom. I used the theoretical constructs of social capital to guide the interview questions and analyze the results of this study. I employed the hierarchical model mapping technique from the convoy model (Fuller et al., 2020) to assess each participant's social network.

The interviews lasted 65-86 minutes (mean 76.1, standard deviation 7.4). During the interview, each participant chose a pseudonym; I present the results using those pseudonyms. As the interviewer, I used the “share screen” function to provide visual aids for topic discussion using a web-based interactive whiteboard application. Using this function allowed the interviewer and participant to create and move “sticky notes” on the screen, as they might do on paper in an in-person interview. I asked participants to name people who were important to them. Each person they named was placed on a “sticky note” on the interactive whiteboard. The participant and I used concentric circles, influenced by the convoy model (Fuller et al., 2020) to identify the degree to which participants felt close, helped, and were helped by the people they identified. Participants directed me to place each person’s name in the box on the interactive whiteboard that represented their relationship with that person.

The participants and I used the “share screen” feature to view and discuss photos. I used questions adapted from the SHOWeD guide (Liebenberg, 2018) to encourage discussion about the photographs. The SHOWeD guide asks individuals to consider the following questions in relation to the photographs: “1) What do you *see* here? 2) What is really *happening* here? 3) How does this relate to *our* lives? 4) *Why* does this concern, situation or strength exist? 5) How can we become *empowered* through our new understanding 6) And, what can we *do*?” (Liebenberg, 2018, p.5). The purposes of the SHOWeD questions are to identify issues, including related factors, and develop approaches to address identified issues (Liebenberg, 2018; Wang, 1999). I used the SHOWeD questions to create questions in plain language for the participants (see Figure 4.4). I asked each participant the same questions using communication aids (e.g., questions typed in the chat). I followed-up with specific questions for clarification and to encourage participants to elaborate when needed to increase understanding. During the interviews, I used participant validation, repeating my understanding of participants' responses to check that I accurately interpreted participant intention and meaning. I used individual interviews to identify preliminary themes from the photos and interviews. I describe the full data analysis process in detail below (see section 2.5).

Part 3. Group meeting

After identifying preliminary themes, I facilitated a 2-hour sharing session for the participants to share photos, discuss themes, and plan the photo exhibition. Each participant shared one photo of their choice with their peers. I facilitated discussion using questions from the SHOWeD guide to learn about the participants' experiences and their thoughts regarding the photos and the initial themes. During the group meeting, participants discussed the extent to which the experiences and themes represented in their peers' photos did or did not resonate with them. Initial themes discussed in the group meeting included importance of family, trying new things, need for supports, and a desire to help others. I describe the full data analysis process in detail below (see section 2.5).

Part 4. Exhibition

The final research component was an exhibition of selected photos. Participants chose to host a one-hour in-person photo exhibition at their university. They invited family, classmates, program staff, and university administration and support personnel. Each participant selected up to 5 photos to display on their 20"x30" posters (see Figure 4.5). I chose relevant participant quotes, and displayed the quotes anonymously on an additional poster (see Figure 4.5). Participants stood with their posters during the exhibition so attendees could ask questions about their photos and their experience with the photovoice project. The purpose of the exhibition was to give participants an opportunity to showcase their work and tell their stories. The exhibition also provided an opportunity family, friends, and members of their academic university to learn more about their perspectives and experiences as both a helper and someone who is helped by others.

2.5 Participant interactions and data collection

I was responsible for all interactions with the program and the participants. I conducted the group meetings and exhibition in person at the partner university and provided a synchronous virtual option for one participant who was learning online due to medical needs. Individual interviews took place virtually on Zoom to provide flexibility and accommodation of participant schedules. I audio and video recorded all individual and group meetings. I transcribed the interviews and meetings and included verbal and nonverbal (e.g., gestures, body language, emotional tone, etc.) communication (Beail & Williams, 2014).

Immediately following each interview and group meeting, I recorded my reflections. These process notes (Lincoln & Guba, 1985) included interpretations of the participants' demeanor; impression of the interview; the person and the setting; personal feelings about the interview experience and content; and notation of anything unusual or noteworthy. Prompts were included at the bottom of the interview guide as a reminder following the interview and a way to keep the reflections with the relevant interview notes (see Figure 4.6).

2.6 Inclusivity

The study was designed to be as inclusive as possible. I incorporated elements of universal design in research (Rios et al., 2016). Universal design is "the design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design" (Connell et al., 1997). Though initially used to describe the built environment, elements of universal design may be used to increase participation of people with disabilities in research (Rios et al., 2016; Vinoski Thomas et al., 2019).

I used a variety of accommodations to increase research participation. I adapted communication to meet participant expressive and receptive language skills (Beail & Williams, 2014). For example, I provided questions in the chat and closed captioning during Zoom meetings, allowed additional time for verbal responses, and conducted frequent checks for understanding and graphics to represent abstract concepts. In addition to printed materials, I distributed a recruitment video with audio and visual information to provide multiple ways for participants to receive and process the information. I wrote study materials, questions and directions in clear, simple language, and included prompts to add clarity when needed. I sent written information (e.g., consent forms) prior to the meeting to allow participants time to review and ask questions. I designed questions, prompts, and directions to address the research questions to avoid leading participant responses and remain as neutral as possible. All spaces used for in-person meetings met ADA requirements. I made virtual accommodations for a participant who was learning online only due to health needs.

2.7 Ethical consideration

This study was approved by the University of North Carolina at Charlotte Institutional Review Board (IRB). The partner university's IRB also approved this work with their students. Anonymity for the partner university was a condition of the agreement. All participant information including recordings, researcher notes, and participant demographic and contact information was encrypted and stored by the principal investigator.

People with impaired decisional capacity are considered a vulnerable group according to the Revised Common Rule (Federal Policy for the Protection of Human Subjects, 2018). There are mixed opinions among stakeholders regarding the capacity of adults with intellectual and developmental disabilities to provide consent (McDonald, et al., 2018). Institutional Review Board members may also consider individuals with intellectual and developmental disabilities more likely to need additional protections (McDonald, et al., 2009). Consent can only be provided by legal guardians or people who have legal independence. Holding one's own legal guardianship is a requirement of the postsecondary education program the participants attended; thus guardianship was not an issue for this study.

2.8 Data analysis

The final analysis was informed by synthesized information from individual interviews, group sessions, exhibition observation and field notes, and participant photos (see Figure 4.7). Because I analyzed both textual and visual data, this analysis had a two-pronged approach: thematic analysis and content analysis. I used NVivo, software that facilitates the analysis of qualitative data and images (i.e., the photos) (QSR International Pty Ltd., 2020), for all analyses.

I used the 6-phase thematic analysis process to analyze the textual data (Braun & Clarke, 2006; Hoyle et al., 2022; Nowell et al., 2017). In Phase 1, I transcribed group participant meetings and individual interviews verbatim, confirmed that the transcriptions represented the recordings accurately, added relevant non-verbal communication notes, and removed any identifying information. The meeting transcripts included the participants' analysis of their photos. I also recorded process and field notes following all interviews and the photo exhibition. I created an initial codebook in Phase 2, using *a priori* codes based on the interview questions (e.g., "being helped," "helping others") and including the initial themes discussed in the group meeting. As I reviewed transcripts, I added and amended codes in response to the data.

In Phase 3, I identified themes based on the frequency, saliency, and intensity of codes present in the textual data. I reviewed on two levels in Phase 4 and used mapping to refine themes. On the first level, I looked for patterns among the themes; on the second level, I reviewed textual data for any theme-related data not previously coded. In Phase 5, I finalized themes and wrote a descriptive analysis of each theme. I chose participant quotes to illustrate each theme in Phase 6.

I used content analysis to analyze the visual data (Bell, 2001). I examined all of the photos that participants submitted and coded information including presence of people and objects, number of people, short description, perspective (e.g., who captured the photo), and whether the photo was taken specifically for the project or was taken in the past. I used these codes to explore similarities, differences, and patterns within the photos (Ronzi et al., 2016). I synthesized the information from the thematic and content analyses using triangulation (Tracy, 2010) in which I compared themes identified in the text and photos, and aligned textual themes with photographic examples, described in the results.

2.9 Presenting participants' words

Qualitative researchers often provide quotations from research participants to illustrate themes. These verbatim quotations, frequently include participants' inadvertent language errors, vocalized pauses, and other features of the participants' speech. These features can sometimes provide insights into the participants' cognitive abilities, language use, and ways of seeing their world (Lingard, 2019). However, others suggest that it is useful for researchers to edit quotations, depending on the study context (Eldhet et al., 2020). Participants also have differing opinions on the use of verbatim quotes, but generally agree that anonymity is the most important issue to consider (Cordon & Sainsbury, 2006).

It is important to consider the issues involved in choosing to present verbatim or edited quotes, particularly for a study that sets out to "give voice" to participants whose voices are often not represented in research. Clean verbatim quotes preserve as much of the text and intention of the original quote while removing filler words or repetitions. This approach may increase the fidelity of the quotations to the participant's intended meaning by removing potential distractions for the reader (Cordon & Sainsbury, 2006).

In this study, most participants needed some level of communication support. The speech of some participants included highly repetitive language, stuttering, and brief periods of speech that was difficult to understand. Some phrases appeared to go in one direction, followed by a course correction. For these reasons, I edited *some* of the verbatim quotations to make them more accessible to readers and clarify meaning while reducing verbal clutter, unnecessary repetition, and vocalized pauses and verbal fillers, retaining a sampling of such features to illustrate the participants' ways of speaking. For example, people who repeat sounds or words due to a stutter or stammer do not typically intend to repeat those words; I believed it was appropriate to edit the participants' words in such cases, consistent with the speaker's likely intention.

To protect participant anonymity, I changed information such as names and places that could be used to identify participants. I present changed information in brackets. I also include bracketed indications of long pauses (>15 seconds) in participants' responses.

I recognize that it may be useful for some readers to see the verbatim quotations as they may provide insights into the participants' communication patterns and suggest how easy or difficult it might be for a given participant to interact with others. I present half of the 27 quotes in the Results section verbatim. I edited the other half to increase clarity. Table 4.1 shows all edited quotes presented in the Results section below, each paired with its corresponding verbatim quote. In addition to providing the edited quotes in the supplemental table, I also follow each edited quote with "[Edited]."

2.10 Methodological and interpretive rigor

I used multiple methods to enhance the methodological and interpretive rigor of this study. To enhance *credibility*, I engaged with participants in multiple ways over a period of several months. I incorporated *member checks* within the group meeting (e.g., assessing group agreement on themes). The *triangulation* of textual and visual data, along with the thick, rich descriptions of participants and their responses also contribute to the *credibility* of this study. I maintained an audit trail including all questionnaire responses, participant communication, interviews, interview notes, recordings, researcher reflections, and study decisions to contribute to the study's *dependability* and *confirmability* (Lincoln & Guba, 1985).

3. Results

The purpose of this study was to better understand how young adults with intellectual and developmental disabilities experience interdependence. Seven students completed the study.

Table 4.2 shows selected participant demographic, health, and other characteristics. Participants averaged 24 years old and were in at least their second year of the four-year program. All except one reported having received special education. None reported being a first-generation college student. Although the program requires students to have a diagnosis of intellectual or developmental disability, two participants described their disabilities euphemistically, and one declined to answer. Most reported good to excellent physical and emotional health.

Five participants (Buster, Emily, Jay, Nomad, and Peter) attended the training session and group meeting in person. All participants completed individual interviews via Zoom. All participants submitted photos. Three participants attended the exhibition (Buster, Jay, and Peter) in person. Elsa joined the training session, the group meeting, and the exhibition via Zoom. Nomad also attended the exhibition via Zoom. Steve did not attend any of the in-person sessions.

Participants submitted a total of 61 photos. Table 4.3 summarizes the characteristics of the photos. All participants submitted a photo of themselves. Most frequently represented in the photos were: family members; a favorite place or a favorite trip, and college-related activities. Two participants included photos of a girlfriend or boyfriend. Five participants included photos taken prior to the study. Participants discussed 28 of the photos with me in the individual interviews. The group discussed 6 photos during the group meeting.

3.1 Themes

I identified 4 themes in the responses to the research question, “for young adults with intellectual and developmental disabilities, what does it mean to be interdependent?”

3.1.1 Openness to being helped

Participants identified half (n=14) of the photos presented in the individual interviews as representing people who help them; another 30% (n=8) represented both people who help them and people they help. All participants said they recognized that they need help from others in certain situations, and described ways they received help from other people. Participants specifically described the kinds of help that were most beneficial to them. Common sources of help included support from people who know the participants well (e.g., family members, friends, and paid supports), learning by example, and using organizational systems.

Jay talked about the advice he receives from his father and others to maintain a healthy lifestyle. In discussing a photo of his bathroom scale, Jay said, “*This photo tells that if you need help with something, people are always there to give you advice to make sure that you’re doing it right, like staying healthy.*” [Edited]

Most of Peter’s photos were from family vacations to a big city, a tropical island, and a waterpark. In discussing his vacation photos, Peter described how he enjoyed travelling with his family and celebrating special holidays with them. Peter also shared how his father supported him financially, “*For example, my dad helps me with my bills. And he pays it on time. And my tuition fees*.” [Edited] Peter also discussed how the responsibility would shift after he graduated, "*And then, for example, in August it's time for me to start paying my bills, because I'm going to be living on my own*." [Edited]

Emily described how she benefited from others giving her reminders, "*Because I forget sometimes. And they tell me, you know, like, my support. They text me and whatnot. Like we're meeting tonight or something. So, I remember. Because sometimes I forget, and I'm like, 'Oh, no!'*" [Edited] In discussing a photo of herself making hummus, Emily described how she benefited from someone showing her how to make the dish, "*We had a person that was helping us measure out the ingredients and whatnot, to put in the hummus. That was very helpful for me.*" [Edited]

Buster chose to share several photos depicting his academic work. He explained how his peer supports used worksheets and visual organization tools to help him academically.

> *It's really helpful because, you know, there's a lot of assignments to do, and also a lot of assignments that I don't like, that I find a pain in the neck, which is typing papers and doing presentations, which I seriously hate. And, it's just, you know, nice to have supports help me with it.* [The photo of the career log] *just goes to show, you know, how they made this and how organized, and how they helped me with it.* [The photo of the superhero assignment] *is telling that someone was, that my support was there to help me, because there's just no way I would have been able to do this whole project myself. There was just no way, and thank goodness she was there.* [Edited]

3.1.2 Families are foundationally important for social capital building

When I asked participants to name people who were important to them, most of them mentioned family members first. All participants mentioned their parents. All but one participant mentioned siblings. Other family members included grandparents, cousins, aunts, uncles, nieces and nephews. Of the 43 photos featuring people, 18 (41.9%) included family members.

Most participants described their parents as helping them "a lot." Some of the ways parents helped included: instrumental support like paying bills, giving gifts, or purchasing needed items; skill development such as how to cook or how to make purchases; and emotional support. All participants talked about their parents at some point during their interviews.

Jay shared a photo of himself as a child, hanging on monkey bars with his father and sister. In reflecting on what others could learn from this photo, he said, "*They can learn that, like, family is important. And you have to have people in your corner to help you get to where you want to go in life.*" [Edited]

Elsa chose to share a photo of herself and her mother during the group meeting. In her individual interview, Elsa said,

> *This photo relates to my life because my mom, she's a very special person in my life and, I really need her support. Because, you know, I struggled sometimes and if she wasn't there to put me back on my feet then, I mean, who else would? Like your mom knows you the best.*

The photo of Elsa and her mother opened up a discussion among the participants in the group meeting about the importance of family members. When asked by the researcher to describe a "*really close family member who's super important*," Emily said,

> *Mine's my dad. Well, and my mom and my brother and sister, but my dad,*

> *because like we, we like to do like farm stuff. Not like farm stuff, but he's an outdoors person too. My mom is too, and my dad and my sister and brother. But mainly my dad. Because I'm very close to him.* [Edited]

In the group meeting, I asked participants to consider how their ideas on the importance of family could be used to improve the lives of people with disabilities. Buster said, "*Understanding that family comes first and understand the fact that they are trying to put you on the right path.*" Regarding parents, Elsa said, "*Students with disabilities need their parents more. And students without disabilities, they don't need their parents as much, but they still do need their parents.*" Emily mentioned feeling a greater sense of comfort with her family because they know her well and she does not have to disclose or educate them about her disability. The other members in the group indicated agreement with these thoughts by nodding and verbally agreeing.

Participants also described how they help and contribute to their families. They described helping with household chores, doing things like completing the postsecondary education program to make their families proud, and providing emotional support through encouraging texts and letters. Buster described helping his mother,

> *Well for me, well, I do support my mom. Whenever she's in the kitchen cooking and everything she knows how tall I am. So if she needs to reach something she'll ask me like, could you get that for me? And I'll just reach up and grab it for her.* [Edited]

Jay said,

> *I think for me, I would say when I go home to visit with my mom, if she's like tired, she'll ask me, can you wash the dishes? I'll just wash them for her, and like,*

> *you know, she always proud of me when I do well in my classes*. [Edited]

3.1.3 Doing new or challenging things

Participants talked about the role other people played in helping them participate in new or challenging things. Most participants reported that it was helpful to have other people support them when doing new or challenging things, although some expressed concerns that the presence of other people during these times could be intimidating.

In his individual interview, Nomad shared a photo of himself, his mother, two sisters, and his sister's boyfriend taken after completing an escape room activity, a popular leisure activity where a group of people are confined in a room together and have to solve puzzles to find their way out. He said he chose the photo because it was "*a family effort*" and "*a big challenge for all of us. They helped me and I helped them.*" In the photo, Nomad is standing in the front center, holding a sign that says, "It's their fault." In describing the photo and his experience with his family in the escape room, Nomad shared that he wanted to "*rest and relax and not go to the escape room again*" but his family convinced him to go. Despite being tired and not wanting to go, Nomad said he had fun working with his family to find the clues to get out of the escape room.

Nomad shared this photo and story in the group meeting. This photo began a discussion among the participants about experiences in which they were challenged to do difficult things and were able to do them with the help of other people. Emily said, "*Ooh! A zip line! Because like I, I didn't want to do zipline at first, but like, my friend, she encouraged me to do it.*" Elsa relayed the story of hiking a mountain with her family,

> So *my uncle wanted to climb* [mountain name]. *It's a mountain, like a few hours away. And so we, we climbed it. And like, the whole time I was complaining. It*

> *was hot, I was tired. I was ready to go. Um, but once we got up to the mountain, it was like beautiful. So, it was worth it for the view*.

Buster described trying new food, "*And for me, my mom cooked this soup that I really didn't think I was going to like but it's called Santa Fe soup. But once I got the hang of it. I thought it was pretty tasty*." [Edited]

Some participants said that having other people present when they were doing something new or challenging could be frightening or intimidating. When asked, "Do you think it's easier, harder, or no difference if you have other people supporting you?" Elsa replied,

> *It could be easier or harder because, like, for me, sometimes I can't do things in front of people. Like if I'm rock climbing, I would be scared if I was gonna fall and then be in front of all those people, you know.* [Edited]

3.1.4 The tension between wanting to help and the vulnerability of being a helper

All participants described how they helped other people including family, friends, people who are paid to support them (e.g., university faculty, program staff, vocational rehabilitation staff), and people they do not know. Participants said that helping others made them "feel good" and also gave them a sense of confidence. Several participants described ways they could help others, indicating a desire to help people. For example, Emily said,

> *Um, I'm also like, a hard worker, too. And I like to help other people out. If like, someone doesn't have a friend, then I'm right there. Be like, "Hey, you know, do you need help with this?" You know, just being nice to them.* [Edited]

Elsa described her desire to engage reciprocally with the people who help her,

> *Um, I try to motivate people as well. And I try to give people advice. So they understand that I'm trying to help them to that. It's not like a one-way street where it's like, "Oh, I'm just trying to help you but you don't help me.*"

This desire to help others was counterbalanced by a recognition that helping others may increase vulnerability and can lead to exploitation. Steve expressed wanting to reciprocate help but not being allowed to do so. In describing a photo of himself holding a twenty-dollar bill, Steve said he received the money from a stranger in a restaurant. He expressed that "*nice people gave to me but I didn't give* [pause] *I never give a homeless money to people.*" When asked about this, Steve said, "*I just like to give them cash but* [pause] *my father says no – can't give the cash to a stranger… He made me not to give the strangers money*." When asked what he liked about the photo, Steve replied, "*This money is like giving other people kindness and I just want to give money for the homeless or giving people* [pause] *the money* [pause] *helping.*"

Elsa described how people in her life, specifically her brother and boyfriend, are protective of her. Of both, she said, "*I rather them be protective over me than not because like what if something happened to me? And then I didn't have people that protected me?*"

In the group meeting, participants discussed barriers to them helping others. Reasons included not having the time to finish their academic work and help others with theirs, people being rude, and not knowing what others need. Jay said that "*getting involved in things around the community*" could increase opportunities to help. The group expressed that it can be difficult for people with disabilities to get involved in community groups and activities that align with their interests but did not elaborate on why they believe this to be so.

3.2 Views about participating in research

The participants indicated through their photos and in their verbal responses that it was important to them to be involved in the research study. Steve shared a photo he took of himself. In the photo, Steve is smiling and the background is blurred. When asked about it, Steve shared that it was a photo of him as a volunteer in the study.

Jay summarized his experience as a participant in the study:

> *Um, it was a good experience. I learned a lot from knowing which people are important in my life. And, you know, it made me realize that some of these people that I'm taking pictures of really helped me a lot. And, you know, they always encouraged me to be the very best that I can be. And, I try to help them the best way that I can.* [Edited]

When planning the exhibition, participants emphasized that they wanted to let others know that they had participated in a research study. Approximately 15 classmates, family members, support staff, and staff of the partner university attended the exhibition. During the exhibition, participants were engaged and shared their experiences with their family, friends, and academic community, and celebrated their accomplishment in completing the study.

4. Discussion

Using photovoice gave us a window to how young adults with intellectual and developmental disabilities view their close relationships with others, and the roles they play in those relationships. Overall, participants were open to being helped, and many described how they have received help from others throughout their lives. Most participants understood and described the help they need.

When asked to identify the people they were closest to, participants most often named family members and close friends, although some participants identified academic program personnel and faculty. This is consistent with previous research examining social ties of university students with disabilities (Hoyle et al., 2022; Stack-Cutler et al., 2015), which found family relationships to be particularly salient. Many of the photos depicted shared activities such as family vacations, through which social capital can be built (Kramer et al., 2013).

Consistent with the research literature on social networks of people with intellectual and developmental disabilities, participants reported small, close family-based networks and fewer peer-centered relationships (Giesbers et al., 2020). These results reinforced the importance of family relationships among people with intellectual and developmental disabilities, consistent with relevant studies that found family relationships are a key source of bonding social capital (Hall & Kramer, 2009; Hoyle et al., 2022; Hamilton et al., 2017; Kramer et al., 2013; Riddell et al., 2001a). These findings are also consistent with previous research in which college students with developmental disabilities identified family relationships as being of primary importance (Hoyle et al., 2022). This result differs from research on young adults without disabilities, who often identify peer relationships as primary sources for close ties and support (Norona et al., 2015).

Participants described how their teachers and peer support workers provided by the college program helped them with academic work and learning. The relationships students experience with faculty and program staff may provide bridging social capital (e.g., connection to supports and services needed to succeed academically). However, participants did not describe many other examples of bridging social capital. This could be related to the way the research question was framed. I asked students to identify experiences of how they help others and how others help them. Framing the question in this way may have prompted participants to focus on directly reciprocal experiences. It is possible that participants did not have as much experience with bridging social capital. Previous researchers have described the potential for strong family ties to inhibit formation of bridging social capital for people with intellectual and developmental disabilities (Hall & Kramer, 2009; Hamilton et al., 2017; Kramer et al., 2013; Riddell et al., 2001a). Although students in this study described strong family ties, I note their unusual opportunities to create bridging social capital as members of the specialized college program.

Although often seen as people in need of help, participants saw themselves as both receiver and giver of help, albeit at different levels (Walmsley, 1993). The vulnerability described by participants echoes concerns expressed by parents and caregivers of people with intellectual and developmental disabilities in other studies (Hall & Kramer, 2009; Hamilton et al., 2017; Kramer et al., 2013; Riddel et al., 2001a). The tension observed in these young adults participating in helping roles is not new. Walmsley (1993) documented the caregiving experience of women with learning disabilities. While many participants valued the opportunity to care for others in a way often experienced by people without disabilities, several described how caregiving roles became burdensome or exploitive (Walmsley, 1993).

The tension between wanting to help and the vulnerability of being a helper parallels the concept of "dignity of risk." Dignity of risk refers to the right to make choices even if those choices may have adverse consequences (Perske, 1972). These choices include forming and participating in relationships in which social capital is exchanged. When forming relationships with others, there is a risk of being exploited or treated poorly, a risk that is disproportionately high for people with intellectual and developmental disabilities (Hoyle et al., 2020). The participants expressed a desire to have the independence associated with dignity of risk despite recognizing their own vulnerability. Specialized postsecondary education programs are uniquely positioned to provide opportunities that promote dignity of risk for students with intellectual and developmental disabilities (Bumble et al., 2022).

The results also suggested implications for designing research using photovoice, interviews, or group meetings when the research participants are people with intellectual and developmental disabilities. This study was designed to be inclusive and accessible. My experience suggests that researchers who design related studies should anticipate that participants are likely to welcome one or more brief breaks during interviews or group meetings. Participants with intellectual and developmental disabilities may also often prefer to receive questions in advance, or to have them presented in writing during interviews or group meetings. People with intellectual and developmental disabilities may have difficulty communicating; researchers who plan studies with this population should consider including an investigator who has experience communicating with this population.

Within social capital theory, an individual's structural position within the social network influences their access to social capital (Lin, 1999, 2001). People with intellectual and developmental disabilities do not often occupy positions of power or prestige. Therefore, participants in the present study may experience a structural disadvantage due to their disability status. However, their status as college students and experiences in the college program set them apart from other individuals who may have similar disabilities. Participants said they depend more heavily on their parents compared to their peers without disabilities. However, most participants described how they used their parents' support in positive ways. Although they perceived their experience to be different than that of their peers, none of the participants expressed a desire for a different experience.

4.1 Limitations and strengths

These findings are limited to the topics represented by the photos shared by the participants. The photos were likely influenced by their interpretation of the research question and the examples discussed in the training session. Most participants focused on interdependence experienced with family members and other close social ties. Few participants mentioned help given to or received from acquaintances, or "weak ties" (Granovetter, 1973). Although not mentioned by all the participants, it is possible that "weak tie" relationships may also be a source of interdependence.

This study examined one aspect of social capital, the help individuals give to and receive from others. I recognize that social capital is a multi-faceted concept. To understand the depth and breadth of an individual's experience of social capital more fully, it would be useful to consider additional factors such as family income and organizational ties beyond the postsecondary education program.

I asked students to commit to a time-consuming, multi-part study with instructions and steps that some participants may have found complex. This may have influenced who chose to participate. Students with fewer social connections or social capital resources may not have felt they had the support needed to participate in this project.

The timing of the study is both a limitation and a strength. Conducted two years into the COVID-19 pandemic, many students were likely continuing to experience additional stress and fatigue associated with the transition back to in-person learning and ongoing health concerns (Koelen et al., 2021; Tasso et al., 2021). This stress and fatigue could have affected the amount of energy students had to contribute to the project. At the same time, this project occurred as in-person classes and activities began to resume. Some students may have been eager to participate in a project with others after experiencing the isolation associated with the pandemic.

People with developmental disabilities have a wide range of abilities and needs (Cooper et al., 2015; Smith et al., 2020). I examined a relatively narrowly defined group in the developmental disability population, which was both a limitation and strength. The relatively narrowly defined group provided a control for levels of ability and impairment. It is likely that participants had higher level communication and academic skills, more motivation, and additional support from others compared to young adults with similar disabilities who are not enrolled in a specialized college program. Despite the specificity of those requirements and the relatively narrow range of those characteristics among the participants, there was considerable variability in the participants’ abilities and needs. Participants also exhibited a range of communication needs and abilities.

This study also has several strengths. By partnering with a university offering a postsecondary program for individuals with intellectual and developmental disabilities, I was able to access an understudied population, college students with intellectual and developmental disabilities in one of 314 such programs in the United States (Think College, 2022). This is the first study I am aware of that examines aspects of social capital in the lives of these students.

A notable strength was the innovative study design, including: group training, individual interviews, a group meeting, and a photo show. The design accommodated a variety of receptive and expressive communication needs. It provided a variety of ways for participants to engage and share information and experiences, and to identify findings of the research. In addition, this study was designed to be accessible and inclusive. For example, although all participants used verbal communication as a primary form of communication, we supplemented verbal communication with written communication and images to meet the expressive and receptive communication needs of the participants. I also incorporated a number of technologies (e.g., study website, video tutorials, QR codes, Zoom interviews, the interactive whiteboard) and principals of universal design to build participants' trust in the researcher, enhance the participant experience, and further accommodate a variety of receptive and expressive communication needs.

My experience and expertise in working with people with intellectual and developmental disabilities for more than 12 years allowed me to effectively plan for, recruit, and work with students with a variety of needs. My expertise also supported analysis of textual data from participants who had substantial communication needs. In addition, I reached out to the partner university program more than a year before recruitment began. I included administrators at the partner university in the early planning stages of the study to ensure successful recruitment and arrangement of spaces needed on their campus to host the training session, group meeting, and photo show. The research also benefitted from the trust that staff at the partner university had developed with the participants, as people with intellectual and developmental disabilities may be reluctant to participate in research.

4.3 Conclusions and implications

These results provide insight into how young adults with intellectual and developmental disabilities experience interdependence. My experiences with participants speak to the need for flexibility, accommodation, and preparation when conducting research with people with developmental disabilities (Beail & Williams, 2014).

This research also advanced our understanding of social capital in the lives of people with intellectual and developmental disabilities. To expand this work, it would be useful to conduct a similar study with college age adults with intellectual and developmental disabilities who do not attend college, or have more complex needs. It may also be useful to interview dyads, such as participants with intellectual or developmental disability and their parents, to explore both sides of the interdependent relationship (Kramer et al., 2013).

Many college students with intellectual and developmental disabilities can engage in interdependence with others, and want to do so. This interdependence allows them to contribute and access social capital and may help young adults with intellectual and developmental disabilities transition into adulthood more successfully. We need interventions to help people with intellectual and developmental disabilities build healthy interdependent relationships that afford them dignity of risk while empowering them to guard against their own vulnerability.

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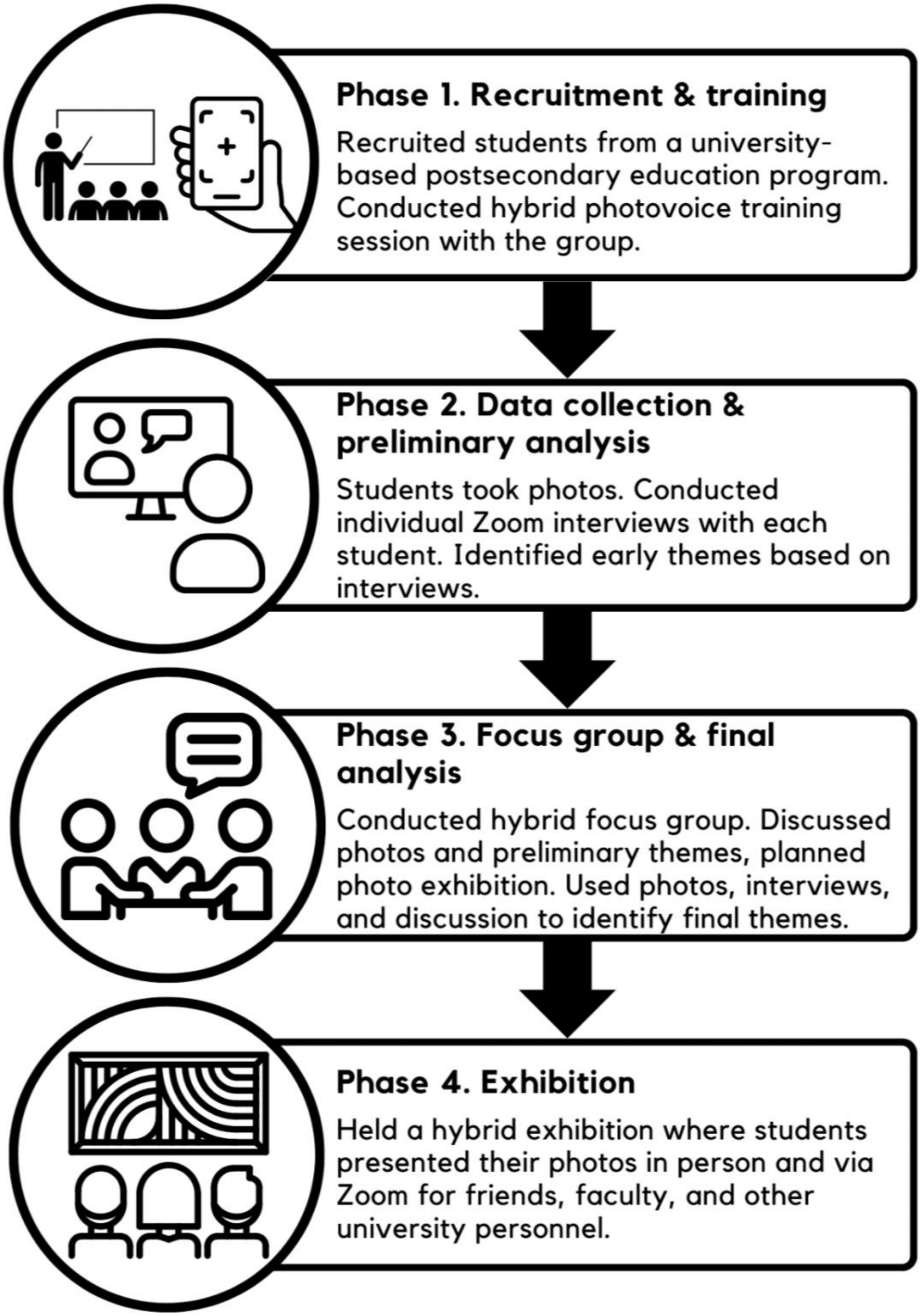
Widmer, E. D., Kempf-Constantin, N., Robert-Tissot, C., Lanzi, F., & Galli-Carminati, G. (2008). How central and connected am I in my family? Family-based social capital of individuals with intellectual disability. *Research in Developmental Disabilities, 29*, 176–187. https://doi.org/10.1016/j.ridd.2007.02.005

Williamson, H. J., van Heumen, L., Schwartz, A. E. (2020). Photovoice with individuals with intellectual and/or developmental disabilities: Lessons learned from inclusive research efforts. *Collaborations: A Journal of Community-Based Research and Practice*, *3*(1): 8, 1–12. https://doi.org/10.33596/coll.45

Zablotsky, B., Black, L. L., Maenner, M. J., Schieve, L. A., Danielson, M. L., Bitsko, R. H., Blumberg, S. J., Kogan, M. D., & Boyle, C. A. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009-2017. *Pediatrics*, *144*(4), e20190811. https://doi.org/10.1542/peds.2019-0811

Figure 4.1. Phases of the photovoice process for this study



Phase 1. Recruitment & training

Recruited students from a university-based postsecondary education program. Conducted hybrid photovoice training session with the group.

Phase 2. Data collection & preliminary analysis

Students took photos. Conducted individual Zoom interviews with each student. Identified early themes based on interviews.

Phase 3. Focus group & final analysis

Conducted hybrid focus group. Discussed photos and preliminary themes, planned photo exhibition. Used photos, interviews, and discussion to identify final themes.

Phase 4. Exhibition

Held a hybrid exhibition where students presented their photos in person and via Zoom for friends, faculty, and other university personnel.

Figure 4.2. Web-based screening questionnaire

I am a PhD student. I am studying how young adults get help and give help to the people they know. The questions below will help me learn if you would like to be in my study, and if you qualify to be in the study. You can probably read this message and answer the questions in less than 10 minutes. I will keep your answers private. I will be the only person who knows that you answered these questions, and how you answered.

Thank you for thinking about being in my study.

= = Next page = =

First, I would like to tell you about my study:

- This study will help us learn how college students with certain diagnoses or disabilities get help from others, and how they give help to others.
- To be in this study, you must be at least 18 years old and not older than 28 years old.
- To be in this study, you must be part of the Integrative Community Studies Certificate Program (Beyond Academics) at the University of North Carolina at Greensboro (UNC-G).
- To be in the study you must have a smartphone and be able to share photos online.
- To be in the study you must have internet and a device that has a camera and a microphone.
- To be in the study you must be able to use Zoom, or have someone who can help you to use Zoom. If you have someone help you to use Zoom, please be sure that you trust that person to hear what you say, or ask that person to leave the room when we start to talk during our Zoom call.
- To be in the study, you will need to participate in all parts of the study:
  - Part 1: Photo training & photo taking
  - Part 2: Individual meetings on Zoom
  - Part 3: Group meeting
  - Part 4: Photo show
- The study will take about 9 hours total, over 4 to 6 weeks.

If you think you might be interested to be in my study, please answer these questions:

1. Are you part of the Integrative Community Studies Certificate Program (Beyond Academics) at UNC Greensboro? (Yes/No)
2. Are you at least age 18 and not older than 28? Yes/No
3. Do you have a device that lets you use Zoom (ex., computer, smartphone, tablet, etc.) with a microphone and a webcam? Yes/No

4. Do you have a device (e.g., digital camera, smartphone, etc.) that allows to you take digital photos and share them using the internet? Yes/No
5. If you are chosen to be in the study, all people in the study will meet in person as a group two (2) times. I will also meet with each person individually in the study on Zoom. You will take photos and share them with the group and with me. The whole group will share photos with people we invite from the community. The entire study will take about 9 hours of your time. Are you able to commit to all the parts of the study? Yes/No

Programming Notes:
If the participant answers "no" to any one or more of Questions 1-5, they will receive the message: "You have not been selected for this study. Thank you for your time."

If the participant answers "yes" to all of Questions 1-5, then the following will be presented:
"You may be eligible to be in the study. That will depend on how many students have already become part of the study. I will tell you through email if you can be in the study. I have just a few more questions:"

6. Are there any accommodations that would make it easier for you to be in the study?

7. If you are in the study, I will contact you via email to schedule our Zoom talk. Please include your email address below: [fill in]

8. I will send text reminders throughout the study. Please enter your mobile phone number below: [fill in]

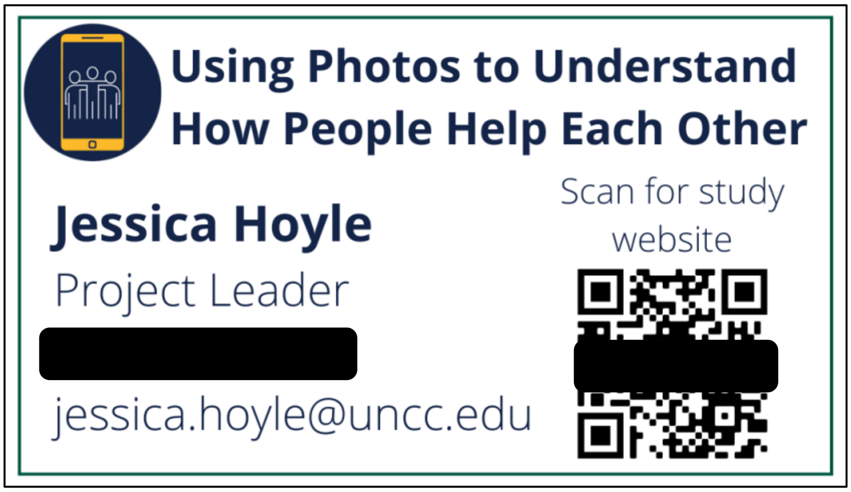
9. Will you require any of the following accommodations for the interview?
    a. Written questions prior to the interview
    b. Adapted or augmented communication (please describe)
    c. A sign language interpreter or closed captioning (please describe)
    d. Questions included in chat during the interview
    e. Other (please describe)

If you are chosen for the study, you will receive community involvement hours for the time you spend in the study. These hours will count toward the requirements for the Integrative Community Studies Certificate Program (Beyond Academics). For participating in the photo exhibition, you will receive a framed copy of the photo you choose.

If you have any questions, please contact me:
Jessica Hoyle, doctoral student and researcher, at: (828) 368-9422 or by email: jessica.hoyle@uncc.edu.

Thank you.

Figure 4.3. Photovoice study cards



Using Photos to Understand How People Help Each Other

Jessica Hoyle

Project Leader

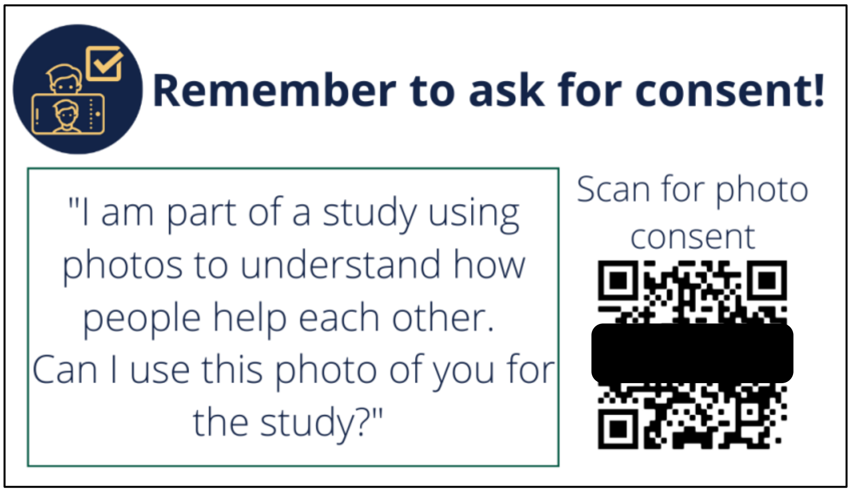
[redacted]

jessica.hoyle@uncc.edu

Scan for study website

[redacted]

(front of card)



Remember to ask for consent!

"I am part of a study using photos to understand how people help each other. Can I use this photo of you for the study?"

Scan for photo consent

[redacted]

(back of card)

Figure 4.4. Individual interview discussion guide

Network Questions (Fuller et al., 2020)

Who are the most important people in your life?

1. Tell me about these people.
2. How close are you to these people?
3. How often do they help you?
4. How often do you help them?

SHOWeD Questions (Liebenberg, 2018)

You will choose your favorite photos and I will ask you the following questions (repeated for each photo):

1. Describe your photo. *Probe: Tell me where you are, what you are doing, who you are with, etc.*
2. Is this photo about people who you help or people who help you?
3. What does this photo tell us about (who you help/people who help you)?
4. How does this photo relate to your life?
5. What do you like about this photo?
6. What would you change about this photo?
7. How can we use this information to make things different or better for other people?

Demographic Questions

1. How old are you?
2. What year are you in college? (first-year, etc.)
3. How do you describe your gender?
4. How do you describe your race/ethnicity?
5. Do you have a disability? If you feel comfortable telling me, what is your disability?
6. Did you have special education in elementary, middle or high school?
7. Did your parents go to college? Did they graduate?
8. How would you describe your overall health: excellent, very good, good, or fair/poor?
9. How would you describe your emotional health: excellent, very good, good, or fair/poor?
10. Describe your living arrangement: by yourself, with a roommate, with your parents, with a spouse, with a group of people, etc.

Figure 4.5. Exhibition poster examples

I try to motivate people as well, and I try to give people advice so they understand that I'm trying to help them too… that it's not like a one way street, where it's like 'oh, I'm trying to help you, but you don't help me.'

Care for other people, not just care about yourself.

… no matter how difficult a project or assignment can be, you can always ask for help. And someone will be right there to guide you.

Family is important… You have to have people in your corner to help you get to where you want to go in life.

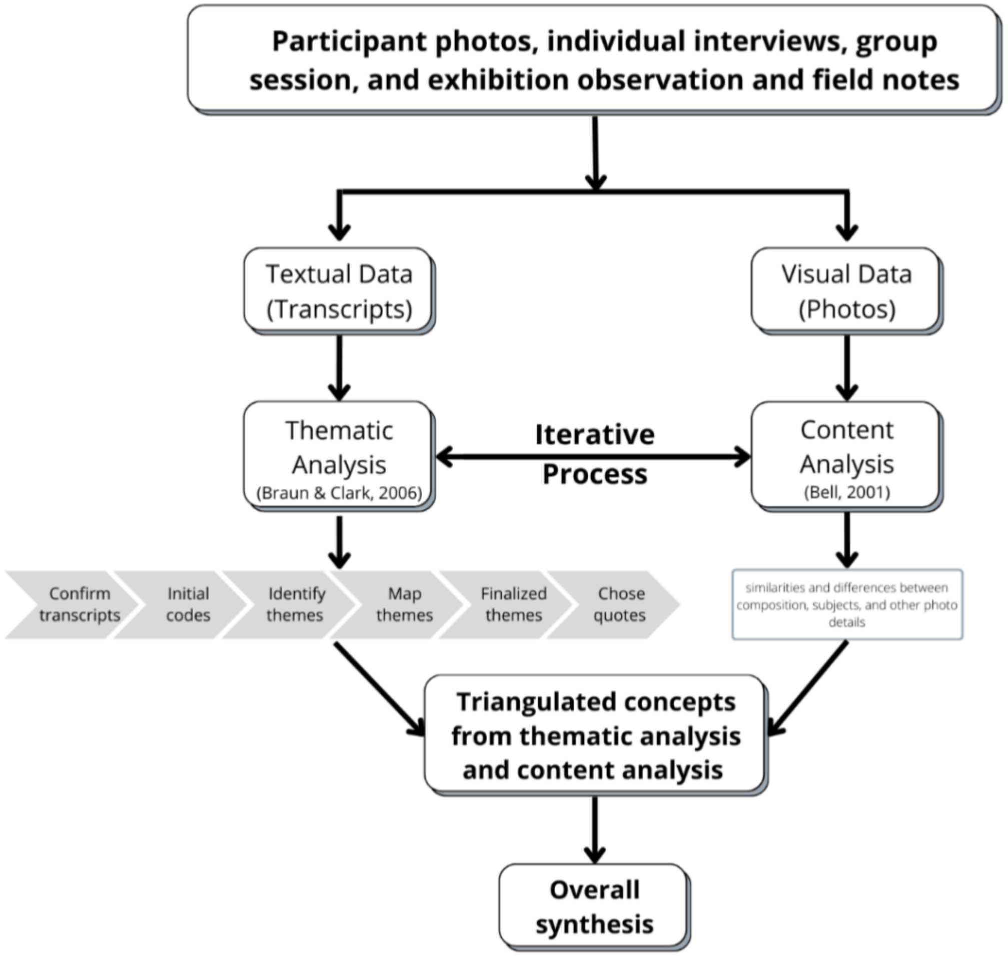
Always give someone a helping hand

Figure 4.6. Process note guide

Complete right after you end the interview and are no longer with the participant on Zoom.

1. Describe the setting.
2. Describe the general demeanor of the participant (e.g., highly engaged in the interview, distracted, nervous, tired, and so forth).
3. Describe how you think the session went (e.g., great, fine, okay, could have been better) and explain.
4. Describe any technical issues or glitches that could affect the results.
5. Describe the participants in terms that would not enable someone to identify the participant. You may revise and extend your description for use when reporting research. Here, capture your dominant impressions.
6. Did the participants have a visible or stated disability? Describe (without details that could be identifying). Did a disability appear to affect the participant's ability to understand or respond to the interview questions? (Describe in terms that would not enable someone to identify the participant)
7. Did anything unusual occur during the interview? (Were you interrupted? Did the persons ask to skip any questions or schedule a different time?)
8. Did any question(s) appear to make participants anxious, sad, troubled? (describe)
9. Did any question(s) appear to make the participant happy, positive? (describe)
10. Did the participant have difficulty understanding one or more questions? (describe)
11. Was there anything about the participant's interactions that made you nervous or concerned? (describe)
12. Did the participant say anything that requires special care for privacy and non-disclosure when handling or transcribing the recordings? (No details here.)
13. Describe any other personal reflections related to the interview experience or content.
14. Did the participant say anything that requires reporting to the Dean of Students or to law enforcement? (Describe in adequate detail for use in legal reporting)

Figure 4.7. Flow chart of data analysis process.



Adapted from Ronzi et al., 2016.

Table 4.1. Edited quotations

Speaker	Verbatim Quote	Edited Quote
	Summary	
Jay	"Um, it was, it was a good experience. I mean, I, I've learned, you know, I've learned a lot from, from it with knowing, like which, like which people are, are important in my life. And, um, and then, you know, it's, it, like, made me like, realize that some of these people that I'm taking pictures of, these are like, the people that, that that really, that really helped helped me a lot. And, you know, they, they, like, always encouraged me to, to be the very best that I can be. And, um, and then they, and then I try to, I try to help them, you know, help them as well, you know, the best way that I can."	"Um, it was a good experience. I learned a lot from knowing which people are important in my life. And, you know, it made me realize that some of these people that I'm taking pictures of really helped me a lot. And, you know, they always encouraged me to be the very best that I can be. And, I try to help them the best way that I can."
	Theme: Openness to being helped	
Jay	"This photo tells, this photo, it, let's see, it lets you know that, that if that if you like, need help with something, people are always there to try to, to try to give you advice to make sure that you're, to make sure that you're doing, doing, doing it, right. And then, like to make sure that to make sure that you're like, staying, like staying healthy. And that they're like always there to like, try to like give you advice."	"This photo tells that if you need help with something, people are always there to give you advice to make sure that you're doing it right, like staying healthy."
Peter	"For example, like my dad helps me I pay and does help with my bills. And he pays it on time. And my tuition fees."	"For example, my dad helps me with my bills. And he pays it on time. And my tuition fees."
	"And then for example, in, in August it's time for me to start doing my stuff like paying my paying my bills, because I'm going to be living on my own."	"And then, for example, in August it's time for me to start paying my bills, because I'm going to be living on my own."

Emily	“Because, like, then like for me, like, I forget sometimes. And like, they like they tell me, hey, you know, like, my support they, like, text me and like whatnot and be like, hey, you know, I have to, um, or like we're meeting tonight or something. So like, I remember. Because like, sometimes, like I forget, and I'm like, ‘Oh, no!’”	“Because I forget sometimes. And they tell me, you know, like, my support. They text me and whatnot. Like we're meeting tonight or something. So, I remember. Because sometimes I forget, and I'm like, ‘Oh, no!’”
	“We had like, we had a person that like was helping us like measure out like, the like the ingredients and whatnot, to like put in the hummus. Which, that was very helpful for me.”	“We had a person that was helping us measure out the ingredients and whatnot, to put in the hummus. That was very helpful for me.”
Buster	“It's really, it's really helpful, you know, because, you know, there's a lot of the assi-, you know, there's a lot of assignments, you know, to do, and um, and, and there's assign- and there's also a lot of assignments that I don't, that I don't like that I find a pain in the neck, which is typing papers and, doing, and doing pre- and doing presentations, which I ser-, which I seriously hate. And, and, and it's just, you know, nice to have, you know, supports, you know, you know, help me with it. [The photo of the career log] tells, it tells that, um, what it tells, like, what they're, you know, you know, one of me, it tells, I don't know how to describe it, it's just, it just goes to show that they're, you know, how they, you know, made this and how and how organized they, they did and,... and how, they wanted me and how they helped me, you know, helped me with it.. [The photo of the superhero assignment is] telling that, it's telling that someone was, that it's telling me it's telling you know that my support was, was was there it was there to help me because there because there's just no way I would have been able to do this whole project myself. There's just there was there was just no way and thank and thank goodness she was you know, there.”	“It's really helpful because, you know, there's a lot of assignments to do, and also a lot of assignments that I don't like, that I find a pain in the neck, which is typing papers and doing presentations, which I seriously hate. And, it's just, you know, nice to have supports help me with it. [The photo of the career log] just goes to show, you know, how they made this and how organized, and how they helped me with it. [The photo of the superhero assignment] is telling that someone was, that my support was there to help me, because there's just no way I would have been able to do this whole project myself. There was just no way, and thank goodness she was there.”
	Theme: Families are foundationally important for social capital building	
Jay	“They can learn, they can learn that, that, like, family is important. And you have to have like people in your people in your corner to help you get to where you want to go in life.”	“They can learn that, like, family is important. And you have to have people in your corner to help you get to where you want to go in life.”

Emily	“Mine's my dad. Well, and my mom and my brother and sister, but my dad, because like we, we like to do like farm, like farm stuff. Not like farm stuff, but like, he like, he's an outdoors person too. Like, I'm, my mom is too, I think like, my mom, and my dad and my sister and brother. But mainly my dad. Because I'm like, I'm like, I'm very close to him.”	“Mine's my dad. Well, and my mom and my brother and sister, but my dad, because like we, we like to do like farm stuff. Not like farm stuff, but he's an outdoors person too. My mom is too, and my dad and my sister and brother. But mainly my dad. Because I'm very close to him.”
Buster	“Well for me, well, my, well, I support you know, I do support my mom and whenever she's you know, like when ,if she's, you know, whenever she's in the in the kitchen cooking and everything she she she knows how tall I am. So if she, if she needs like to reach something she'll like ask me like, could you get that for me? And I'll just reach up and grab it for her.”	“Well for me, well, I do support my mom. Whenever she's in the kitchen cooking and everything she knows how tall I am. So if she needs to reach something she'll ask me like, could you get that for me? And I'll just reach up and grab it for her.”
Jay	“I think for me, I would say like like, like when I go home to visit with my mom, like, she'll, like if she if she's like tired, like she'll ask me, can you like wash the dishes? I'll just like wash them for her, and like, you know, just doing well in school she's she always proud of me when like, I do well in my classes.”	“I think for me, I would say when I go home to visit with my mom, if she's like tired, she'll ask me, can you wash the dishes? I'll just wash them for her, and like, you know, she always proud of me when I do well in my classes.”
	Theme: Doing new or challenging things	
Buster	“And for me, my mom, you know, cooked this soup that I really didn't think I was going to like but it's called, it's called Santa Fe soup. But once I once I got the hang of it. I thought it was pretty tasty.”	“And for me, my mom cooked this soup that I really didn't think I was going to like but it's called Santa Fe soup. But once I got the hang of it. I thought it was pretty tasty.”
Elsa	“It could be easier or harder because, like, for me, sometimes I can't do things like in front of people. Like if I'm climbing a rock, like rock climbing, I would be scared like, if I was gonna fall and then be in front of all those, like, people, you know.”	“It could be easier or harder because, like, for me, sometimes I can't do things in front of people. Like if I'm rock climbing, I would be scared if I was gonna fall and then be in front of all those people, you know.”
	Theme: The tension between wanting to help and the vulnerability of being a helper	
Emily	“Um, I'm also like, a hard worker, too. And I like to give, you know, I like to help other people out. If like, someone doesn't have a friend, then I'm right there. Be like, ‘Hey, you know, do you need help with this?’ You know, just like being nice for them being nice to them.”	“Um, I'm also like, a hard worker, too. And I like to help other people out. If like, someone doesn't have a friend, then I'm right there. Be like, ‘Hey, you know, do you need help with this?’ You know, just being nice to them.”

Table 4.2. Demographic characteristics of the photovoice study sample (n=7)

Pseudonym	**Age**	**Gender Identity**	**Year in College (Undergraduate)**	**Race/ Ethnicity**	**Self-Described Disability**	**Special Education (yes/no)**	**First-generation college student (yes/no)**	**Self-Rated Physical Health**	**Self-Rated Emotional Health**
Buster	26	M	Junior	African American	Hard time keeping up	Yes	No	Very Good	Very Good
Elsa	21	F	Sophomore	White	Intellectual Disability	Yes	No	Fair	Poor
Emily	21	F	Sophomore	White	Intellectual Disability	Yes	No	Very Good	Good
Jay	32	M	Junior	African American	Autism	Yes	No	Excellent	Excellent
Nomad	23	M	Senior	White	Epilepsy	No	No	Excellent	Excellent
Peter	23	M	Senior	Asian & Hispanic	Special Needs	Yes	No	Excellent	Excellent
Steve	23	M	Junior	White	Declined to answer	Yes	No	Did not answer	Did not answer

M=Male; F=Female

Table 4.3. Characteristics of photovoice participant photos

Name	Number of photos submitted	Family members	Girlfriend or boyfriend	Friends	Self	Strangers/ Acquaintances	Photos from past	Instructors	College related activities	Favorite places or trips	Food	Animals
Ethan	11	X			X	X	X			X		
Emily	11	X		X	X		X	X	X	X	X	
Elsa	12	X	X	X	X		X		X	X	X	X
Nomad	14	X			X	X	X			X		X
Jay	6	X	X	X	X		X		X		X	
Steve	2				X							
Buster	5				X				X			X

CHAPTER 5: DISCUSSION

The three research studies in this dissertation focus on the following gaps in the literature, the need to: understand the use of social capital within developmental disability research across disciplines; use nationally representative data including individuals with lifelong disabilities; and better understand the lived experience of people with developmental disabilities.

1. Review of findings

This dissertation research used three distinct research methodologies to explore how people with developmental disabilities experience social capital from childhood to young adulthood. First, using a scoping review, I summarized the definition, measurement, and application of social capital in the developmental disability literature from childhood to emerging adulthood and identified gaps in our current knowledge. In the studies reviewed, researchers note the lack of a single definition of social capital as a challenge in reviewing social capital literature (De Silva et al., 2005; Rotenberg et al., 2020). The social capital definitions used in the reviewed studies had common threads, most notably the exchange of resources within social network relationships. There is a clear need for more widespread use of a standardized measure of social capital that is validated for individuals with developmental disabilities. In applying the concept of social capital to the developmental disability literature, researchers most often used individual or family characteristics (including disability status) as potential precursors to social capital development, and mental and physical health as potential outcomes of social capital. Within the reviewed studies, there was little consistency in developmental disability definition and age range of participants. This diversity within the literature would make a systematic review or meta-analysis difficult but invites additional research into the various ways social capital is already included in developmental disability literature.

Second, I conducted an analysis of longitudinal, nationally representative data to examine the differences among children with and without developmental disabilities in extracurricular activity participation rates and the relationship between extracurricular participation and mental health outcomes in young adulthood. This analysis found that, on average, children with and without developmental disabilities spend similar amounts of time in extracurricular activities. However, when categorized (none, some, and high levels of participation), children without developmental disabilities were twice as likely to participate in high levels of extracurricular activity compared to children with developmental disabilities. Children with and without developmental disabilities who participated in group activities had lower levels of psychological distress and higher levels of flourishing than those who did not participate in group activities. For children with developmental disabilities, high levels of participation in group activities were most strongly associated with these positive mental health outcomes.

The third study used photovoice to amplify the voices of young adults with intellectual and developmental disabilities enrolled in a college program as they described what it means to be interdependent. This study was innovative in its use of universal design elements (e.g., supplementing verbal communication with written words and images to meet expressive and receptive communication needs of participants, and using technology familiar to the participants; Connell et al., 1997; Rios et al., 2016) to increase the accessibility of the research and included people with intellectual disabilities and communication difficulties who are often be excluded from research. The photos and stories shared by the participants showed that the students were open to being helped and identified the kinds of help they needed and who they preferred to provide that help. All students identified family as being important and foundational to their experience of interdependence. The students also discussed how having others to help when they are doing new or challenging things can be beneficial but may also be intimidating due to a fear of failure. Finally, participants expressed ways that they help other people and indicated a desire to help others. Some participants indicated they experienced tension between wanting to help other people while recognizing that providing help to others may lead to exploitation or mistreatment. The tension participants described is similar to the idea of "dignity of risk," or the right to make choices even if there is a risk of negative consequences (Perske, 1972). Participating in postsecondary education programs can provide students with intellectual and developmental disabilities dignity of risk similar to that experienced by students without disabilities (Bumble et al., 2022).

2. Collective implications

Collectively, the three studies described above increase our knowledge of the role of social capital in the lives of children, adolescents, and emerging adults with developmental disabilities. The scoping review is the first to summarize social capital as it pertains to children, adolescents, and emerging adults with developmental disabilities. This study identifies gaps in the literature; two of those gaps are addressed by the secondary data analysis and photovoice studies. The secondary analysis is the first to look at the relationship between childhood extracurricular activity and young adult mental health, comparing results for individuals with and without developmental disabilities.

This work expands on previous analyses using a comprehensive definition of developmental disability that allows us to examine the lives of people with lifelong disabilities using a nationally representative dataset. The photovoice study identifies themes surrounding the experience of interdependence through images and stories collected directly from individuals with intellectual disabilities.

My use of a life course perspective in this research advances the understanding that life experiences are cumulative (Bardo & Vowels, 2021) and an individual's relationships and experience of social capital may change over time (Ehsan et al., 2019). The evidence supports this understanding as we consider how people with developmental disabilities experience social capital. From childhood, individuals with developmental disabilities experience what has been termed a "cascade of disparities" (Krahn et al., 2006), an accumulation of social, physical or intellectual barriers that prevent them from engaging in opportunities to develop relationships with others (Agran et al., 2017; Clement & Bigby, 2009). For example, children and adolescents with developmental disabilities are more likely than those without disabilities to have problems communicating, to have limited opportunities to engage in accessible social activities, and to experience discrimination or violence (Agran et al., 2017; Hoyle et al., 2020).

Developing social relationships takes time, particularly for children and adolescents with developmental disabilities, who disproportionately experience such barriers to building relationships and social capital. At the same time, social capital may be particularly important for people with developmental disabilities. For example, many people with developmental disabilities have special supports throughout their school years. They may also benefit from public social programs during their developmental period. Often, such supports and benefits are no longer available when the individual reaches young adulthood, or are available only in less supportive ways, such as the transition from legally mandated special education from early childhood through high school to the college supports offered only if requested by the student. People with developmental disabilities may especially benefit from social capital as they navigate such life course changes. Although most of the articles included in the scoping review were cross-sectional, the social networks and connections studied by the researchers took months, perhaps years to develop. The secondary data analysis showed evidence of associations between childhood activities and mental health in young adulthood. The photovoice study emphasized the importance of families and the foundation and ongoing support they provide for young adults with intellectual and developmental disabilities.

3. Overall limitations

Each of the three manuscripts has limitations specific to the design and implementation. However, there are overall limitations that should be discussed. This dissertation is limited to the study of people within the childhood-emerging adult life stages. While these stages are critically important to an individual’s life trajectory, I recognize the need to understand the role of social capital more fully in the lives of adults in midlife and older ages with developmental disabilities. I focus on the critical period of life from childhood to emerging adulthood (ages 5-29 years old). The focus on these specific life course stages allowed me to take a closer look at the key transition times from childhood to emerging adulthood. This period of life is critical to an individual’s development and life trajectory (Elder, 1998) due to the changes in an individual’s status and social roles (e.g., student, employee, spouse; Bardo & Vowels, 2021). People with developmental disabilities may not transition into traditional emerging adult roles in the same ways as their peers without disabilities and are more likely to remain in dependent roles in young adulthood (Giesbers et al., 2020a,b; Walmsley, 1993).

Having a disability in childhood can substantially impact key elements of the transition to adulthood (e.g., education, employment, income, independent living, social and family status) (Janus, 2009; Bardo & Vowels, 2021). Disability in childhood is associated with an accumulation of disadvantage over time (Bardo & Vowels, 2021) and may affect individuals as they age into later life and contribute to health disparities described in previous passages (Havercamp et al., 2004; Hoyle et al., 2020; Krahn et al., 2006; Latham, 2015; Latham-Mintus & Aman, 2019; Laditka, et al., 2022; Li et al., 2018; Lunsky et al., 2011; Ouellette-Kuntz, 2005; West & Kamis, 2022).

Each of the studies includes individuals with developmental disabilities. Due to the wide range of diagnostic possibilities within the developmental disability umbrella, the samples for each of studies are not exactly the same. The scoping review included studies on developmental disability based on a list of diagnoses (e.g., Zablotsky et al., 2019); this study was not limited to individuals who also had evidence of lifelong impairment but rather diagnoses that often result in lifelong impairment. The secondary data analysis limited samples to individuals who had developmental disabilities with evidence of lifelong impairment starting in childhood (e.g., Hoyle et al. 2020). Individuals without lifelong impairment may experience the effects of having a disability in childhood. The photovoice study included only individuals with intellectual disability and met the admission criteria of the college program from which I recruited. In addition, participants in the secondary data analysis and photovoice studies only included people who had the communication and intellectual skills needed to participate in these methodologies. In the photovoice study, no one was excluded from participation due to ability. However, the photovoice study was limited to students in a college program with specific skill requirements. Therefore, the results in that study do not represent the experiences of individuals with extensive support needs. On the other hand, this feature of the study provided a useful control for the severity of impairment.

4. Overall Strengths

This research portfolio is strengthened by its use of multiple research methodologies, innovative and rigorous design, and triangulation of multiple guiding theories.

I employed three distinct, complementary, methods that each addressed an aspect of the research question, “how do people with developmental disabilities experience social capital from childhood to young adulthood?” I analyzed evidence from the current literature, nationally representative longitudinal data from multiple sources (e.g., children, parents, teachers), and firsthand accounts of people with developmental disabilities.

Each of the studies included innovative design elements. The scoping review provides a comprehensive overview of the social capital literature and identifies areas requiring additional investigation. The secondary data analysis used a comprehensive definition of developmental disability and 20 years of data to offer insight into the differences in extracurricular participation and its associations with mental health outcomes among people with and without developmental disabilities. Through the use of universal design and intentionally inclusive research, the photovoice study provides a better understanding of the importance of social connections and the challenges faced by college students with intellectual and developmental disabilities as they navigate interdependence in emerging adulthood.

The rigor of each method used is described in each of the manuscripts. For example, in the scoping review, I conducted interrater reliability checks to enhance the credibility of the study. The secondary data analysis uses a nationally representative, longitudinal dataset with high response rates (McGonagle & Sastry, 2015). I used multiple measures to examine the concepts of interest. The photovoice study exhibits established elements of rigor for qualitative studies (Lincoln & Guba, 1985) including member checks and triangulation of textual and visual data.

I used multiple theories to guide this work: social capital (Bourdieu, 1986; Lin, 2001; Portes, 1998; Putnam, 2000), life course perspective (Alwin, 2012; Elder, 1998), convoy model (Antonucci et al., 2014; Fuller et al., 2020), universal design (Connell et al., 1997; Rios et al., 2016), and disability frameworks (Halfon et al., 2012; Oliver, 1996). The triangulation of these guiding theories is a strength of this research (Denzin, 1978).

5. Future Directions and Implications for Public Health Policy

Each of the studies focused on at least one of the following life course stages: childhood, adolescence, emerging adulthood. A useful way to extend this research is to expand the age range of participants. As people age, they continue to experience transitions (e.g., jobs, family formation, living situation, divorce, separation, experiencing loss of family and friends). Additional work is needed to better understand the role of social capital in the lives of adults and older adults with developmental disabilities, specifically as they experience some of these transitions.

As children who participated in the 1997 Panel Study of Income Dynamics (PSID) Child Development Supplement (CDS) cohort age into midlife, we have opportunities for continued research using the PSID. By using the longitudinal and comprehensive data in the PSID, researchers can examine how experiences captured in the current study evolve throughout the life course and can increase our understanding of the long-term effects of early life experiences related to opportunities to build social capital have on adult development and health. For example, as children from the 1997 CDS cohort age into midlife and participate in the PSID, we could examine the cumulative effects of extracurricular activity and other social capital building activities from childhood and young adulthood on the mental health of midlife adults with developmental disabilities.

Replicating the photovoice study with adults in midlife and older adults would help researchers understand if similar patterns and themes can be observed throughout the lifespan or if the findings in the present study are unique to emerging adults. It would also be useful to conduct a similar study comparing emerging adults who are not attending a college program with those who are attending such a program, to better understand what unique role postsecondary education programs may play in the experience of social capital for emerging adults with developmental disabilities.

Each study used a different methodology to assess aspects of the same research question. Moving forward there are opportunities to extend the use of each of these methods. As the field continues to evolve, systematic review will be needed to evaluate the evidence and continue to identify areas of needed research.

The comprehensive nature of the PSID CDS allowed me to identify individuals with and without lifelong disabilities. Because of this stratification, there were individuals in the group of participants who did not have a lifelong disability who may have had a disability diagnosis in childhood. Future research could include three groups, “no diagnosis,” “developmental disability diagnosis without evidence of lifelong impairment” and “lifelong developmental disability.” Splitting the sample into three groups could provide valuable information about the effects of disability in childhood even if there is no evidence of lasting impairment.

The photovoice study proved useful as a research method accessible to participants with a range of needs and abilities. Incorporating elements of universal design expanded the accessibility of the method. Difficulties with communication can be a barrier to participation in research. People with developmental disabilities are more likely to have communication needs requiring extra attention or accommodation (Smith et al., 2020). Future research should consider how to be even more inclusive of individuals with extensive communication needs: for example, people who use alternative forms of communication such as communication devices, gestures, or sign language. Adapting the photovoice method to accommodate diverse communication needs can ensure that voices of all individuals, regardless of their abilities, are heard and valued in research.

In addition to expanding each of these methods individually, the use of mixed methods to address the multidimensional nature of social capital (Uphoff, 1996; De Silva,

2005) could substantially contribute to the field. Combining qualitative and quantitative approaches would strengthen our knowledge base by triangulating evidence through multiple sources, providing a more complete understanding of the issue and potential solutions, and facilitating instrument and intervention development and testing (Doyle et al., 2016; Regnault et al., 2018).

Given the growing importance of online social networks, it might be useful for future research to consider the potential for online social capital among individuals with developmental disabilities. Studies examining online social capital were underrepresented in the scoping review (Chadwick & Fullwood, 2018; Kim & Qian, 2021; Shpigelman, 2018). Future qualitative research could incorporate social media analysis or include questions about social media use. The CDS began asking questions about social media use in 2014. Therefore, future PSID analysis could also incorporate elements of online social capital.

This dissertation presented primarily the positive side of social capital, with a focus on the benefits derived from social connections. However, social capital has potential for negative effects, as well. While social networks can provide beneficial resources and support, these same networks can be sources of interpersonal conflict, exclusion, and exploitation (Song et al., 2021). Future work should explore potential barriers and harm associated with social capital. However, I found evidence that extracurricular activity, and presumably therefore also social capital, was associated with positive outcomes for mental health. Although social capital may carry harms that were not explicitly measured in the models, that result suggests that on balance the mental health outcomes linked with social capital may be positive.

This research is important for legislators and policymakers as they consider funding and support for individuals with developmental disabilities. Developing the relationships that comprise an individual’s social network takes time. Many of the skills needed to foster the development and maintenance of these relationships are modeled by families and formed in childhood and adolescence (Bubolz, 2001; Kramer et al., 2013). One key to helping people with developmental disabilities build and access their social capital may be in the support provided to families of children with developmental disabilities. Families need the resources and knowledge to help their children learn critical social skills that will allow them to build their social networks. Individuals with developmental disabilities need opportunities to practice these social skills in natural settings that foster reciprocal relationships with others in which individuals with disabilities both receive support and provide support to others. As people with developmental disabilities age, they may need continued residential, career, leisure, educational, and social supports to maintain, expand, and access their social capital resources (e.g., Elias & Cook, 2016; Giesbers et al., 2021; Haider et al., 2014; Hall & Kramer, 2009).

Our understanding of the relationship between social capital and health has steadily increased in recent decades; however, there remains a need for research on social capital interventions to promote health (Villalonga-Olives et al., 2018). Within my scoping review, only two studies (Patterson & Loomis, 2016; Webber et al., 2019) described interventions to build social capital. Providing interventions to promote social inclusion and community participation and teach people how to recognize and access their social capital resources can empower people with developmental disabilities to benefit from their social networks.

Researchers should also consider how to include people with developmental disabilities in general public health intervention research. One way to increase representation of people with developmental disabilities in social capital intervention research would be to emphasize universal design principles (e.g., plain language, captions, large print, accessible facilities) to increase the accessibility of research (Rios et al., 2016; Vinoski Thomas et al., 2019). Tools used to measure social capital should also incorporate universal design. Tools should be validated for people with and without developmental disabilities. Universally designed validated measures of social capital would increase our ability to study social capital among people with developmental disabilities and would allow us to compare outcomes for people with and without developmental disabilities.

Most developmental disability research is limited to people with developmental disabilities who are receiving services. Including people with developmental disabilities into universally designed general public health research could provide valuable information about the experiences of people with developmental disabilities who are not receiving formal services. To identify people with developmental disabilities within general public health research, investigators could ask about special education history (Laditka et al., 2022; Laditka et al, 2021). Asking this question presents low burden on the researcher and the participant and can help us identify people with developmental disabilities who are not receiving services (Laditka et al., 2022; Laditka et al, 2021).

Public health has often regarded disability as something to be prevented; however, not all disabilities are preventable (Swenor, 2021; The Lancet Public Health, 2021). Researchers and practitioners within the public health field call for a shift in public health research to one of health equity for people with disabilities (Swenor, 2021; The Lancet Public Health, 2021). My research supports this view. All public health programs and policies should include individuals with disabilities (Centers for Disease Control and Prevention [CDC], 2020). Public health interventions aimed at increasing social capital among the general public should also incorporate universal design and consider the needs of individuals with developmental disabilities. Program materials and facilities should be developed and chosen to be as accessible as possible to as many people as possible. Expanding CDC supported state-based disability and health programs and National Centers on Health Promotion for People with Disabilities could better equip public health professionals to include people with developmental disabilities in more public health programs and services (CDC, 2020). The voices of people with developmental disabilities should be included in the planning and implementation of public health interventions. Public health education programs should examine how they address health issues related to disability and include students, faculty and practitioners with disabilities in their work (Swenor, 2021).

Public health professionals should view the health of people with disabilities as an issue of health equity. By doing so, we expand our focus to include people with disabilities as individuals who experience disparities due to social determinants of health and not just as a byproduct of their disability. The experience of social capital described in this research is one example of a social determinant that public health interventions can use to improve the overall health and wellbeing of people with developmental disabilities.

6. Conclusion

This dissertation research sheds light on the importance of social relationships and social capital in the lives of people with developmental disabilities during the critical stages of childhood to young adulthood. Individuals with developmental disabilities can develop and maintain social networks through which they may access social capital resources. These resources may be beneficial to their mental health and well-being. People with developmental disabilities may need external support to foster the development and maintenance of these social networks. Results of this research suggest that participation in group activities outside of school and home may provide useful opportunities for individuals with developmental disabilities to build social capital. This research also challenges researchers to consider not only the benefits individuals with developmental disabilities receive from their social capital, but also how individuals with developmental disabilities can be supported to invest in their own social capital by providing help to others, as well.

By recognizing the role of social capital in the lives of individuals with developmental disabilities, we can identify needed policies and supports that may enhance the overall quality of life for individuals with developmental disabilities throughout their lifespan. Ultimately, this research serves as a stepping stone toward a more inclusive and supportive society for individuals with developmental disabilities, highlighting their agency and contributions in developing social capital and fostering interdependent relationships.

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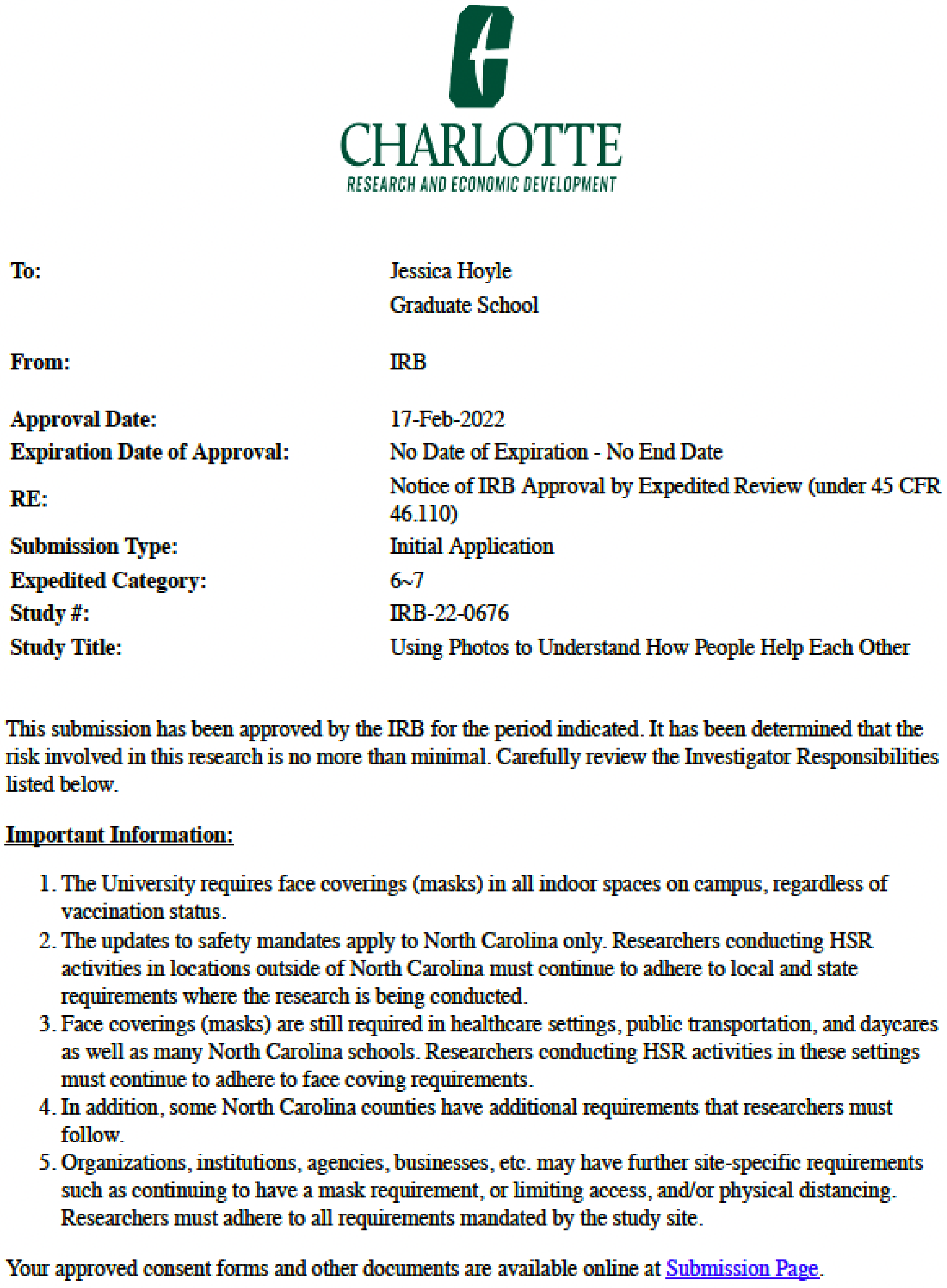
APPENDIX B: ETHICAL APPROVAL LETTERS



CHARLOTTE
RESEARCH AND ECONOMIC DEVELOPMENT

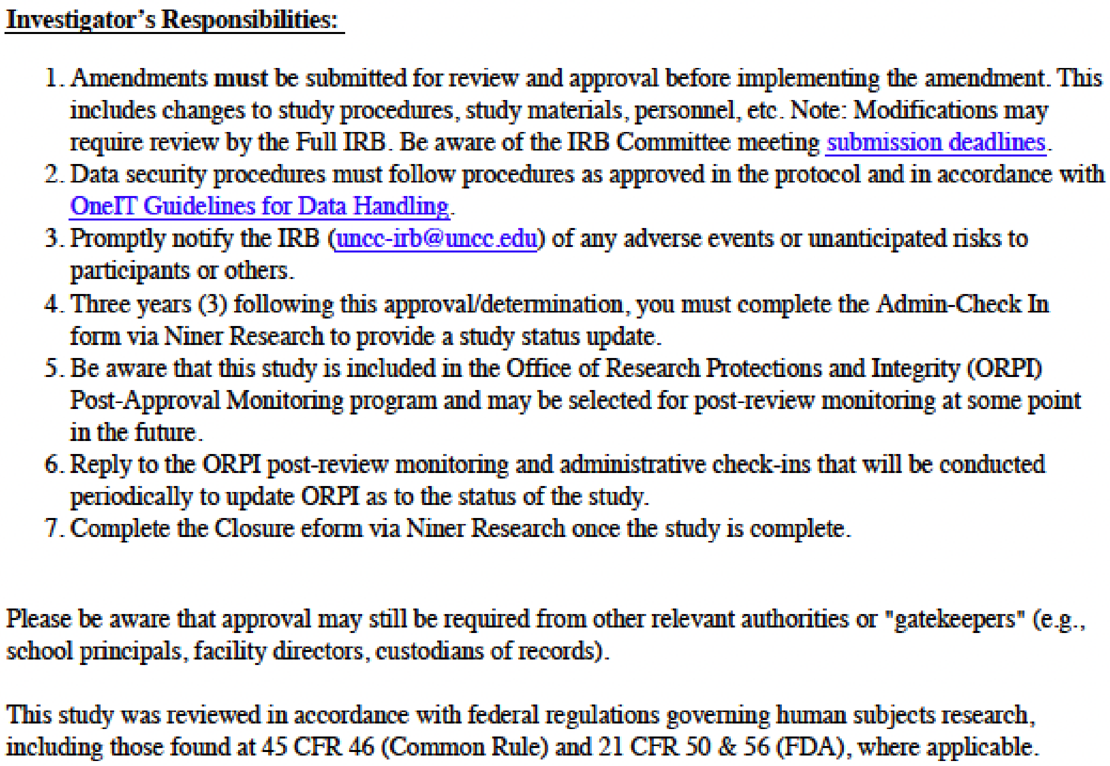
To:	Jessica Hoyle Graduate School
From:	IRB
Approval Date:	17-Feb-2022
Expiration Date of Approval:	No Date of Expiration - No End Date
RE:	Notice of IRB Approval by Expedited Review (under 45 CFR 46.110)
Submission Type:	Initial Application
Expedited Category:	6~7
Study #:	IRB-22-0676
Study Title:	Using Photos to Understand How People Help Each Other

This submission has been approved by the IRB for the period indicated. It has been determined that the risk involved in this research is no more than minimal. Carefully review the Investigator Responsibilities listed below.

Important Information:

1. The University requires face coverings (masks) in all indoor spaces on campus, regardless of vaccination status.
2. The updates to safety mandates apply to North Carolina only. Researchers conducting HSR activities in locations outside of North Carolina must continue to adhere to local and state requirements where the research is being conducted.
3. Face coverings (masks) are still required in healthcare settings, public transportation, and daycares as well as many North Carolina schools. Researchers conducting HSR activities in these settings must continue to adhere to face coving requirements.
4. In addition, some North Carolina counties have additional requirements that researchers must follow.
5. Organizations, institutions, agencies, businesses, etc. may have further site-specific requirements such as continuing to have a mask requirement, or limiting access, and/or physical distancing. Researchers must adhere to all requirements mandated by the study site.

Your approved consent forms and other documents are available online at Submission Page.

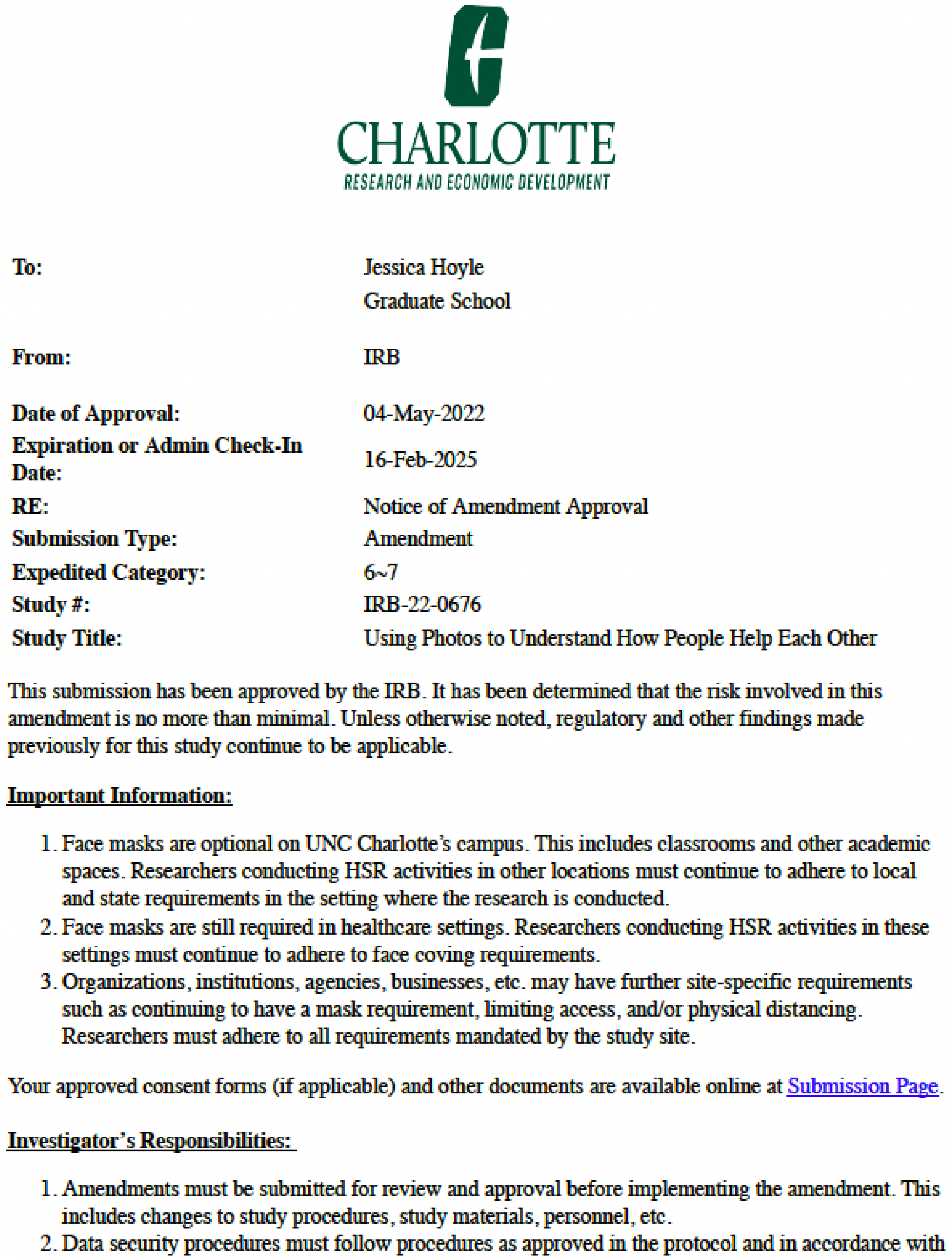


Investigator's Responsibilities:

1. Amendments **must** be submitted for review and approval before implementing the amendment. This includes changes to study procedures, study materials, personnel, etc. Note: Modifications may require review by the Full IRB. Be aware of the IRB Committee meeting submission deadlines.
2. Data security procedures must follow procedures as approved in the protocol and in accordance with OneIT Guidelines for Data Handling.
3. Promptly notify the IRB (uncc-irb@uncc.edu) of any adverse events or unanticipated risks to participants or others.
4. Three years (3) following this approval/determination, you must complete the Admin-Check In form via Niner Research to provide a study status update.
5. Be aware that this study is included in the Office of Research Protections and Integrity (ORPI) Post-Approval Monitoring program and may be selected for post-review monitoring at some point in the future.
6. Reply to the ORPI post-review monitoring and administrative check-ins that will be conducted periodically to update ORPI as to the status of the study.
7. Complete the Closure eform via Niner Research once the study is complete.

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule) and 21 CFR 50 & 56 (FDA), where applicable.



CHARLOTTE
RESEARCH AND ECONOMIC DEVELOPMENT

To:	Jessica Hoyle Graduate School
From:	IRB
Date of Approval:	04-May-2022
Expiration or Admin Check-In Date:	16-Feb-2025
RE:	Notice of Amendment Approval
Submission Type:	Amendment
Expedited Category:	6~7
Study #:	IRB-22-0676
Study Title:	Using Photos to Understand How People Help Each Other

This submission has been approved by the IRB. It has been determined that the risk involved in this amendment is no more than minimal. Unless otherwise noted, regulatory and other findings made previously for this study continue to be applicable.

Important Information:

1. Face masks are optional on UNC Charlotte's campus. This includes classrooms and other academic spaces. Researchers conducting HSR activities in other locations must continue to adhere to local and state requirements in the setting where the research is conducted.
2. Face masks are still required in healthcare settings. Researchers conducting HSR activities in these settings must continue to adhere to face coving requirements.
3. Organizations, institutions, agencies, businesses, etc. may have further site-specific requirements such as continuing to have a mask requirement, limiting access, and/or physical distancing. Researchers must adhere to all requirements mandated by the study site.

Your approved consent forms (if applicable) and other documents are available online at Submission Page.

Investigator's Responsibilities:

1. Amendments must be submitted for review and approval before implementing the amendment. This includes changes to study procedures, study materials, personnel, etc.
2. Data security procedures must follow procedures as approved in the protocol and in accordance with

OneIT Guidelines for Data Handling.
3. Promptly notify the IRB (uncc-irb@uncc.edu) of any adverse events or unanticipated risks to participants or others.
4. Complete the Closure eform via Niner Research once the study is complete.
5. Be aware that this study is included in the Office of Research Protections and Integrity (ORPI) Post-Approval Monitoring program and may be selected for post-review monitoring at some point in the future.

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

This study was reviewed in accordance with federal regulations governing human subjects research, including those found at 45 CFR 46 (Common Rule) and 21 CFR 50 & 56 (FDA), where applicable.