

**Social Relations of Older Adults with Intellectual Disabilities from a Life Course
Perspective**

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DISSERTATION

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This dissertation is dedicated to my mother, Anne Boerboom, whose life stance has so deeply influenced mine.

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SUMMARY

Social relationships are important to how people define the quality of their lives (Barrera, 2000; Bigby, 2004; C. H. Kennedy, 2004), and social well-being is of particular importance to older adults, who rate social relationships among the most important determinants of aging well (Cavanaugh, 1999). There is minimal knowledge of the views of older adults with intellectual disabilities as to how their social relations impact their well-being. By integrating aging and disability literatures, theories and research methodologies, this study aims: 1) to contribute to the available knowledge on the social networks of older adults with intellectual disabilities from a life course perspective; 2) to increase the limited understanding of the individual experiences of these adults; and 3) to identify strategies for supporting their social networks as they age.

A process of paired recruitment was employed to generate a sample of 12 adults with intellectual disabilities age 50 and over each with at least one key support person. Data collection consisted of in-depth qualitative interviews with the participants and their key support persons. Social network maps were filled out for participants, and their life histories were recorded. A vertical timeline of key events in each individual life history (Assink & Schroots, 2010; J. Caldwell, 2010) served as a visual cue for each participant.

Data analysis followed an inductive process and started with case-analysis (Patton, 2002) that resulted in 12 individual stories that provided context to the subsequent analysis. The second step of data analysis consisted of the creation of a comprehensive summary of the structural characteristics of the participants' present social convoys based on the case-analysis. The third step of data analysis consisted of thematic analysis of the interview transcripts (Braun & Clarke, 2006).

The participants were mostly positive about both their convoy members and their social supports. The participants were closest to their sisters and female direct support staff who provide the bulk of supports to them. Participants had few relationships with people without disabilities other than staff and relatives.

Four common themes emerged from the participants' experiences with social convoys across their life courses. The first theme, 'Positive Impact of Social Convoys in Early and Mid-Life', captures how the participants' convoys facilitated positive experiences in the first parts of their lives. Parents and siblings were the most important members of the participants' convoys in their first life stages. The second theme, 'Emotional Impact of Early and Mid-Life Transitions', describes the participants felt their lives were disrupted by several convoy related transitions as they reached young and middle adulthood. Moving out of family homes and the deaths of parents were the most poignant transitions in the participants' lives. The third theme, 'Interpersonal Conflict across the Life Course', describes challenging encounters with convoy members caused distress and negatively impacted the participants' well-being at various points in their lives. The fourth theme, '(Be)Longing in Late Life', captures the parallel sentiments of longing and belonging that were in the foreground in the participants' experiences.

The present study demonstrates that social network mapping and life story methods can be effectively applied in research with older adults with intellectual disabilities. Study findings indicate that supporting older adults with intellectual disabilities as they age in coping with age-associated losses needs precedence in support practices. Social network mapping and life history work are strategies that can support the social relations of this population and make person-centered future planning more effective. Future research should be longitudinal in nature, investigating differences in social relations between older men and women with intellectual

disabilities, studying relationships among people with intellectual disabilities and direct support staff, and developing and testing standardized social network mapping and life story work tools.

I. INTRODUCTION

This study investigates the social convoys of older adults with intellectual disabilities from a life course perspective. It is unique in that it retrieves the perspectives of older adults about their social relations and social supports throughout their lives.

The literature review chapter presents the conceptual framework that underlies this study. It also provides an introduction to critical thinking about aging with disability, and situates this phenomenon at the intersection of gerontology and disability studies. The chapter includes background on social relations with aging and discusses the available knowledge about the social relations of people with intellectual disabilities as they age. The chapter concludes with an analysis of the needs for future research on social relations of older adults with intellectual disabilities.

The method chapter outlines the study's aims, research questions, design, and data collection procedures. In line with dyadic interviewing (K. Caldwell, 2013), the individuals with intellectual disabilities were supported by a key support person during the interviews. The chapter outlines the use of social network mapping (Tracy & Whittaker, 1990) in investigating the individuals' current social convoys and describes the application of the Lifeline Interview Method (Assink & Schroots, 2010) in exploring the individuals' life experiences. As the study is qualitative in nature and the researcher is intricately woven into the context of the study, the chapter includes a discussion of the researcher's orientation. The chapter concludes with a description of the data analysis techniques that were applied.

The study's results are presented in three chapters. The first presents life stories of all individuals with disabilities who participated in the study. The stories include backgrounds on these individuals and detailed descriptions of their social convoys and life histories. The stories

inform the analysis that is presented the next two results chapters. The second provides a comprehensive overview of the structural and functional characteristics of the current convoys of the study's participants. The third explores the four common themes that emerged from the participants' experiences with social convoys across their life courses.

The final chapter discusses the major study findings. The chapter also includes discussions of the study's methodological implications, implications for practice and policy, recommendations for future research, and the study's limitations.

II. LITERATURE REVIEW AND THEORETICAL FOUNDATION

This chapter presents the conceptual framework that underlies this study and provides a background on aging with disability. The chapter also discusses why aging with disability needs to be studied from a life course perspective. It presents supportive social relations as an important element in aging well. Additionally, it provides a background on research on social relations of people with intellectual disabilities.

This study aims to understand how the experiences of older people with intellectual disabilities with their social relations across their lives influence their aging experiences and how their social relations can be supported to promote aging well. The conceptual framework that underpins this study presents an integrated way of looking at the social relations of older people with intellectual disabilities, as it cannot be meaningfully researched with reference to a single theory or concepts within one theory (Liehr & Smith, 1999). The framework draws upon existing theories in disability studies, specifically those related to life course perspectives on disability (Heller & Parker Harris, 2012; Priestley, 2003) and to aging of people with intellectual disabilities (Heller, 2004). The framework also uses gerontological theory, specifically the social convoy model (Kahn & Antonucci, 1980).

Life course perspectives on disability acknowledge the importance of insight into previous life experiences to understand aging experiences. To understand the social relations of older people with intellectual disabilities we need to obtain their life histories. Life course perspectives also consider cohort factors to influence the life experiences of different generations.

The supports-outcome model of aging well by Heller (2004) conceptualizes what successful aging looks like for people with intellectual disabilities. The gerontology field has

traditionally understood successful aging to be characterized by high cognitive and physical functioning and low incidence of disease and disability (Rowe & Kahn, 1987). Heller's model (2004) provides an alternative to these normative notions of successful aging that do not apply to the experiences of those aging with lifelong disabilities (J. Kennedy & Minkler, 1999). The supports-outcomes model acknowledges the central importance of social support in aging well of older people with intellectual disabilities.

The social convoy model conceptualizes the impact of social relations on the experience of aging from a life course perspective. It proposes that individuals are surrounded by a convoy, a relatively stable set of supportive relationships that either facilitates or hinders individuals' development as they age (Kahn & Antonucci, 1980). This model is used in aging research with the general population. It remains unclear if the social convoy model is a useful tool to understand the social relations of older people with intellectual disabilities from a life course perspective and how applicable the model's assumptions are to the experiences of this population.

The conceptual framework of this study applies a historical perspective to the experiences of those aging with intellectual disabilities. It assumes that individuals with intellectual disabilities travel through life and life course transitions accompanied by a social convoy. The convoy of social relations can positively affect their aging experiences by providing social support and a sense of belonging or negatively impact aging if the opposite is true. Individual and environmental factors influence the development and stability of the social convoy through the life course. Figure 1 illustrates the conceptual framework underpinning this study.

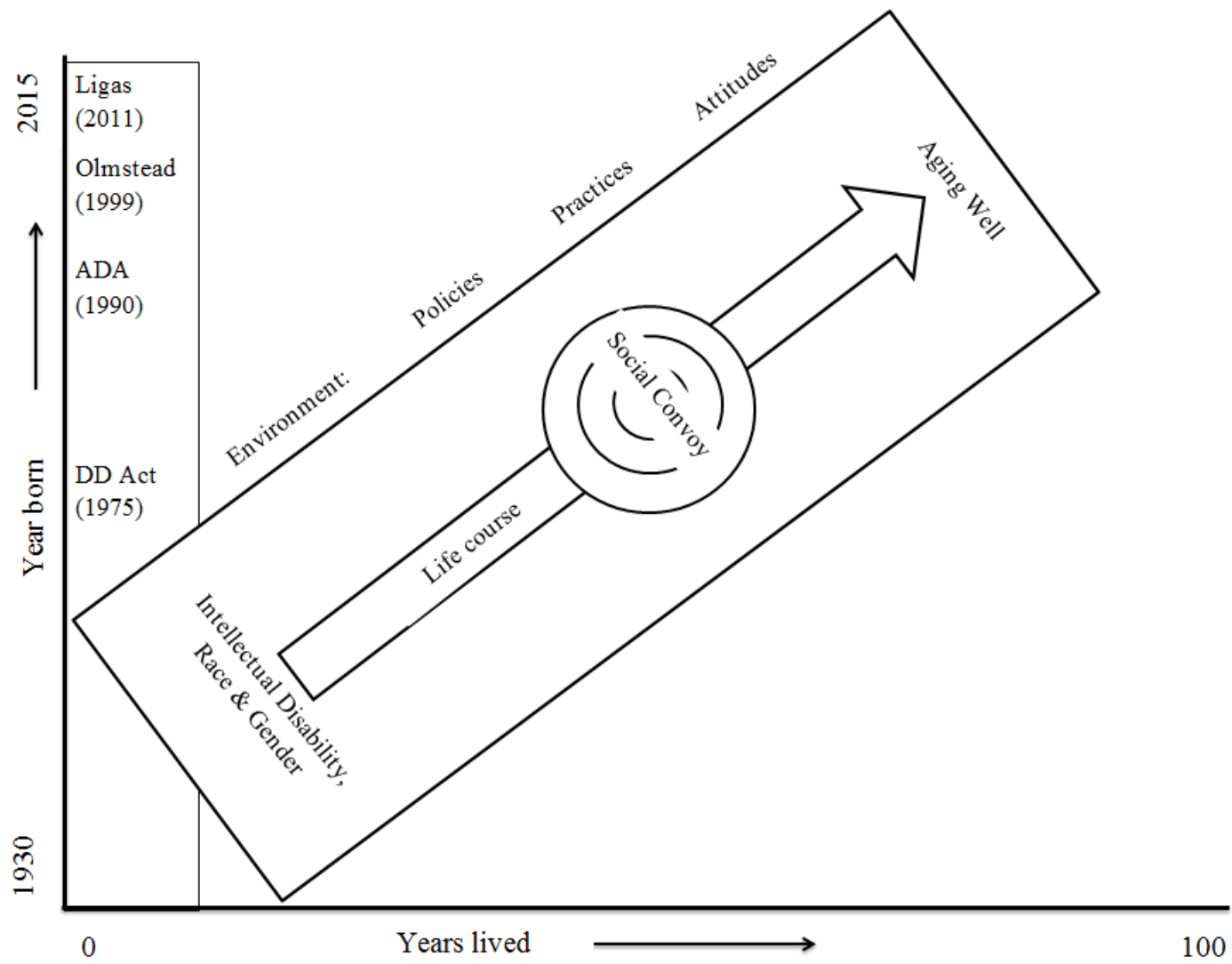


Figure 1. Conceptual Framework

A. **Aging with Disability**

1. **Aging from a life course perspective**

There has been an increase in overall life expectancy at birth worldwide due to improved health and social care (Sheets, 2011). A child born in the U.S. in 2011 can expect to live 78.7 years, about 30 years longer than a child born in 1900 (Administration on Aging and Administration for Community Living, 2012). During the past half century, the world's population aged significantly in both absolute and relative terms (Victor, 2010). The population is getting older, and the worldwide cohort of older people is larger than ever before. Since 1900, the number of older Americans increased over 13 times (from 3.1 million to 41.4 million) and the percentage of older Americans more than tripled (from 4.1% in 1900 to 13.3% in 2011) (Administration on Aging and Administration for Community Living, 2012). One in every eight Americans is now over the age of 65 (Administration on Aging and Administration for Community Living, 2012).

Because of societies' increasingly aged population the study of aging is a high priority concern (Birren, 2007). Aging is a complex and dynamic process that can only be understood by considering multiple perspectives that take into account different developmental forces. Physiological changes are often emphasized in explanations of aging even though their effects are intertwined with psychological and socio-cultural forces. Psychological or behavioral forces include all internal perceptual, cognitive, emotional, and personality factors that affect development. Socio-cultural forces include interpersonal, societal, cultural, and ethnic factors (Dannefer & Settersten, 2010).

Chronological age is another factor that is overstressed in understandings of aging. A persons' chronological age is not a meaningful indicator of aging. Aging is affected by

experiences that occur with the passage of time, not by time itself (Dannefer & Settersten, 2010). An adequate understanding of aging and what it means for an individual to grow old requires knowledge of the lifelong context in which different developmental forces occur. The life course perspective has therefore emerged as a key arena of scholarship for understanding aging (Dannefer, 2011; Elder, Kirkpatrick Johnson, & Crosnoe, 2004).

The life course perspective acknowledges that aging is a lifelong process that occurs from birth through death. Circumstances, events and behavior earlier in life influence human development at older ages, and the life courses of individuals are shaped by cohort factors (Elder & Giele, 2009; Elder et al., 2004). These are events or circumstances that most people in a specific culture experience at the same point in time which can provide a generation with a unique identity (Cavanaugh, 1999). Birth cohorts can age in different ways if they have different experiences at different times in their lives (Elder et al., 2004). The moments when events or transitions occur in a person's life, whether early or late relative to other people and normative expectations, are additional factors that influence the life course (Elder & Giele, 2009). Furthermore, human lives, experiences, and aging cannot be adequately represented when removed from relationships with significant others since lives are lived interdependently within a network of shared relationship (Elder et al., 2004).

Universal changes occur for all people as they age, but the rates and nature of change are different based on variability in individual circumstances across the lifespan (Heller & Marks, 2006; Kelley-Moore, 2010; Mosqueda, 2004). The resulting heterogeneity or diversity among older persons was recognized in gerontology as early as the 1970s. The occurrence of poverty and inequality in old age is another elaborately discussed theme in the field. These combined observations have led to the formulation of the cumulative advantage/disadvantage theory. This

theory defines cumulative advantage/disadvantage as “the systemic tendency for inter-individual difference in a given characteristic (e.g., money, health, or status) with the passage of time” (Dannefer, 2003, p. S327). Cumulative advantage/disadvantage has been operationalized not for individuals, but as “a property of populations or other collectivities (such as cohorts), for which an identifiable set of members can be ranked” (Dannefer, 2003, p. S327). Childhood conditions such as illness, economic adversity and instability in the family of origin appear to have formative and cumulative effects on long-term economic, social, psychological, and physical well-being (O’Rand, 2009).

2. **Disability from a life course perspective**

Disability is a complex process. It is not a dichotomous phenomenon of presence or absence or a static condition, although it is often characterized as such (Kelley-Moore, 2010). More than 15 % of the world’s population are estimated to live with some form of disability. This is one billion people (World Health Organization, 2011). In 2010, approximately 56.7 million people in the United States had some kind of disability comprising 18.7 % of the 303.9 million people in the civilian noninstitutionalized population that year (Brault, 2010).

People with disabilities have been restricted in their opportunities to participate in our communities on an equal basis with others, and share a history that has been oppressive and has included abuse, neglect, segregation, and institutionalization (Braddock & Parish, 2001). Barriers include disabling environments, attitudes, institutions, discourses, policies, and practices. The global politics of disability rights has launched a social model of disability in which disability is seen as the relationship between people with impairment and a disabling society (Shakespeare, 2006). People with disabilities have since started to claim an identity as well as political power (Braddock & Parish, 2001).

To understand the experiences and the needs of adults with disabilities as they age it is important to have insight into their experiences in earlier stages of life. Aging is a lifelong process, and circumstances, events, behavior, and relationships earlier in life influence the development of people with disabilities at older ages (Elder et al., 2004; Marshall, 1996; Passuth & Bengtson, 1988). Unfortunately little research has addressed lifelong disability from a life course perspective (Jeppsson Grassman, Holme, Taghizadeh Larsson, & Whitaker, 2012; Kelley-Moore, 2010; Parker Harris, Heller, & Schindler, 2012; Priestley, 2003; Yorkston, McMullan, Molton, & Jensen, 2010). Disabilities among younger persons, mid-life adults, and older adults are frequently considered independently, with little cross-fertilization of ideas or acknowledgement of life-course processes (Kelley-Moore, 2010).

A life course approach that addresses disability issues across generations and through various life stage transitions is complex, but useful to inform and further our understanding of disability (Irwin, 2001; Parker Harris, Heller, & Schindler, 2012). Disabling barriers affect the circumstances, experiences, and opportunities of people with disabilities of different generations in different ways through the life course (Parker Harris, Heller, & Schindler, 2012). As a consequence there are differences in the life experiences of different age cohorts of persons with disabilities. Additionally, disability can be experienced differently in different life stages (Parker Harris, Heller, & Schindler, 2012).

3. **The intersection of aging and disability**

a. **The demography of aging with disability**

The same medical and social factors that have led to the increase in longevity of the overall population have also significantly increased the lifespans of people with lifelong disabilities (Kemp & Mosqueda, 2004; Sheets, 2011). The evidence base regarding the

demography of aging with disabilities in the United States is growing even though substantial gaps remain (Freedman, 2014). We know that people aging with a disability form an increasing proportion of the population (Sheets, 2005). Data from the 2008-2012 American Community Survey five-year estimates indicated that 38.7 % of the population of adults aged 65 and over reported having one or more disabilities, the equivalent of 15.7 million people (He & Larsen, 2014).

b. **Aging ‘with’ versus ‘into’ disability**

Various pathways lead to the intersection of aging and disability. A prominent conceptualization of aging and disability distinguishes between people with early-onset or lifelong disabilities (who are said to ‘age with disability’) and people with mid- or late-life onsets (who are said to experience disability ‘with’ aging or age ‘into’ disability) (Putnam, 2007; Verbrugge & Yang, 2002). Those who ‘age into disability’ include people who experience an acute health event such as stroke, spinal cord injury, or a hip fracture later in life and those who experience a decline in function resulting from the cumulative effects of health conditions associated with aging (Kelley-Moore, 2010; Yorkston et al., 2010).

The opinions on the validity of drawing clear distinctions between groups aging ‘with’ and ‘into’ disability vary, as aging and disability are dynamic processes that interleave and interact in complex ways across the life span (Verbrugge & Yang, 2002; Yorkston et al., 2010). For example, those with early-onset disabilities will also often acquire additional impairments in old age (Priestley, 2003). The age of onset, the number of years spent with a disability, the degree to which disability is lifelong, its severity and progression, and the extent to which its manifestations are cyclical all further complicate efforts at drawing rigid distinctions with reliable predictive power. These factors affect the way individuals interact with the larger social

environment, including family, work, and the healthcare system, and hence, influence individual outcomes over the life course (Institute of Medicine, 2007; Jeppsson Grassman et al., 2012; Kelley-Moore, 2010; Parker Harris, Heller, Schindler, & van Heumen, 2012). The types of disability-related impairments among the older population will extend with the increase of the population of people aging with a lifelong disability. This means that the experiences people bring with them into old age will create “a more heterogeneous older population” (Putnam, 2007, p. 12).

c. **Common concerns among people aging ‘with’ and ‘into’ disability**

Aging and disability experiences interact, influence, and shape each other not only through physiological changes, but through social experiences as well (Kelley-Moore, 2010). In modern western societies, both old age and disability are devalued social conditions to be avoided, postponed, or denied. There are common sources of prejudice and discrimination against older adults and people with disabilities (Alkema & Alley, 2006; Sheets, 2005). Both groups are often considered dependent and incompetent and are systematically denied the right to decide how to live their lives (S. D. Stone, 2002). People who are both older and disabled may have a double diminished social status (Bigby, 2004; Breitenbach, 2001).

Both old age and disability are often viewed as organic and naturalized characteristics of individuals (Achenbaum, 2005; Baars, Dannefer, Phillipson, & Walker, 2006; Chappell, Goodley, & Lawthom, 2001; Dannefer, 2011; Goodley & Rapley, 2001, 2002). Since this perspective considers functional limitations as individual ‘defects’ it limits the applications of

supports (Kane & Kane, 2005; Sheets, 2005) and environmental adaptations to improve individual quality of life.

Examples of supports and adaptations important to adults with disabilities of all ages are the availability of affordable residential options, long term support, family caregiver support, accessible transportation, access to health care, economic stability and security, and self-direction in services and support. Despite these common challenges and needs, much of the research, policy, practice, and advocacy efforts in both the aging and disability fields fail to take these commonalities into account (Lightfoot, 2007; Sheets, 2005).

d. **Differences between people aging ‘with’ and ‘into’ disability**

Despite some similar needs on a functional level, people aging ‘with’ and ‘into’ disability are quite different in many ways (Bigby, 2004; Breitenbach, 2001). An important distinction between both groups is that they generally perceive themselves and are perceived by others as being very different from one another (Breitenbach, 2001; Kelley-Moore, Schumacher, Kahana, & Kahana, 2006; Priestley, 2003; Zink, 1992). The social meanings of age structure the life course through age expectations, (in)formal sanctions and social timetables (Elder et al., 2004).

In many western cultures, you are not considered old until you have a disability (Oldman, 2002; Sheets, 2005). Becoming functionally limited in older adulthood tends to be framed as normative, and age related impairments deemed add-ons to life. In contrast, becoming disabled prior to old age is often viewed as disruptive to the life course. Long life impairments are considered to have influenced the paths individuals have taken in life (Kelley-Moore, 2010).

Early- and mid-life roles held by individuals influence the determination of their achievements and values to society. Becoming disabled early in life can affect some of these

roles, such as those of being a spouse, parent, or employee (Zink, 1992). The inability to achieve normatively expected roles such as these can greatly influence perceptions of social worth and identity (Kelley-Moore, 2010; Zink, 1992). Unwittingly, families can also be agents for reinforcing stereotypes about persons with disabilities by informally discouraging life choices such as marriage, parenthood, independent living arrangements, or educational opportunities (K. Johnson, Traustadottir, Harrison, Hillier, & Sigurjonsdottir, 2001).

e. **Aging with lifelong disability**

Study of those aging with a lifelong disability is a relatively new field of inquiry and limited knowledge is available on how this group ages (Kemp & Mosqueda, 2004; Sheets, 2005). The experiences of older adults with disabilities are likely to be different from their non-disabled peers. The inequalities that they have experienced have the tendency to become more pronounced as they grow older (Phillipson & Baars, 2007). They accumulate over time posing increasing risks to health, wealth and well-being (Alkema & Alley, 2006; Biggs & Daatland, 2004). Understanding the lived experience of aging with a lifelong disability from a life course perspective helps us understand more clearly how disability and aging are produced, socially constructed, and regulated across the life course (Irwin, 2001; Parker Harris, Heller, & Schindler, 2012; Priestley, 2004).

4. **Aging of people with intellectual disabilities**

The largest group of people aging with lifelong disabilities is those with intellectual disabilities (Bigby, 2004). The life expectancy of people with intellectual disabilities is lower than the life expectancy of the general population. Those with moderate and severe intellectual disabilities live into their late 60s and late 50s, respectively, while the life expectancy

of those with mild intellectual disabilities is 74 years, and approaches that of the general population (Bittles et al., 2002; Haveman et al., 2009).

Over the next 20 years the U.S. population of older adults with intellectual disabilities will increase considerably. Based on data from the U.S. Census (Population Division U.S. Census Bureau, 2008; U.S. Census Bureau, 2010) and the work by Larson and colleagues (2001), and Factor, Heller, and Janicki (2012) estimated there are 850,600 people with intellectual and developmental disabilities age 60 and older living in the country. By 2030 their numbers are expected to swell to an estimated 1.4 million due to increasing life expectancy and the aging of the baby boomer generation.

Despite their increase in numbers, older people with intellectual disabilities remain a small group within the general older population. This means there is a danger that their specific needs will be neglected among demands of larger groups (Bigby, 2004). This is of concern for several reasons. Persons with intellectual disabilities on average have twice as many health problems than those in the general public (van Schrojenstein Lantman de-Valk & Noonan-Walsh, 2008). They are likely to develop secondary and unique conditions related to their disabilities as they age (Lightfoot, 2007). This population therefore requires more health care (Heller, 2004) and is confronted with complex medical decisions (Kapp, 1999). Several social factors are thought to predispose individuals with intellectual disabilities to health problems later in life. These include lack of education, institutionalization at an early age, limited social networks, loss of close and confiding relationships, bereavement, absence of valued social roles for them, low income and poverty, service breaks and transitions, and shifting patterns of interdependence with parents during the life cycle (Grant, 2005).

Because this is the first time that large numbers of people with disabilities are living into middle age and beyond, it is unknown what to expect, and major policy issues may be raised by the existence of this population. There is a tendency to accept changes in health and function as inevitable outcomes of aging or the primary disability. However, some changes that are common are not inevitable (Heller & Marks, 2006; Mosqueda, 2004). The natural processes of aging may be more stressful for older adults with intellectual disabilities because of their greater need for everyday support, limited ability to understand what is happening to them resulting from communication or cognition impairments, or societal attitudes that deny them access to information and support needed to successfully cope with and adjust to losses. In addition, they are at a higher risk to face their own mortality alone as they lose their next of kin (Parker Harris, Heller, Schindler, et al., 2012). Older adults with intellectual disabilities need adequate support to promote their well-being. Unfortunately the fields of disability studies and gerontology lack research on the views of older people with intellectual disabilities themselves on aging, on how they would like to be supported to have a better quality of life, and on what they consider important to age well (Bigby, 2004).

5. **Aging well with disability**

Successful aging has traditionally been defined as aging accompanied by high cognitive and physical functioning and low incidence of disease and disability (Rowe & Kahn, 1987). For those who age ‘with’ disability rather than ‘into’ disability, this common characterization of successful aging is exclusionary. The supports-outcomes model of aging well by Heller (2004) is valuable, as it posits that successful outcomes of aging for this population relate to independence, quality of life, physical and emotional well-being and community

inclusion. Because of its inclusive nature, this study utilizes the supports-outcomes model and uses the term ‘aging well’.

The supports-outcomes model of aging well combines discourse on intellectual disability with aging theory. It stipulates that successful outcomes of aging of those with disabilities depend on the following factors: capabilities, including intellectual level and adaptive behavior; physical and emotional health; physical functioning; environment, including home, work, and other community environments; and the amount and kind of support persons receive. The model emphasizes that aging successfully evolves from exercising self-determination to create a successful and productive life.

In this model desirable environments are seen to possess three main characteristics: opportunities for fulfilling people’s needs; possibilities for fostering physical, social, material, and cognitive well-being; and prospects for realizing a sense of stability, predictability, and control. The physical, social, and attitudinal environments within the home, community, and society, therefore, play a large role in aging well. Supports may come from a variety of sources including people, technology, and services. Supportive resources come from companionship, family and friends, financial planning, employee assistance, emotional and behavioral support, in-home living assistance, community access and use, and health promotion and care. Effective supports employ consumer-directed models that are person-centered (Heller, 2004).

As they age, people with intellectual disabilities experience unique physical and psychosocial changes as well as changes in their social and physical environments. Central to successful aging are adaptations to these changes that reflect individuals’ choices and goals (Bigby, 2004). It is, therefore, important to consider aspects of self-determination that provide support and opportunities for people with intellectual disabilities as they age (Heller, 2004).

B. **The Intersection of Gerontology and Disability Studies**

The fact that more people are living longer with a disability, whether the onset is early in life or comes with aging, raises new questions about the direction of future scholarship, research, and practice (Putnam, 2007). To understand how the experience of living with disability influences the experience of aging and vice versa, scholarship between the fields of gerontology and disability studies must integrate (Bickenbach et al., 2012; Putnam, 2007). Unfortunately, there is a lack of conceptual crossover and integration of scholarship between these two fields (J. Kennedy & Minkler, 1999; Putnam, 2007). There has been very limited debate about the usefulness of links between aging and disability studies (Oldman, 2002) and scholars in both fields have not yet fully engaged with one another's work (Chivers, 2011). Additionally, aging persons with lifelong disabilities are often overlooked (Zarb, 1993a, 1993b) in research in both gerontology and disability studies.

The aging literature has mostly addressed the aging processes and characteristics of the general population. Traditionally, gerontology scholars have not given attention to people with lifelong disabilities. When considering disability the field has mostly focused on impairments caused by the aging process and on manifestations of psychiatric disabilities in later life. People with cognitive impairments associated with older age, such as dementia, have been an important focus of study for example.

The notions that disability is a typical part of the individual's aging process and that living with a disability interacts with the experience of aging have not adequately been acknowledged in the aging field. Aging scholars see disability most often as a category that older people risk falling into, and do not yet fully recognize the critical and cultural potential that a disability perspective can bring to their work (Chivers, 2011). This perspective holds that

different ways of being in the world can be sources of knowledge, satisfaction, creativity, and happiness (Chivers, 2011). A dialectical and inclusive vision on aging that recognizes both able-bodiedness and disability as parts of the aging experience is needed (J. Kennedy & Minkler, 1999). Applying a disability studies perspective can contribute to such a perspective on aging.

In turn, disability studies has had the tendency to distance itself from associations with aging. Research and theory on aging are scarce in disability studies. Some exceptions are the works of Priestley (2003) and Heller and Parker Harris (2012), on theorizing disability from a life course perspective. There is only a modest body of work in disability research addressing aging of persons with intellectual disabilities. A critical disability studies framework has been applied to expand the knowledge of this population on only a limited basis. This situation is starting to change slowly. Examples are the work of Noonan Walsh and LeRoy (2004), Buys et al. (2008), Hamilton and Atkinson (2009), Cadbury and Whitmore (2010), Johnson (2005), Brown and Gill (2009), and Rogers et al. (1998).

In summary, few disability studies scholars have acknowledged the importance of aging as a factor in the experience of disability and applied a critical aging perspective to their work. Also they have rarely articulated how disability theories apply to persons of all ages (Chivers, 2011; J. Kennedy, 2000).

C. **Social Relations**

1. **Definitions and concepts in research on social relations**

The past decades have seen a major increase in research on social relations. The discourse on social relations is broad and complex, and there are different opinions on what aspects of social relations should be studied and how (Due, Holstein, Lund, Modvig, & Avlund, 1999; Hogan, Linden, & Najarian, 2002). Despite the enormous interest in this area of research,

the literature reveals a lack of consensus as to how to characterize the structural matter which it addresses. The main concepts appear to be ‘social support’ and ‘social networks’. Additionally, the literature includes concepts such as ‘social relations’, ‘social integration’, ‘social participation’, ‘social capital’ and ‘social anchorage’.

The term ‘social relations’ has been used as an umbrella term for the various support and network terms (Antonucci & Knipscheer, 1990; Due et al., 1999). The advantage of this characterization is that it enables the consideration of various related research endeavors, often conducted under very diverse labels, under one overall heading. These endeavors include research on attachment, helping behavior, close primary relationships, and loneliness.

Despite the diffuse conceptualization of social relations, a clear distinction has been made between the use of structural and functional measures. Structural measures describe the interpersonal relationships of an individual and the linkages between these relationships. They include contact frequency and geographic proximity (Antonucci, Ajrouch, & Birditt, 2014).

Functional measures complement structural measures and describe the interpersonal interactions within the structure of the social relations. Functional measures generally ask individuals about their perceptions of the availability or adequacy of social support provided by their relations as well as relational strain and social integration (Cohen & Syme, 1985; Due et al., 1999; Tracy & Whittaker, 1990). Social support refers to the assistance people provide one another with. Types of social support include emotional, informational, and instrumental support (Antonucci & Knipscheer, 1990; Barrera, 2000; Bigby, 2004; Hogan et al., 2002; House & Kahn, 1985; Tracy & Whittaker, 1990; Wills & Shinar, 2000). Emotional support involves verbal and nonverbal communication of caring and concern (Hogan et al., 2002) and includes providing compliments (also referred to as appraisal support). Informational support involves providing

information used to guide or advise. Instrumental support involves the provision of physical assistance or transportation (Hogan et al., 2002) and also includes material support (e.g., provision of money or material goods).

In studies of social relations, the term ‘social network’ is used to describe those people who provide social support to an individual. The network consists of points and bonds and is assessed by identifying complex characteristics such as density and homogeneity and by classifying the characteristics of the network members such as age, gender, and relationship (Knipscheer & Antonucci, 1990). Antonucci and Knipscheer (1990) describe three approaches to measuring social networks. The ‘exchange’ approach documents the people who have done some service for individuals, or have provided them with something they need. Measures of exchanges tend to produce the largest social network sizes. Measures that focus on ‘role relations’ document people who are related to the individual in some formalized or prescribed way. An assessment of an individual’s role relationships is likely to produce a more complete picture of the life experiences of an individual than the exchange approach. Finally, ‘affective relationships’ can be documented. In this approach people are asked who they care about or feel cares about them. This assessment is especially important if one wants to understand the long-term nature of these relationships.

Some researchers have argued that both structural and functional measures of social relations are less important than the individual’s perception of the amount and quality of received social support. Non-evaluative functional measures simply assess the presence or absence of specific support without examining the quality of the support provided. The objective characteristics of the support exchanged may only partially be related to the perception of

support receipt (Antonucci & Knipscheer, 1990). It is the individual's own evaluation of available supports that matters (Antonucci & Knipscheer, 1990; Carr & Moorman, 2011).

2. **Social relations with aging**

a. **The significance of social relations for older people**

Supportive networks play a critical role in older individuals' life quality and happiness (Barrera, 2000; Bigby, 2004; C. H. Kennedy, 2004). Satisfaction of the fundamental human need to develop close, long-lasting, and supportive relationships (Baumeister & Leary, 1995) is associated with positive health outcomes (Knipscheer & Antonucci, 1990), subjective well-being, happiness, and positive affect in general (Baumeister & Leary, 1995; Hogan et al., 2002). People with strong social relations have lower rates of morbidity and mortality (Due et al., 1999). Strong social relations can also offset the relationship between low social economic status and poor health. Antonucci and colleagues (2003) found that middle-aged men with lower levels of education who reported high quality relationships had the same high levels of health as men with higher levels of education.

When persons experience social isolation and a lack of social support they are prone to experience negative affect, depression, loneliness, and anxiety as a consequence (Antonucci, Akiyama, & Sherman, 2007; Baumeister & Leary, 1995; Berkman, Ertel, & Glymour, 2011; Broese van Groenou & van Tilburg, 2007a; Cohen & Syme, 1985; Due et al., 1999; Hogan et al., 2002; Knipscheer & Antonucci, 1990; Stevens, Martina, & Westerhof, 2006; Wills & Shinar, 2000).

The extent to which social relationships protect well-being in late-life depends on the structure, nature and quality of the relationships (Carr & Moorman, 2011).

b. **Social relations of older people from a life course perspective**

The social networks of older people are shaped by the lives they have lived (Knipscheer & Antonucci, 1990). These networks reflect earlier life circumstances and transitions and affect opportunities and individual needs and choices to maintain and develop supportive relationships (Antonucci & Knipscheer, 1990; Broese van Groenou & van Tilburg, 2007a).

Research findings provide insight into how characteristics such as personality, gender, and race shape the experience of social relations in later life. It was found that extroverted older adults make more friendships than introverted older adults (Krause, Liang, & Keith, 1990). This had led Antonucci (1990) to hypothesize that older individuals with very restricted networks may have always preferred such restricted networks and may not experience large reductions in network size over time. Older women tend to have significantly larger networks than men. They have more friends but about the same number of family members. This finding had one exception: older women are less likely to be married than men. Older women also reported providing more support and having more frequent contact with network members (Antonucci et al., 2014). African-Americans tend to have smaller networks that are more likely to be dominated by family members. Additionally, they have more frequent contact with their convoy members than Caucasians. However, these differences between these racial groups diminish with increasing age (Ajrouch, Antonucci, & Janevic, 2001).

As people age, their networks are fluid and vulnerable to shrinkage and disruption (Bigby, 2005). Although the size of personal networks do not consistently decrease with age (Broese van Groenou & van Tilburg, 2007b), the composition of the networks change and the frequency of contact decreases with aging (Broese van Groenou & van Tilburg, 2007b;

Carstensen, 1992; Due et al., 1999). Therefore, loneliness has long been identified as a problem associated with old age (Wenger, Davies, Shahtahmasebi, & Scott, 1996). However, loneliness and social isolation are neither inevitable nor universal features of aging (Carr & Moorman, 2011) and most older people are not lonely at all (Broese van Groenou & van Tilburg, 2007a; de Jong Gierveld & van Tilburg, 1996).

The socio-emotional selectivity theory tries to explain the research evidence that social relationships change as people age. This theory posits that individuals reduce the number of close contacts in their social networks and become more selective in their relationships as they age. At the same time, however, the emotional closeness to these contacts increases (Carstensen, Isaacowitz, & Charles, 1999).

c. **The social convoy model**

The gerontological social convoy model (Kahn & Antonucci, 1980) is unique in its lifespan focus (Levitt, Weber, & Guacci, 1993). The model acknowledges that the social network of an older adult is the result of a lifelong process of acquiring, developing and breaking off social relationships (Knipscheer & Antonucci, 1990). It postulates that each person moves through time, circumstances, life events and transitions surrounded by a convoy, a set of supportive others. These relationships fluctuate in their closeness, quality, function, and structure (Antonucci et al., 2014; Antonucci, Akiyama, & Takahashi, 2004; Antonucci & Knipscheer, 1990; Broese van Groenou & van Tilburg, 2007a; Crohan & Antonucci, 1989), and are influenced by personal and situational characteristics (Antonucci et al., 2014).

Convoys provide aid, affect, and affirmation to the individual (Kahn & Antonucci, 1980). The convoy places emotionally close and important individuals into three concentric circles representing three levels of closeness: close, closer, closest (Antonucci et al., 2014). Inner circle

members are hypothesized to be attachment relationships. Kahn and Antonucci (1980) operationalize inner circle members as persons “so close and important to you that it is hard to imagine life without them”. Very close (attachment) relationships include mother, father, spouse, and sometimes other caregivers or relatives. Middle and outer circles are described respectively as “people not quite that close, and less close, but still important” (Antonucci et al., 2004, p. 354). Less important, but-still-close relationships can include peers, other relatives, friends, coworkers and classmates.

The social convoy model incorporates individuals’ evaluations of their relations (Bengtson, Gans, Putney, & Silverstein, 2008). The application of the social convoy model to the study of social relationships gives attention to individual experiences.

i. **Social network typologies based on the social convoy model**

Using the social convoy model, researchers have created typologies of social networks. Employing cluster analysis, Fiori and colleagues (2006) found family, friends, diverse, and restricted network types among 1,669 adults aged 60 or older from the Americans’ Changing Lives study. The family network was the least prevalent of all the network types (12% of the sample). Adults with family networks had the highest number of children and frequent contact with those children. They also frequently attended religious services. The friends network (24% of the sample) was characterized by its highest score on frequency of contact with friends. Individuals in this network also had fairly frequent contact with children, but they attended meetings and religious services relatively infrequently. The diverse network was the most prevalent (32% of the sample) and the most extensive of all the networks. Adults with diverse networks were most likely to be married, had frequent contact with children and friends, and were most likely to attend meetings and religious services.

Fiori and colleagues (2006) found two restricted types of networks: the non-family network and the non-friends network. Individuals in the non-family restricted network (16% of the sample) had the most limited social ties compared to individuals in other networks. Members of this network were unlikely to be married or to have children, and if they did have children they had the least contact with them. The non-friends network (16% of the sample) was distinguished by its low scores on frequency of contact with friends, attendance at meetings, and attendance at religious services. Individuals in this network were on average more likely to be married, had a higher number children and a higher frequency of contact with these children.

Fiori and colleagues (2006) found that depressive symptoms were highest for individuals in non-friends networks and lowest for individuals in diverse networks. Their results also suggested that having no family members in the context of friends was less detrimental than the absence of friends in the context of family.

ii. **Life course development of social convoys**

Life circumstances influence development of individuals and their social convoys. The social convoy model predicts relative stability in convoy membership. Stable personal and situational factors can lead to consistency in social relations. At the same time, changes these factors can cause transitions in the nature of these relations (Antonucci et al., 2004). How close one feels to a convoy member as well as the support needed from this individual can shift over the life course (Carr & Moorman, 2011).

The model assumes a curvilinear pattern in convoy membership across the life span based on changing individual and family life cycles. Young children have few but growing numbers of close relations. As roles and family size increase through young and middle adulthood the convoys expand. When roles and families become more limited in later life the

convoys decrease (Antonucci et al., 2004). The model emphasizes “reciprocity and support banks, where deposits are made early in the life course in anticipation of future needs or withdrawals” (Carr & Moorman, 2011, p. 10). Adult children may feel obligated to give back to the parents and grandparents who supported them earlier in life (Carr & Moorman, 2011).

The convoys influence individuals over time. Some individuals benefit by their social relations in many ways, such as in helping them cope with life’s challenges and helping them learn, grow and mature. Other individuals might experience negative consequences from their social relationships, hindering their ability to cope with life’s challenges (Antonucci et al., 2004).

The social convoy model has been used primarily to provide understanding of the development of social relations in the general population throughout the life course, and only rarely in those of older adults with intellectual disabilities.

3. **Social relations of people with intellectual disabilities**

a. **Social networks, social support, and well-being of people with intellectual disabilities**

The literature on social relations of people with intellectual disabilities is limited but diverse. It has primarily explored the association between well-being and social relations for people with intellectual disabilities, the number and types of social relations included in their social networks, and the social interactions between those with and without intellectual disabilities (Kersh, Corona, & Siperstein, 2013).

The literature has found that the networks of people with intellectual disabilities are generally small. Their networks lack contact with people who do not have intellectual disabilities outside of family members and direct support staff (Lippold & Burns, 2009; van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014; Verdonshot, Witte, Reichrath, Buntinx, & Curfs, 2009).

Many adults with intellectual disabilities spend free time alone (Krauss & Erickson, 1988) and loneliness is prevalent in all age groups of those with intellectual disabilities (Hogg, Moss, & Cooke, 1988; Krauss & Erickson, 1988; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006; Stancliffe et al., 2007).

Qualitative research with people with intellectual disabilities indicates that they value companionship, closeness, support and stability as the most noteworthy aspects of their friendships (Kersh et al., 2013). A growing number of studies have documented their desire to engage in more community activities and to have more friends (Abbott & McConkey, 2006).

b. **Formation and maintenance of social relations of people with intellectual disabilities**

Often overlooked is that people with intellectual disabilities need externally provided support to develop and maintain their social networks (Bigby, 2002; McConkey, 2005). Both personal skills and social opportunities are required for individuals to develop relations (McConkey, 2005; Newton, Olson, Horner, & Ard, 1996). People need to actively contribute to the process of making friends. Important personal skills to do so include motivation, self-confidence, interpersonal skills and abilities to resolve conflict and express feelings. Research shows that people with intellectual disabilities can benefit from social skills training (McConkey, 2005). As a lack of social intuition can place them at a heightened risk for abuse, gaining these skills is important for them (Heller et al., 2010).

The severity of the person's impairment may impact his or her skills and capacity for relationships (Kersh et al., 2013). However, impairment is in part a social construct, and personal skills are also influenced by environmental factors. Personal skills can only be supported and developed when there are social opportunities to do so (McConkey, 2005). People with

disabilities are faced with a different social reality than people without disabilities (Hopps, Pepin, Arseneau, Frechette, & Begin, 2001).

People with intellectual disabilities face “a mix of patronization, fear, an unwillingness to understand ‘non-standard’ forms of communication, and a strong sense of ‘difference’ in public life” (Hall & Kearns, 2001, p. 240). Others have low expectations of them and devalue the importance of their relationships (Bigby, 2002, 2003). Issues such as housing, finances, transport, mobility and experience of public and segregate spaces all play key roles in understanding the context of the social relations of people with intellectual disabilities (Noonan Walsh & LeRoy, 2004; Power, 2010). People with intellectual disabilities have reported lack of transportation and restrictions imposed by caregivers or staff as challenges to making and maintaining relationships (Kersh et al., 2013).

Deinstitutionalization has brought people with intellectual disabilities physically into society but has left them, in many cases, socially isolated and largely invisible (Hall & Kearns, 2001). Many people with intellectual disabilities still live in seclusion (Power, 2010) and their interaction with the community is often regulated and controlled by professionals (Parker Harris, Heller, & Schindler, 2012). The social relations at work in the sheltered workshop or the group home are often not ones that promote autonomy and self-esteem (Power, 2010). Many people with intellectual disabilities are in a “double-bind” of marginalization. They experience both exclusion from and discrimination within the social spaces that should promote a policy of social inclusion (Hall, 2005, p. 110).

Inclusion requires connection to others. Simply providing services in community-based settings does not ensure the social inclusion of persons with intellectual disabilities within those communities (Bigby, 2005). Membership in community groups, having acquaintances, spending

time with others, and shared activities and concerns all provide pathways to social opportunities and the development of relationships (Bigby, 2005; McConkey, 2005).

Support from formal relationships can foster development of informal relationships but also, through neglect and ignorance, obstruct or disrupt them (Bigby, 2008). Service providers often view their role from a limited perspective as other facets of support are given priority (McConkey, 2005). Direct support staff can encourage the growth of informal networks of supports (Power, 2010) by implementing network interventions to expand and strengthen social networks (van Asselt-Goverts et al., 2014).

4. **Social relations of older people with intellectual disabilities**

a. **Familial relations of older adults with intellectual disabilities**

Familial relations are important for the optimal development and well-being of individuals with intellectual disabilities (Bigby, 2003; Buys, Aird, & Miller, 2012; Noonan Walsh, 2002). For example, a study by Buys et al. (2012) with 16 older adults with intellectual disabilities and their key support persons found that family members and extended family members play a crucial role in facilitating independent living arrangements that promote autonomy, the maintenance of practical skills, community participation, and the pursuit of interests in line with individuals' preferences, as well as providing those living in group homes with ongoing opportunities to participate in recreational and leisure activities as part of their families' lives.

However, many older persons with intellectual disabilities have limited or no contact with family members and/or only have contact with parents and siblings (Maaskant, 1999, 2007; Meeusen & Maaskant, 2004). Most older people with intellectual disabilities do not have spouses and children (Bigby, 2004, 2005; Seltzer, 1985) on whom they can depend for support (Seltzer,

1985). This also means they do not assume the roles of being grandparents or in-laws. As they tend to have long-lasting close relationships with their siblings who often become primary caregivers after parents die (Bigby, 2002; Heller & Arnold, 2010) sometimes adults with intellectual disabilities assume the roles of being (great-)aunts and (great-)uncles (Bigby, 2004, 2005).

Older people with intellectual disabilities tend to have fewer stable and close friendships to complement their familial relationships than older adults in the general population. Instead they are more likely to have acquaintances rather than close friends (Bigby, 2002; Lippold & Burns, 2009; Maaskant, 1999, 2007; Meeusen & Maaskant, 2004; Robertson et al., 2001).

b. **Social relations of older people with intellectual disabilities with family caregivers**

The available studies show remarkable similarities between countries in the size and composition of the networks of adults with intellectual disabilities living at home with aging caregivers (Bigby, 2000a). In the United States, the majority of adults with intellectual disabilities live at home with family caregivers (Braddock et al., 2011). In Australia, Bigby (2003) found that these networks tend to be small, with an average size of five to seven people. In the US, Krauss and Erickson (1988) found that the networks of older people with intellectual disabilities living at home with family caregivers tend to be smaller than the networks of those who have left parental care. The social networks of such people residing with family consisted primarily of relatives in contrast with the adults in residential settings, who had support networks composed equally of family, friends, and professionals. Networks of people with intellectual disabilities living at home tend to be dominated by females, as women are likely to have the informal care roles (Bigby, 2002).

Research has also demonstrated that adults with intellectual disabilities living with aging parents generally live in a social world dominated by family members (Bigby, 2000a; Krauss & Erickson, 1988; Krauss, Seltzer, & Goodman, 1992). Although the provision of hands-on-care is primarily a responsibility assumed by mothers, siblings (Bigby, 2000a; Heller & Arnold, 2010; Prosser & Moss, 1996) and other relatives provide support and companionship to both parents and the adult with an intellectual disability (Bigby, 2000a). Friends appear to play only a minimal role (Bigby, 2000a; Prosser & Moss, 1996).

Adults with intellectual disabilities at home with family caregivers tend to share friendships with their parents and have few friends of their own (Bigby, 2000a, 2005). The norms of caring developed by parents sometimes include reluctance to seek support and protection of their adult children. Consequently, adults with intellectual disabilities who have lived with family members may have been shielded from the community and have had few opportunities to make their own choices or build their social networks (Bigby, 2000a, 2000b).

With longer life expectancy, parents have a longer period of responsibility and are more likely to face dealing with their own aging in addition to the aging of their adult children (Heller, 1999; Heller & Caldwell, 2006; Heller, Caldwell, & Factor, 2007; Heller & Marks, 2006). It is also more common for adults with disabilities to provide support to their aging family members (Heller et al., 2007). Strong bonds of mutual aid and a sense of interdependence may develop between an older parents and an adult with an intellectual disability (Bigby, 2000a, 2003; Knox & Bigby, 2007). The lifestyle of the adult with a disability may also become restricted by the care needs and decreased mobility and stamina of a caretaker parent (Bigby, 2002).

Additionally, there is a greater likelihood of the adult with a disability outliving his or her parents than in the past (Heller & Caldwell, 2006). Relocation after the death of parents often

results in a loss of relationships (Bigby, 2000b). When parents die, there is a danger that incidental contact with extended family such as cousins, nieces, nephews, aunts and uncles is lost (Bigby, 2005; Hogg et al., 1988). Effort is required from relatives to involve the older adults with intellectual disabilities in family gatherings, as they usually no longer live in the parental home where family events took place. Although contact with shared family friends might be retained after the death of parents, such friends are likely to be from an older generation and to predecease the adult with a disability (Bigby, 2005).

For some people with intellectual disabilities the loss of their parents can signify a shift to an adult rather than child role and create the opportunity to develop new intimate friendships (Bigby, 2005). For these people later life can be a time when their social worlds expand and, freed from the restrictions imposed by parents, they can build new relationships as participants in community activities (Bigby, 2002).

c. **Social relations of older people with intellectual disabilities in residential settings**

A study by Anderson, Lakin, Hill, and Chen (1992) revealed low levels of social integration among older people with intellectual disabilities in residential settings (N=235). Half of the adults in their sample reported they had no contact with family members. Half of the adults had no friends or never visited friends. Only a third of the residents had regular social contact with persons who did not have disabilities, other than staff members. Robertson et al. (2001) found that older adults with intellectual disabilities living in residential settings reported smaller social networks than younger residents, and were less likely to have individuals in their networks other than direct support staff members, relatives, or peers with disabilities. Krauss and Erickson (1988) found that direct support staff and friends provided the majority of

support and companionship to older adults with intellectual disabilities in residential settings (N=49).

Adults with intellectual disabilities from older generations were likely to be institutionalized at a young age (Hogg et al., 1988). Segregation in institutions limited the opportunities of these individuals to participate in social networks and to have close relationships (Carson & Docherty, 2002). Those institutionalized early in life have restricted ties with family and less informal support available to them in later life compared to those who remained at home until middle age (Bigby, 2000b).

The deinstitutionalization movement has resulted in the relocation of many older adults with intellectual disabilities to community settings (Heller, 1985). Some of these adults lost touch with family or friends in the community after they relocated. In these cases a move to the community was likely to cause social isolation, unless appropriate networks of care and support were available (Hogg et al., 1988).

A study by Bigby (1997b, 2000b) of the networks of older persons with intellectual disabilities who left parental care after mid-life, found that these networks were small, and dominated by family members. A defining characteristic of the networks of this study's participants was the existence of a 'key person' who took responsibility for oversight of the well-being of the participant. This key person had a close long-term relationship with the participant and demonstrated considerable commitment to the participant's well-being. The key person was likely to be a sibling, a distant relative or a long-term family friend who had been informally nominated by a parent to assume responsibility for the participant following the parent's death. Bigby noted that the key persons were from the same as or an older generation than the participants, and hence might predecease them. Some key persons planned their own

replacement, often a participant's niece or nephew. Bigby warned that as people with intellectual disabilities age, the likelihood of losing a key person and not having a replacement increases.

As adults with intellectual disabilities age, direct support staff members increasingly replace parents as primary caregivers. They become an integral part of the support networks of many older people with intellectual disabilities (Bigby, 2000b, 2002). Lippold and Burns (2009) concluded that the social networks of older people with intellectual disabilities who rely on formal services may not be stable over time, as the relationships within these convoys are role-prescribed and characterized by minimal reciprocity.

Formal supports cannot fully replace the affective support provided by informal network members (Bigby, 2000a, 2002, 2003). Older people with intellectual disabilities who lack informal network members may have no one to protect their rights and oversee their well-being. It is difficult for formal organizations or paid relationships to commit to advocating for an individual long-term (Bigby, 2005). It is important that formal services nurture, build and strengthen informal supports for the individual (Bigby, 2000a, 2005). However, many residential settings do not provide sufficient opportunities for older residents to participate in community activities (Hsieh, Heller, & Freels, 2009; McConkey, 2005).

Little research has explored the perspectives of older adults with intellectual disabilities on their social relations. Buys et al. (2008) interviewed older service users with intellectual disabilities (N=16) and found these individuals valued satisfying relationships and support as elements to active aging. These individuals defined companionship as having someone to do activities with, and friendship as having a trusting and satisfying relationship. Some participants reported that church or social group membership and employment enhanced their social

interaction and supported their friendships. They reported needing both formal and informal supports to participate in desired activities.

d. **Gender differences in social relations of older people with intellectual disabilities**

Even though much of the research literature in the field of intellectual disability is not gendered, there are some indications of gender differences in social relations of older adults with intellectual disabilities. Women with intellectual disabilities who live in residential settings have been found to have larger networks than their male counterparts (Lunsky & Benson, 1999).

Research also found that women with intellectual disabilities who live at home with their aging mothers are less likely to attend day programs, play a greater role in undertaking daily household tasks, and are subject to greater vigilance by mothers compared to their male counterparts (Fullmer, Tobin, & Smith, 1997). This may impact their opportunities to build relationships in the community. Sisters rather than brothers tend to replace mothers as primary caregivers after parental death (Prosser & Moss, 1996). Women with intellectual disabilities who have a brother as the most involved or only sibling, may be at the highest risk to receive limited family support after the death of their parents (Bigby, 2002).

e. **Gaps in research on social relations of aging people with intellectual disabilities**

Research gaps exist in our knowledge on the cumulative dynamic of social relations across the life course (Elder & Giele, 2009) and on the relationship between types or styles of relationships and successful development and healthy outcomes (Antonucci et al., 2004). Longitudinal research is still limited. Carr and Moorman (2011) further argue that as the

demographics of older persons shift, social gerontologists should document the nature and consequences of social relationships for all ethnic and racial groups. Older people with disabilities are a growing minority group as well, and are often not included in attempts to diversify future research.

The body of knowledge on the social relations of older adults with intellectual disabilities is incomplete, and some of the research on the social relations of this population is dated. Research has addressed the social relations of young adults with intellectual disabilities and matters concerning people with mild to moderate intellectual disabilities rather than those with more severe disabilities.

Even though the importance of including perspectives of individuals with intellectual disabilities in research has been widely acknowledged, research of this nature remains limited (Lunsky, 2006; Mactavish, Mahon, & Lutfiyya, 2000). Anderson, Lakin, Hill, and Chen (1992), Robertson et al. (2001), Krauss and Erickson (1988), and Prosser and Moss (1996) used only secondary informants in the gathering of data, such as direct support staff, family members, or friends. They did not take the perspectives of the people with intellectual disabilities into consideration. The views of secondary informants do not necessarily reflect the perspectives of people with intellectual disabilities themselves on their social relations and the social support they receive.

Research has addressed the social relations of older adults with intellectual disabilities in different residential settings, but the role of these settings in the development and satisfaction with social relations remains unclear. Gender differences have also remained largely unexplored. One of the most glaring gaps in the research is the lack of a life course approach to the study of the social relations of older adults with intellectual disabilities. Studies thus far have only

gathered information about the social relations of older adults with intellectual disabilities at specific moments in time, which by definition does not provide insight into the development of these relationships over the life course.

D. **Gaps Addressed in the Present Study**

Social relations and social support are important to adults with intellectual disabilities as they often need additional supports as they age. The social support systems of aging people with intellectual disabilities have rarely been investigated. Scholars have expressed serious concerns about the quality and availability of the social networks of this population (Anderson et al., 1992; Hogg et al., 1988; Robertson et al., 2001; Seltzer, 1985) and have warned that its well-being is at risk. The present study provides a greater focus on social relations in research in the field of aging and intellectual disability. The study will also examine the impact of different pathways in life (including residential histories) on social relations and later life needs of adults with intellectual disabilities. The application of a life course perspective is intended to better inform the needs of this population and the challenges it faces. Additionally, the impact of individual variables such as gender and race on the development and satisfaction with social relations in this population is taken into consideration in the present study.

Furthermore, the present study includes the voices of older people with intellectual disabilities themselves, which is often neglected in research. By obtaining the perspectives of older people with intellectual disabilities we can gain a better understanding of how their relations influence their well-being and aging experiences.

Further integration of practice, research and policy on aging and disability is valuable to adults aging with intellectual disabilities, as they can benefit from insights in both fields. Because of the lack of conceptual crossover between these fields, aging theories have rarely been

applied to older people with disabilities. The social convoy model has particular theoretical relevance for intellectual disability research, as it helps explain individuals' social relations based on the lives they have lived. The life experiences of people with intellectual disabilities may have impacted their social relations in ways different both from the general population and from people with different types of disabilities.

Knowledge gained by the present study can inform the development of effective interventions that support the social networks of adults with intellectual disabilities and promote their well-being as they age.

III. METHODS

This study aimed: 1) to contribute to the available knowledge on the social networks of older adults with intellectual disabilities from a life course perspective; 2) to increase the limited understanding of the individual experiences of these adults; and 3) to identify strategies for supporting their social networks as they age.

A process of paired recruitment was employed to generate a sample of 12 adults with intellectual disabilities age 50 and over with at least one key support person each. Data collection consisted of in-depth qualitative interviews with the participants and their key support persons (K. Caldwell, 2013). Social network maps (Tracy & Whittaker, 1990) were filled out for participants and their life histories were recorded. A vertical timeline of key events in each individual life history (Assink & Schroots, 2010; J. Caldwell, 2010) served as a visual cue for the participants.

Data analysis followed an inductive process and started with case-analysis (Patton, 2002) that resulted in 12 individual stories that provided context to the subsequent analysis. The second step of data analysis consisted of the creation of a comprehensive summary of the structural characteristics of the participants' present social convoys based on the case-analysis. The third step of data analysis consisted of thematic analysis of the interview transcripts (Braun & Clarke, 2006).

A. **Research Aims**

Social relationships are important to how people define the quality of their lives (Barrera, 2000; Bigby, 2004; C. H. Kennedy, 2004), and social well-being is of particular importance to older adults, who rate social relationships among the most important determinants of aging well (Cavanaugh, 1999). There is minimal knowledge of the size and characteristics of the social

networks and social support received by older adults with intellectual disabilities. In addition, there is only limited understanding of the perspectives of these older adults themselves on how their social relations impact their well-being as they age. Previous research has also only marginally acknowledged life course processes in the development of social relations of adults with disabilities.

By integrating aging and disability literatures, theories and research methodologies, this study aimed: 1) to contribute to the available knowledge on the social networks of older adults with intellectual disabilities from a life course perspective; 2) to increase the limited understanding of the individual experiences of these adults; and 3) to identify strategies for supporting their social networks as they age.

To meet these objectives the study posed the following research questions:

From a life course perspective: 1) what are the structural and the functional characteristics of the social relations of older adults with intellectual disabilities; 2) how do the social relations of older adults with intellectual disabilities develop and change throughout their life courses; 3) how does the social convoy model apply to the experiences of older adults with intellectual disabilities; 4) what are the main facilitators and barriers experienced by older adults with intellectual disabilities to the development and enjoyment of social relations; 5) how do older adults with intellectual disabilities experience their social relations as they age; and 6) how can these relations be supported to promote aging well?

B. Use of Inclusive and Qualitative Research Methodology

The history of oppression, discrimination, exploitation and unheard voices of people with disabilities has caused sensitivity regarding disability research. People with disabilities argue disability research has been conducted “within an oppressive theoretical paradigm and within an

oppressive set of social relations” (E. Stone & Priestley, 1996, p. 499). There is particular skepticism regarding traditional scholarly approaches that are dominantly positivist and quantitative.

To address part of this concern this study embraced principles of inclusive research. Inclusive research addresses issues of importance to people with intellectual disabilities, serves as a tool to improve their lives, accesses and represents their experiences, treats them with respect (Walmsley & Johnson, 2003) and supports their participation (Walmsley, 2004). Inclusive research changes the traditional dynamic between research and the people who are being researched; it is conceived as research by, with, and sometimes for them (Nind, 2014).

The ability of people with intellectual disabilities to participate in research has been questioned. However, the challenge is one of method (Booth & Booth, 1996). Adaptations need to be made to effectively include people with intellectual disabilities in research. Inclusive research lends itself well to this purpose as it allows for creative and flexible approaches and solutions to research challenges.

The study also employed qualitative research methods and applied a phenomenological approach. The phenomenological approach seeks to gain “a deeper understanding of the nature and meaning of everyday experiences” (Patton, 2002, p. 104) and to understand the lived experiences among people who shared experiences (Thomas, 2006).

Qualitative research has the potential to give voice to oppressed people. It contributes to the representation of disability and people with disabilities in research and enhances diversity. The use of qualitative methods is based on the assumption that all perspectives on an issue or event are inherently valuable and potentially credible and useful (Taylor, Bogdan, & Lutfiyya, 1995), including the perspectives of people with intellectual disabilities. Qualitative research

methods are therefore particularly well-suited to collect data from individuals with intellectual disabilities (Taylor & Bogdan, 1998). Qualitative interviews have for example been acknowledged as beneficial for collecting the perspectives of this population (Mactavish et al., 2000).

C. **Research Design**

This study used a combination of data-collection strategies to allow for checking and cross-referencing of data. Researchers suggest this is the most effective design for intellectual disability research (Bigby & Balandin, 2004; Mactavish et al., 2000). A number of authors have also argued that it is important to cross-reference data across multiple sources of evidence; for example, from support persons and other secondary informants (Gilbert, 2004), or to conduct a joint interview with a support person (Goodley, 1996). These approaches enable triangulation and the validation or questioning of the participants’¹ responses.

The use of joint interviews with family or staff is prevalent in intellectual disability research. This technique has been deemed problematic from a disability studies perspective as it has the potential for proxy or facilitated responses to suppress the voices of persons with intellectual disabilities (K. Caldwell, 2013; Goodley, 1997; Goodley & Rapley, 2002; Rodgers, 1999).

The method of dyadic interviewing approaches the selection and purpose of the involvement of the secondary informant thoughtfully. In dyadic interviewing the person with a disability identifies the key support person of his or her choice. According to K. Caldwell (2013, p. 11) this “removes an element of paternalism on the part of the researcher and facilitates the role of those individuals with intellectual disabilities in the research as having choice and a voice

¹ Hereinafter ‘participant’ is used to refer to the older adults with intellectual disabilities, not to be confused with the key support persons.

in how they are represented”. The strength of this approach is that it recognizes the value of interdependence and support in providing accommodation for persons with intellectual disabilities in research participation (K. Caldwell, 2013).

In line with dyadic interviewing, each participant in this study was asked to select a key support person to assist during the meetings. The nature and the level of involvement of each key support person throughout the research process differed as each participant had different needs and preferences. Only one participant opted not to have a key support present for any of the interviews. Three participants decided to have the key support person present for all the interviews. The other eight participants were only supported by their key support person during the first interviews and completed their work with me independently. The key support persons assisted with rephrasing questions, complementing or clarifying answers provided by the participants, and by facilitating the overall communication. At times the key support person would also ask questions as part of naturally flowing conversations. The participants with intellectual disabilities were seen and treated as the primary source of information in this study. The data collected from the key support person functioned as a secondary data source. It is possible to encounter more discrepancies than agreements between primary and secondary informants. It has been argued that this should not be assumed to be a shortcoming but rather an indication of success as points of disagreement can be valuable and rich sources of information (K. Caldwell, 2013).

Data collection in this study consisted of in-depth qualitative interviews during which social network maps were filled out for the participants and their life histories were recorded. A vertical timeline of key events in each individual life history (J. Caldwell, 2010) served as a visual cue for the participants.

All contact with research participants was treated as ethnographic field contact.

Throughout the course of the study I made detailed field notes. These consisted of process notes describing day-to-day activities, methodological considerations and decision making procedures; personal notes about describing motivations and experiences with primary and secondary informants; and notes relating to instrument development such as revision of interview questions.

A characteristic of qualitative research is that a study's elements are not set in stone. Qualitative research often require spontaneous decisions to be made in the field (Collins & Cooper, 2014). During the research process I was faced with certain problems and challenges. A few details of the methods and procedures had to be revised accordingly. These revisions will be elaborated upon in the further discussion of the data collection procedures and elements.

D. **Data Collection Procedures**

1. **Pilot interview**

A pilot was conducted to test the effectiveness of the interview questions. A woman with an intellectual disability, a family member of a University of Illinois at Chicago (UIC) employee, was asked to volunteer in this process. The pilot interview demonstrated the drafted questions were effective. It also affirmed that I would need several meetings with each participant to discuss all relevant topics.

2. **Sampling**

A process of paired recruitment was employed to generate a sample of 12 adults with intellectual disabilities age 50 and over with at least one key support person each. Participants who used intellectual disability services were included in the study. Even though chronological age is not a meaningful indicator of aging (Dannefer & Settersten, 2010) and any chronological cut-off is arbitrary (Bigby & Balandin, 2004), a decision about an age cut-off point

for inclusion in the study had to be made. No consensus exists on exactly how old a person with an intellectual disability needs to be to be considered ‘an older person’ (Bigby & Balandin, 2004). Because some groups of people with intellectual disabilities age prematurely, such as people with Down syndrome (Strydom et al., 2009), a younger age than that used for the general population has been taken to denote ‘an older person’ in research in the field (Bigby & Balandin, 2004). Therefore, the age of 50 was the criterion used in this study. Furthermore, participants had to be able to communicate verbally and needed to be able to understand the consent process and to give assent or consent to participate in the study.

Purposeful sampling was employed. The selection of the participants was made on the basis of their expertise in providing relevant information regarding their life stories and experiences with their social networks. The aim was to sample those people “most likely to have sufficient knowledge and experience related to the topic of the study” (Jeon, 2004, p. 252), also called “rich cases” (Patton, 2002, p. 230). Since the sample was small, saturation could not be achieved. Hence, sampling criteria (residential history, race and gender) were applied to allow for a diverse research sample and a fairly balanced representation of variables considered being consequential in studying social relations of older adults with intellectual disabilities. The research literature has demonstrated residential history, race and gender to be important variables in social relations of persons with intellectual disabilities (Chapter II). As the process of recruitment progressed, the sampling became more selective to allow for the sampling criteria to be applied. Age was intended as a sampling criterion; however the participants did not vary greatly in age. This limited my ability to make meaningful comparisons between participants based on their age.

The participant (and his or her guardian if applicable) was asked to nominate the key support person. Key support persons who were paid support staff were required to know the person with an intellectual disability for two or more years to qualify for participation in the study. All selected key support persons met this inclusion criterion. On one occasion, a third informant was recruited (with permission of the participant) to provide additional insights into the life history of the participant.

Additionally, I provided the participants the option to have an advocate present during research contacts. This could be the key support person, a third informant, a guardian or another third party. A benefit of this approach is that an advocate might be able to assist in the communication with the participant and to provide certain information the participant is unable to give. A disadvantage of having an advocate present is that the participant might consciously or subconsciously be influenced by the third party. None of the participants (or their guardians if applicable) decided they wanted to have an additional third party advocate present. The key support persons, potential third informants and potential advocates had to be over the age of 18 to be included in the study. All selected individuals met this inclusion criterion.

3. **Recruitment**

Participants were recruited in the Chicago area. Letters of support were gathered from organizations in the Chicago area that support people with intellectual disabilities, namely Envision Unlimited, the Ray Graham Association, the Anixter Center, and Lambs Farm. I had previous working relationships with Envision Unlimited, the Anixter Center, and Lambs Farm which facilitated my access to these organizations and the communication with their staff. Personnel from these organizations were asked to approach older people with intellectual disabilities and their families or staff, to inform them about the study and to invite them to

participate. I asked the interested older adults and/or their advocates contact me by phone or email. In this way, the privacy of potential participants would be maintained, but at the same time an opportunity would be offered to people who wished to participate (Knox & Hickson, 2001). The recruitment materials can be found in Appendix A. The recruitment materials include: 1) a flyer used at the community agencies and at the University of Illinois at Chicago; 2) an accessible flyer with pictograms and short sentences for persons with disabilities used at the community agencies; 3) a PowerPoint presentation with a background on the study for the community agency staff and research participants; 4) a script for the researcher and community agency staff used while approaching potentially interested participants; and 5) a script used by the researcher when potential participants contacted her by phone.

Management at of the agencies selected potentially interested individuals with disabilities and provided me with their age, gender, races/ethnicity, and living situation so I could establish their eligibility. No individuals at Envision Unlimited were interested in participating in the study. The management of the three other agencies either arranged a first meeting or gave me permission to contact the older adults that were interested and/or their advocate/guardian directly. As my recruitment became more selective, I asked the agencies to identify potentially interested African American women as they were underrepresented in the pool of potential participants. Two participants with disabilities were not recruited through the community agencies but by word of mouth. All potential participants who contacted me outside of the community agencies were eligible to participate. None of the adults with disabilities who participated in this study made the initial contact with me themselves.

One issue of concern regarding the recruitment was that the management of the agencies made a first selection of potential participants. It is unclear to me if any considerations or

political factors were at play in addition to the inclusion and sampling criteria I provided the agencies with. These factors might have had an impact on the nature of the selection of participants and consequently the stories included in this research. The fact that I worked with participants supported by a total of five different agencies might have minimized the influence of these factors by diluting the impact of these factors over multiple populations of people with disabilities and support organizations.

At the first meetings with the participants and a support person, I explained the importance of the participants selecting their key support persons themselves. A support person (staff or family member) would already be present at this point, and hence the ability of the person with a disability to freely select their key support person might have been compromised. I reiterated to the participants that they could opt for a key support person different from the person already present. In all cases the participants said they were comfortable with the support person who was present being their key support person. The practical difficulty of this procedure demonstrates the common challenge of gaining access to this population, as staff or family members often serve as gatekeepers, even when the person with a disability is his or her own guardian. I gathered the demographic information of the selected key support persons during the first meetings.

The recruitment reached people who live in residential settings, as well as older adults living in family homes and using day supports. The sampling strategy did not reach people who do not use services. However, these adults might have valuable experiences for me to become familiar with as well. Recruitment was ongoing as data collection with certain participants was taking place.

4. **Participant demographics**

The older adults were between ages 51 and 71. Their average age was 60. They had mild to moderate intellectual disabilities. Nine of the 12 older adults had additional disabilities, of whom five had histories of mental illness. Eight of them were Caucasian and four African-American, six were male, and six were female. The sample did not include Asian-Americans and Hispanics or Latinos. Two of the 12 older adults had a guardian, in both cases a sibling. The older adults lived in various residential setting and had various residential histories. The key support persons included siblings, direct support staff and a friend. Eleven of the 13 key support persons were female. They were between 29 and 76 years of age and their average age was 49. An online random name generator was used to create pseudonyms for all research participants. Rather than using additional pseudonyms, participants' family members, friends, and direct support staff were referred to by their type of relationship to the participant (i.e., mother, uncle, sister, brother-in-law, colleague, housemate, etc.). In Table I the demographic information of all participants can be found. The table presents the participants in the order of the start of my work with each of them.

TABLE I
PARTICIPANTS' DEMOGRAPHICS

PWD* Pseudonym	Henry	William	Lucy	Charlotte	Barbara	Philip
PWD Age	59	71	51	58	55	52
PWD Gender	Male	Male	Female	Female	Female	Male
PWD Race	Caucasian	African-American	Caucasian	Caucasian	Caucasian	Caucasian
Guardian	Yes	No	No	No	No	No
PWD Level of Intellectual Disability	Moderate (Down syndrome)	Moderate	Mild	Mild	Mild	Mild (Down syndrome)
PWD Additional Disabilities	Significant hearing loss	Mild hearing loss, seizure disorder, osteoarthritis, gastritis	No	Depression	Depression, TGM, tardive dyskinesia	No
PWD Current Residence	Group home	Group home	Own apartment	Private ICF/DD	Group home	Private ICF/DD

* PWD stands for 'person with disability'.

TABLE I (continued)
PARTICIPANTS' DEMOGRAPHICS

PWD* Pseudonym	Betty	Roger	Matthew	Mary	Linda	Zach
PWD Age	66	67	69	54	55	59
PWD Gender	Female	Male	Male	Female	Female	Male
PWD Race	Caucasian	Caucasian	African-American	African-American	African-American	Caucasian
Guardian	Yes	No	No	No	No	No
PWD Level of Intellectual Disability	Mild	Mild	Mild	Mild	Mild	Moderate
PWD Additional Disabilities	Bipolar disorder	No	Arthritis, high blood pressure	Schizophrenia, diabetes	Depression, arthritis	Cerebral palsy, epilepsy
PWD Current Residence	Family home	Group home	Group home	Group home	Group home	Group home

* PWD stands for 'person with disability'.

TABLE I (continued)
PARTICIPANTS' DEMOGRAPHICS

PWD* Pseudonym	Henry	William	Lucy	Charlotte	Barbara	Philip
PWD Residential History**	Family home; Sister's home; 94 bed facility; group home (moved once with group)	Family home; Dixon state school; two nursing homes; five group homes	Family home (moved once); two homes on campus private ICF/DD; group home	Family home (moved twice); own apartment	Family home; two boarding schools; campus ICF/DD; own apartment	Family home; private ICF/DD (moved once on campus)
PWD Number of Residences in Lifetime***	4	10	5	3	6	3
Institutionalization before Adulthood	No	Yes	No	No	Yes	No

* PWD stands for 'person with disability'.

** The residential history does not include the current residence.

*** The number of residences in lifetime includes the current residence, but not moves of a residential setting without a change in composition of the cohabitants (for example, the move of the family to a new home or the move of a group of people with disabilities to a new home).

TABLE I (continued)
PARTICIPANTS' DEMOGRAPHICS

PWD* Pseudonym	Betty	Roger	Matthew	Mary	Linda	Zach
PWD Residential History**	Family home	Family home; Kennedy school; nursing home; apartment with roommate; two group homes	Family home (moved twice); sister's home; Dixon state school(?)	Grandparents' home; family home (moved three times); two group homes (moved once with group from last home)	Family home; aunt and uncle's home; own home with husband; aunt's home; mental health facility; own apartment; three group homes	Family home (moved twice); two group homes (moved once with group from last home)
PWD Number of Residences in Lifetime**	1	7	4	5	10	4
Institutionalization before Adulthood	No	Yes	No	No	No	No

* PWD stands for 'person with disability'.

** The residential history does not include the current residence.

*** The number of residences in lifetime includes the current residence, but not moves of a residential setting without a change in composition of the cohabitants (for example the move of the family to a new home or the move of a group of people with disabilities to a new home).

TABLE I (continued)
PARTICIPANTS' DEMOGRAPHICS

PWD* Pseudonym	Henry	William		Lucy	Charlotte	Barbara	Philip
KSP* Pseudonym	Danielle	Louise	Andrew	Robert	Lauren	Diana	Andrea
Relationship of KSP to PWD	Sister	Staff	Staff	Staff	Staff	Staff	Staff
KSP Age	62	49	54	42	55	54	29
KSP Gender	Female	Female	Male	Male	Female	Female	Female
KSP Race	Caucasian	Afr.- Am.	Caucas.	Caucasian	Afr.-Am.	Caucasian	Caucasian
Years KSP has known PWD	59 years	14 years	10 years	6 years	5 years	18 years	2 years

* PWD stands for 'person with disability.'

** KSP stands for 'key support person'.

TABLE I (continued)
PARTICIPANTS' DEMOGRAPHICS

PWD* Pseudonym	Betty	Roger	Matthew	Mary	Linda	Zach
KSP** Pseudonym	Amanda	Louise	Sandra	Rhonda	Martha	Doris
Relationship of KSP to PWD	Sister	Staff	Friend	Staff	Staff	Sister
KSP Age	61	49	35	37	33	76
KSP Gender	Female	Female	Female	Female	Female	Female
KSP Race	Caucasian	Afr.-Am.	Caucasian	African-American	Caucasian	Caucasian
Years KSP has known PWD	61 years	5 years	12 years	2 years	3 years	59 years

* PWD stands for 'person with disability'.

** KSP stands for 'key support person'.

5. Consent procedure

One of the major ethical considerations of this study was the procedure by which the consent of research participants was obtained. The study and the consent process were discussed at the first meeting with each participant and/or the key support person. Gaining the consent of people with intellectual disabilities poses certain difficulties because the concept of consent is not simple (Perry, 2004). A number of steps were taken to facilitate this process. Information on the study was presented in a as simple and straightforward way possible (Perry, 2004). One consent form was written for the person with a disability in simple language and was signed by the participant, the selected key support person and the guardian (if applicable). The information in this form was also presented verbally. An accessible consent form with short sentences and pictograms was provided as well. A second consent form was written for the key support person and or third informant and signed by the key support person or third informant, the person with a disability and the guardian (if applicable). The consent forms can be found in Appendix D.

Before consent was requested, I sought to ensure that potential participants understood the purpose of the research, what would be required of them, what impact participation in the research would have on them and others, and what impact not participating would have. I provided all participants with the opportunity to ask questions. Additionally, I asked them questions to establish whether the information had been understood. I did not attempt to induce potential participants to consent, ensured that participants were made aware that non-participation would have no adverse consequences, that they could withdraw from the study at any time, without giving reasons and without negative consequences. I also ensured that they were given reasonable time to consult with others and consider whether or not to participate.

Both the participants and the key support persons were asked to bring personal artifacts to the interviews. I explained to the participants that even though these objects would assist in the research process, they would remain in their possession. During the consent procedure participants were informed that all data collected including the life story and personal documents, would be treated confidentially and that they would not be identified in the course of disseminating the results. I discussed with the participants that they would have ownership over the lifeline created in the study. With permission of the older adults and their guardians (if applicable) I made a photograph of each lifeline for analysis. These photographs will be destroyed one year after completion of the study.

Permission was obtained from all participants for the interviews to be audio taped. Each participant was assured that the tapes would not be available to anyone but the participant and the researcher and that the tapes will be erased one year after completion of the study. I also explained to participants that I would transcribe the interviews and that even though the transcripts will be needed as a record for one year after completion of the study, I would use pseudonyms in the transcripts and alter identifying details to protect their privacy.

Two of the 12 older adults had guardians who were also the key support persons. The guardians consented to participation in the study and both of these older adults assented to participate after consent from the guardian was given. For all but one participant, the first interview commenced during the same meeting as the consent process. All participants were provided with a copy of the consent forms.

The signing of the formal consent forms was only an initial step in the ongoing consent process. During the research process I repeatedly asked participants if they still wanted to participate. Furthermore I asked the participants if they were having a good time working with

me. By aiming at a mutual pleasurable working relationship, pressure on both the researcher and the participants was alleviated which contributed to rapport. One research participant decided after three interviews that she no longer wanted to meet with me. She did not withdraw her consent but decided to finish our work together earlier than I anticipated.

As an incentive for participation and a gesture of appreciation for the time and effort invested in a study, participants with disabilities received a \$15 gift card for a business of their choice. I explained to the participants that if they withdrew from the study they would still receive the gift card. The participant received the gift card during the last interview.

A subsample of six participants consented to being contacted at a later time to share their stories on video. I explained that the videotapes will be used to produce a film to be disseminated to the public including agencies and universities, as a resource and educational and advocacy tool. The film will describe individual life stories, provide information about social networks of older adults with intellectual disabilities and promote the development of their social networks. I clearly explained to the participants that they will be recognizable if they participate in the film project and hence they will not remain anonymous. I did not attempt to induce individuals to consent to participate in the film project. Additionally, I tried to ensure that participants were made aware that they could still participate in the study if they decide not to partake in the film project. The subsample also consented to use of their photographs in research reports.

6. **Research contacts**

The settings and times of the interviews were mutually agreed upon. All interviews took place in person with the exception of one brief interview with a key support person that was completed by telephone. As many people with intellectual disabilities are unable to travel independently and the cost of travelling can be prohibitive I met with participants in

venues that were easily accessible to them (Perry, 2004). Interviews took place at the participants' homes, day programs, offices of the community agencies, at local coffee shops, and at the University of Illinois at Chicago. I tried to ensure that the research settings were as quiet and free from interruptions as possible for comfort and to safeguard privacy and confidentiality. I encouraged participants with disabilities to speak to me independently if they so desired, so they could speak freely and I could ensure the experiences captured were indeed those of the participant.

A total of 51 research meetings took place of 30 minutes to 2 hours in length. I met with each participant and/or their key support person between two and seven times, several days to two weeks apart, within a period of a month to six weeks. An overview of all the research contacts with the participants can be found in Table II.

7. **Interviews**

a. **Interviews with key support persons**

Qualitative, semi-structured interviews were conducted with key support persons and participants using an interview guide approach. Semi-structured interviewing follows the open-ended approach used in ethnographic and qualitative research. Even though the interviewer follows a written list of questions in a particular order no set responses are used, such as those found in the survey style of structured interviewing. In semi-structured interviewing, the interviewer elicits answers from the perspective of the respondent, and tries to gain understanding of the context and meaning of those responses (Patton, 2002).

TABLE II
OVERVIEW OF ALL RESEARCH CONTACTS

Pseudonym PWD*	Meeting 1	Meeting 2	Meeting 3	Meeting 4	Meeting 5	Meeting 6
Henry	KSP**: Consent, social network map and life history interview	KSP and PWD: individual interview and lifeline				
William	KSP 1 and PWD: Consent, social network map	KSP 1 and PWD: Life history interview	KSP 2: Life history interview	PWD: individual interview and lifeline	PWD: individual interview and lifeline	
Lucy	KSP and PWD: Consent, social network map	KSP and PWD: Life history interview	KSP and PWD: individual interview and lifeline	PWD: Member checking		
Charlotte	KSP and PWD: Consent, social network map	KSP and PWD: Life history interview	PWD: Individual interview and lifeline	PWD: Member checking		

* PWD stands for 'person with disability'.

** KSP stands for 'key support person'.

TABLE II (continued)
OVERVIEW OF ALL RESEARCH CONTACTS

Pseudonym PWD*	Meeting 1	Meeting 2	Meeting 3	Meeting 4	Meeting 5	Meeting 6
Barbara	KSP** and PWD: Consent, social network map	KSP and PWD: Life history interview	KSP and PWD: Individual interview and lifeline	KSP and PWD: Individual interview	PWD: Member checking	
Philip	KSP and PWD: Consent and social network map	KSP and PWD: Life history interview	KSP and PWD: Individual interview and lifeline	KSP and PWD: Individual interview and lifeline		
Betty	KSP**: Consent, social network map and life history interview	KSP and PWD: Individual interview and lifeline	KSP and PWD: Individual interview and lifeline	KSP and PWD: Individual interview		
Roger	KSP and PWD: Consent and social network map	KSP and PWD: Life history interview	PWD: Individual interview	PWD: Individual interview and lifeline	PWD: Individual interview and lifeline	

* PWD stands for 'person with disability'.

** KSP stands for 'key support person'.

TABLE II (continued)
OVERVIEW OF ALL RESEARCH CONTACTS

Pseudonym PWD*	Meeting 1	Meeting 2	Meeting 3	Meeting 4	Meeting 5	Meeting 6
Matthew	KSP** and PWD: Consent and social network map	KSP and PWD: Social network map and life history interview	PWD: Individual interview and lifeline	PWD: Individual interview and lifeline		
Mary	KSP and PWD: Consent	PWD: Social network map	PWD: Social network map and individual interview	PWD: Social network map and individual interview	PWD: Individual interview and lifeline	PWD: Individual interview and lifeline
Linda	KSP and PWD: Consent and social network map	KSP and PWD: Life history interview	PWD: Individual interview and lifeline			
Zach	PWD: Consent	PWD and KSP: Consent, social network map KSP: Life history interview	KSP: Life history interview (finished on the phone)	PWD: Individual interview and lifeline	PWD: Individual interview and lifeline	

* PWD stands for 'person with disability'.

** KSP stands for 'key support person'.

The study was designed to first complete a life history interview with the participant and the key support person followed by an individual interview with the participant. Ten of the 12 recruited participants were their own guardian and hence it was appropriate to do all interviews with them, with the assistance of the key support person if so desired by the participant. Two guardians decided to meet with me first before I interviewed their wards.

The semi-structured interview guide for the life history interviews with the key support persons was only used with the three key support persons who were siblings of the participants. This interview guide (Appendix B) included the following topic areas: residential history, history of social relationships, the disability, religion, sexuality, educational history, employment history, life events, and social network over time.

Even though the other 10 key support persons knew the participants for at least two years, they did not have intimate knowledge on the life histories of the participants and many of the questions in the interview guide for the key support person were not applicable to their experiences. With the permission of the participants, they all used case files to find information on the participants' life histories. Unfortunately these files were incomplete. Only minimal information was available and had to be collated from different files which dated from different times in the participants' lives. I asked the participants permission to view their files. At one agency the management made it clear to me that I was not allowed to view any files, even with the permission of individuals with disabilities who were their own guardians.

b. **Interviews with individuals with disabilities**

Conducting interviews with people with intellectual disabilities can be challenging (Gilbert, 2004). Their responses may be affected by the question format. Open-ended questions are the preferred format for qualitative interviewing. This format may be less

appropriate for individuals with lower levels of cognitive and communicative skills (Perry, 2004). Closed questions tend to achieve a higher response rate, but limit the range of responses, may increase acquiescence, and do not allow for the participants to convey experience in their own way or to explore issues in great depth (Perry, 2004). Because of these disadvantages, I posed open questions in the study. I avoided posing dichotomous questions, unless I needed to check the interpretation of an answer already given. I also asked the same question in a number of different ways to estimate the consistency of the response (Gilbert, 2004).

People with intellectual disabilities experience a range of impairments. Consequently, different individuals within the same study may require different approaches by the interviewer (Booth & Booth, 1996). I estimated the individuals' cognitive abilities and communication skills through interaction with the participants during the consent process and spontaneous conversation, and matched my approach and questions accordingly. I also observed the participants' body language to decide whether to proceed with a line of questioning, or to hold back (Booth & Booth, 1996). When I noticed fatigue or waning concentration was setting in, I proposed a break or ended the interviews. This happened mostly on warm days when the heat became oppressive.

Rapport is critical to the development of trust and comfort between the participant and the researcher, and enhances the quality and trustworthiness of the data. A single meeting with an unknown researcher provides a very limited opportunity for persons with intellectual disabilities to give an account of their feelings, experiences, or insight into their personal world (Bigby & Balandin, 2004). I had multiple contacts with participants over prolonged periods of time which strengthened rapport (Mactavish et al., 2000; Taylor & Bogdan, 1998). The participants with disabilities seemed comfortable during our meetings, said they had a good time

working with me, and that they enjoyed seeing me. They actively participated in the research process and the majority of the participants with disabilities seemed genuinely excited to work with me.

For some participants a larger number of meetings were needed than for others to facilitate and support meaningful participation and to complete our work together in a manner satisfactory to both the participant and the researcher. Conducting several interviews gave the participants the opportunity to share more of their experiences if desired and gave me the opportunity to come back to important issues discussed in previous interviews, to discuss topics in greater detail, and to clarify unclear answers.

The interview guide for the individual interviews with the participants (Appendix B) included the following topic areas: current social network, religion, sexuality, the disability, residential history, history of social relationships, educational history, employment history, life events, and social network over time. I provided each participant with an accessible interview guide consisting of pictograms and short sentences. This guide can be found in Appendix B.

Despite the use of the semi-structured interview guide, I approached the interviews as guided conversations with the aim to flow naturally. I encouraged spontaneous conversation by asking informal questions and by having a casual attitude. I occasionally omitted questions, changed the order of topics, and added probes to clarify or further investigate responses (Whitehead, 2005).

The key support persons and the participants with disabilities brought pictures and other personal artifacts such as certificates, diplomas and medals to assist in communicating their life story. The artifacts served as visual cues and helped participants express their experiences. All interviews were audiotaped. I made only brief handwritten notes during the interviews.

c. **Member checks**

The research design originally included in-person member checks with each participant and their key support person. Separate meetings for member check only took place with a selection of three of the 12 participants. During the data collection process it became clear to me that an additional meeting for a member check after two to six interviews was too burdensome for the majority of my participants. Since multiple interviews were conducted, member check was built into the data collection process. I started each interview by repeating the highlights of what was discussed in the previous interview and asked the participants if they wanted to change or clarify anything they had mentioned or if they wanted to add to certain topics. Most life events were discussed multiple times at several interviews.

The plan for the study included providing transcripts to each participant for verification. This element of the plan was not executed, as the practicality of the data collection logistics did not allow enough time for all audiotapes to be transcribed during data collection, and the limited written verbal skills of the participants would have been challenged by this task.

8. **Social network maps**

During the first interviews a social network map was completed (Tracy & Whittaker, 1990) for each person with a disability. Social network mapping techniques are based on the social convoy model (Kahn & Antonucci, 1980). They identify and visually display network composition and membership using concentric circles with three levels of closeness: attachment figures, people not quite that close, and people less close but still important. The social network map also includes questions on functional characteristics of social relationships, namely the closeness, frequency, and stability of each relationship. Each social network map captured the present social relations of the person with a disability, not past ones. My use of the

social network mapping technique concluded with questions on the frequency and intensity of the perceived social supports to the person with a disability. These included instrumental support, material support, informational support, emotional support and appraisal. I added normative and companionship support to the social network map based on the literature on social relations of people with intellectual disabilities (Bigby, 2005; McConkey, 2005) and my experience working with this population. Normative support referred to corrections in behavior or rules and restrictions set by the convoy member. Companionship support included the undertaking of shared activities with the convoy member. I also inquired about negative interactions between the person with a disability and the convoy member as well as the nature of reciprocity in the provision of social support between the person with a disability and the convoy member. The social network map instrument can be found in Appendix C.

After completing the social network map with the first two participants, it became clear that the proposed quantitative approach was too tedious for the participants, and not effective in retrieving their rich qualitative descriptions of the experience with social relations and social support. Hence, I adjusted my approach to complete the social network map in a more conversational way, asking participants for their experiences with selected individuals in their social convoy. Even though I had planned to inquire about the social support provided by the five closest members of the social convoy, it became clear that doing so for three members of the convoy was sufficient and less burdensome for the participants.

The visual nature of the social network mapping technique based on the social convoy model was very effective for use with the participants. I wrote the name of the participants in the middle of the three circles. This assisted them to understand the concept of the social convoy. The procedure of placing important relationships in a circle close to the middle and less

important relationships in a circle further from the middle was understood well by the participants. The inner circle (intimate relationships) and the middle circle (friends) were understood best. The third circle (acquaintances) seemed less tangible in the understanding of the participants. I provided examples of the types of relationships that go in each circle. I also mentioned the relationships in my own convoy to illustrate the use of the social network map. An added benefit of this approach was that disclosing some of my personal information helped build rapport.

At times I had to clarify that the social network map aimed to describe the present social relationships, as the participants would add deceased individuals to their social network map. After the first relationships were marked on the social network map, these were used to determine the relative closeness of other relationships.

9. **Retrieval of life stories**

a. **Storied lives**

We “story” our lives, we “story” who we are and we “story” the world around us (Kenyon & Randall, 2001, p. 4). The stories these processes produce concern our lives as a whole. The stories reflect on our past, present, and future and provide our lives with a sense of unity and purpose (Basting, 2009; Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001; Meininger, 2001). We create and discover meaning and coherence within our life stories (Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001; Meininger, 2005).

Life stories are created within the context of the societies people live in. Lives are affected by the structure of societies, such as social policies, power relations and economic realities. Structural dimensions can foster but also constrain, stunt and silence voices. Lives are also affected by sociocultural dimensions, specifically as concern us here, the social meanings

within a given cultural context associated with aging and the life course (Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001). Life stories reflect “these values, norms and power differentials inherent in the societies wherein they have their constitutive meanings” (McAdams, 2001, p. 118). Additionally, lives are fundamentally interpersonal. Stories live to be told to others and are shaped by and entwined with the life stories of others (Gubrium, 2011; Kenyon & Randall, 2001; McAdams, 2001; Meininger, 2005).

Life stories are important to older adults, as the longer lives are, the more there is to be told. The subjective well-being of older adults is not only determined by what they experience today, but also by what happened to them in the past, and by their retrospective view on those life events (Westerhof, Dittman-Kohli, & Thissen, 2001). Life review promotes successful aging (Butler, 1963) and the retrieval of memories is an important activity in late life stages (Erikson, 1997). By talking about their lives older people gain insight into the persons they have become, and make peace with themselves and their accomplishments (van den Brandt-van Heek, 2011). As people get older they share their wisdom by telling their stories to younger generations (McAdams, 2001).

A central feature of narrative gerontology is that it recognizes storytelling as a fundamental aspect of being human. Life course perspectives have gained prominence in the field of gerontology because of the growing recognition that the meaning of aging to individuals is influenced by the ways they experience and interpret their lives (Schroots & Birren, 2001). Narrative gerontologists aim to get a better understanding of aging through the stories older people use to express their experiences.

b. **The value of life story research**

Life story research focuses on individual accounts of aging, puts a human face on growing old, and produces emancipatory and empowering knowledge that combats stereotypes and prejudice against older people (Bornat, 2002; Estes, Biggs, & Phillipson, 2003; Jamieson, 2002; Minkler, 1998). Life story research brings lives to the foreground that have been disregarded (Bornat, 2002). This holds potential for people with disabilities who have lived marginalized lives.

Life story research embraces the postmodern insight that objectivity is a myth, and acknowledges that all knowledge is contextual. It contributes to recovering meaning as phenomena are not seen as given, but as stories and constructions. Life story research acknowledges that too often particular research methods guide the problem or phenomenon to be investigated, rather than the problem suggesting the method that is appropriate to be used (Kenyon & Randall, 2001). This philosophy is valuable for people with intellectual disabilities for whom research methodology has often proved inaccessible.

c. **Life story research with people with intellectual disabilities**

In the past people with intellectual disabilities were forgotten people, leading forgotten lives. Their voices have been unheard (E. Stone & Priestley, 1996) while other voices have been heard speaking for them (Atkinson & Walmsley, 1999). Their life stories, like those of women, black people and mental health survivors (Atkinson, 2005), can recount their resilience and struggle against discrimination and exclusion (Goodley, 1996). Older adults with intellectual disabilities might have experienced segregation, discrimination, and oppression for decades. The sharing of their stories holds significant value for advocacy and empowerment.

Because of its important implications for the field, life story work has begun receiving increasing attention in the intellectual disability research, particularly in Europe (e.g. Atkinson, Doeser, & Varga, 2000; Atkinson, Jackson, & Walmsley, 1997; Atkinson & Walmsley, 1999; Cadbury & Whitmore, 2010; Goodley, 1996; Gray, 1997; Hreinsdottir, Stefansdottir, Lewthwaite, Ledger, & Shufflebotham, 2006; Husain, 1997; Mee, 2010; Roets, Goodley, & van Hove, 2007; Roets, Reinaart, & Van Hove, 2008; Roets & Van Hove, 2003; Van Puyenbroeck & Maes, 2004).

Three main perspectives can be identified in work done to date with the life stories of people with intellectual disabilities (Meininger, 2003, 2005; Van Puyenbroeck & Maes, 2008). In all three approaches, the process is more important than the product. In other words, most important is that the telling of the story is meaningful to the person with an intellectual disability (Van Puyenbroeck & Maes, 2008). The critical approach revolves around recovering the voices of people with intellectual disabilities. In this approach, the facilitator is a critical educator who coaches persons with intellectual disabilities to claim authorship and ownership of their own life stories. In this approach life histories, autobiographies and narratives stimulate people with intellectual disabilities to become critically aware of their past (Van Puyenbroeck & Maes, 2008).

The person-centered approach refers to ‘life story work’. It aims to “retell, study and discuss life stories in contacts between persons with intellectual disabilities, their relatives and friends and caregivers” (Meininger, 2005, p. 108). Life story work also aims to inform the attitudes and acts of the persons involved in everyday support of the person with an intellectual disability (Meininger, 2003, 2005; van den Brandt-van Heek, 2011) and, therefore, resembles strategies for person-centered planning (Aspinall, 2010; Van Puyenbroeck & Maes, 2008). The

moral focus of this approach is not on empowerment, but rather on dialectical understanding and relational intimacy. This approach includes activities that create a written record of a life story such as compiling a life book (Van Puyenbroeck & Maes, 2008).

In the clinical approach, reminiscence is presented as an alternative diagnostic instrument and counseling method for people with intellectual disabilities (Van Puyenbroeck & Maes, 2008).

d. **Considerations of the use of life history methodology with people with intellectual disabilities**

One of the most important methodological issues in life history research concerns how to collect valid information from inarticulate people (Van Puyenbroeck & Maes, 2008). Unfortunately, the issue of impairment is often circumvented in methodology, with a possible mismatch between the used methodology and the characteristics of the population as a consequence. It is important to consider this issue for research to be appropriate and valid as well as respectful, meaningful and engaging to research participants.

The most common way for life story work to be captured with persons with an intellectual disability has been through face-to-face interviews (Aspinall, 2010). Inarticulateness, unresponsiveness, a concrete frame of reference and difficulties with the concept of time are challenges in life story work with this population. None of these are unique to persons labeled intellectually disabled; they are also encountered with other informants (Atkinson & Walmsley, 1999; Booth & Booth, 1996; Schroots & Birren, 2001). People with intellectual disabilities have little access to the written word and sometimes struggle with the spoken word as well (Atkinson et al., 1997). They might have limited ability to answer some types of questions. It has been observed that the concrete frame of reference typical for many people with intellectual

disabilities restricts their capacity to look back on their own lives with reflexivity (Booth & Booth, 1996). They may have difficulty in providing details about their past, often confusing sequences of events (Aspinall, 2010; Goodley, 1996). Usually, their memory is impaired (Vicari, 2012). They experience problems with the concept of time marked by a strong present orientation and difficulties with dates and numbers (Booth & Booth, 1996), depending on the severity of their impairment (Sharpe, Murry, McKenzie, Quigley, & Patrick, 2001). While ways can be found around some of these problems, they put limits on the important referential function of narrative which is essentially a story in time (Booth & Booth, 1996).

Problems with time are indicative of lives which lack many of the opportunities, life tasks, challenges and milestones people use to order their past and to mark the passage of time (Booth & Booth, 1996). It is generally acknowledged that difficulties in the understanding of time and other abstract concepts are common in people with intellectual disabilities. However, the implications of a deficit in time understanding are less clear (Owen & Wilson, 2006). It is unclear what the concept of time means to persons with various intellectual disabilities, whether they construct and structure their life in a chronological order of past-present-future, how they experience the present versus the past and the future and whether they think and frame their lives in terms of stories. It is, therefore, important not to make assumptions of what is important and meaningful to this population. Additionally, it is important to acknowledge environmental influences in their understanding of time. It has been advised that increasing the availability and reliability of external time cues in the immediate environment of persons with intellectual disabilities may help reduce these problems. Improving time perception abilities in this population is important as “it may reduce feelings of powerlessness and anxiety and increase feelings of self-efficacy and the individual’s sense of self as having a past, and a future” (Owen

& Wilson, 2006, p. 9). The use of life story methods with this population might in itself help address this issue.

Sources of bias are well documented within life history research. These include informants' tendencies to rehearse a story and/or in some cases lie. Checks for consistency between accounts of the same experience or event in different interviews, is one method to address this bias (Goodley, 1996). Goodley (1996) suggested that the question whether persons with an intellectual disability are telling the 'truth' may be irrelevant. It is important to understand why these individuals present their stories like they do. Subjective experiences do not necessarily accurately reflect objective situations.

e. **The use of life lines as a life history methodology**

Lifelines are part of life history methodology. They visually depict the individual life events in a chronological order. Lifelines can include interpretations of these life events. The lifeline can be triangulated with other data collection methods to confirm and complete a life history (Gramling & Carr, 2004).

The 'Lifeline Interview Method' (Assink & Schroots, 2010) was developed in the field of gerontology. It uses the metaphor of the footpath, representing the journey of life from birth to death. "A graphical, two-dimensional representation of a footpath, with time on the horizontal axis and affect on the vertical axis, symbolizes the course of human life" (Schroots & Birren, 2001, p. 54). The interviewer asks the interviewee's perceptions of his or her life visually by drawing a lifeline representing the time from birth to the present age. When the lifeline has been drawn, the interviewee is asked to label each peak and each dip by chronological age and to explain what happened at these moments. After the past has been visualized and described, the

future is explored in the same manner. This method is praised because of its self-pacing quality and nondirective nature (Schroots & Birren, 2001).

Lifelines have been used in various ways in research with vulnerable groups such as African-American women who smoke crack (Boyd, Hill, Holmes, & Purnell, 1998), people in the early stages of Alzheimer's disease (Dienstag, 2003), and incarcerated women (Hanks & Carr, 2008).

f. **The use of life lines in context of the study**

This study used lifelines to place life histories within a historical context and to map the sequence of key life events (J. Caldwell, 2010), life course transitions, and age-related changes. An additional goal of creating the lifelines was to assist non-intrusively with the participants' interviews (Goodley, 1996).

Between interviews, I constructed a vertical timeline of key events in the individual life story of each participant. I meticulously pieced together sources of information to create the timelines. I also had to ascertain the chronologies in each life story. When the participants told me about an event but could not indicate when it happened or how old they were at the time of the event, I asked if it had happened before or after another reported life event or where they lived at the time of the event. This strategy proved helpful in clarifying the order of life events. I used flipchart paper to draw a single horizontal line across the landscaped page with the birth year of the participant on the far left and the year 2014 on the far right. With pencil I marked the major life events discussed in previous interviews. With my assistance the empty paper was then decorated by the participants during the interviews.

The lifelines were based on a simplified version of the Life Line Interview Method (Assink & Schroots, 2010). They did not include peaks and dips to visualize negative and

positive effects of life events, as this concept would have been too abstract for this study's participants.

Even though the primary goal of using the lifelines was to provide a visual probe to aid with the interview process, the effort it took to create the timelines paid off in a number of less expected ways. First, the work on the lifelines reduced tension during the interviews and helped the interaction between the researcher and the participant feel more natural and relaxed. Instead of the interviewer firing questions to an interviewee while sitting on opposite ends of the table, we sat next to each other both looking at the lifeline. The work on the lifelines was a fun activity to the participants and provided a pleasant experience. It built rapport.

Second, the lifelines were an effective tool to involve and engage the participants in the research process and enabled their meaningful participation. When we were talking about a life event, I asked whether the participant wanted to include it on their lifeline. In order to make the process of creating the lifelines more accessible, I did not exclusively focus on facts related to a life event but rather aimed to retrieve the individuals' opinions and emotions surrounding that event. I also asked questions about their social network at the times of these life events and the roles various people had pertaining to these events. I asked if they wanted to write or draw something on their lifeline about each life event and if they wanted my assistance. Some individuals chose to write or draw by themselves while others asked me to assist. A number of participants were interested in decorating their lifelines with pastels and drawings. I asked the participants which color marker or pastel they wanted to use. This captured the experiences of the participants in an accessible and creative manner². Some individuals wanted to include

² This approach was imported from work in person centered planning with persons with intellectual disabilities, such as Planning Alternative Futures with Hope (Wetherow & Wetherow, 1998).

pictures on their lifelines. Other just showed me pictures and did not want any on their lifeline. Some individuals did not have pictures or did not bring them. I found pictures of places participants had lived and these were also used to decorate the lifelines.

I explained to the participants that their lifelines would continue beyond the year 2014 by gesturing towards the end of the line and extending it by moving my hands in an onward motion. This visualization helped me ask questions about the participants' wishes for the future. I also pointed to the year I was born on the lifelines to explain to the participants that they had already lived for several decades longer than I had. This visualization helped me ask questions about growing older and about life lessons they wanted to share with me as their junior.

To complete the construction of each lifeline, I asked the participants if they wanted to give their lifeline a title. After each lifeline was completed I took a photograph for future analysis. Each participant partook in the lifeline differently and made different decisions in its creation regarding what life events they wanted to include and how they wanted to decorate it. As a result, each lifeline looked different. Only one participant did not have an interest in using the lifeline. Table III provides an overview of each participant's decisions regarding the decoration of his or her lifeline.

The lifelines provided the participants access to their memories and a sense of history about their own lives. Some participants seemed to not have had this type of access before. The chronological review of their live events and the presentation of their lives as a whole seemed to be new experiences to a number of participants. The participants took ownership of their lifelines (as was the intent of this procedure). They all kept their lifelines. The lifeline was also a source of pride to the participants. They showed their lifelines to their friends and direct support staff and asked for it to be put on their walls for display.

The key support persons who were direct support staff of the participants learned new information about the participants' life histories through the lifeline creation process.

10. **Data management**

The audio recordings were saved on a USB drive at the research sites. Before leaving the sites, the data was encrypted using Truescript encryption software. The data was then transferred to a secure drive on the network of the Department of Disability and Human Development. Identifiers such as names of persons and places as well as dates (except for years) were removed once data collection was completed and data analysis started. Pictures and artifacts used for the construction of the lifelines remained in the possession of the participants at all times during the data collection. A description of the pictures and artifacts was included in the data for subsequent analysis.

TABLE III
LIFELINE DECISIONS

Pseudonym PWD*	Title Lifeline	Pictures	Writing	Drawing/coloring
Henry	‘Henry’ with a smiley face	5 family photographs	Researcher	Some drawing and shading
William	No title	10 online pictures	Researcher and William	Some drawing
Lucy	No title	2 family photographs and 2 online pictures	Researcher	No drawing/coloring
Charlotte	‘Picture of my life’	1 family photograph and 3 online pictures	Researcher and Charlotte	Some drawing
Barbara	‘The wonderful purple of Barbara’	10 family photographs and copy of social convoy	Barbara	Shading
Philip	No title	No photos or pictures	No writing	No drawing/coloring

* PWD stands for ‘person with disability’.

TABLE III (continued)
LIFELINE DECISIONS

Pseudonym PWD*	Title Lifeline	Pictures	Writing	Drawing/coloring
Betty	No title	Two online pictures	Betty	Extensive drawing and shading
Roger	No title	Four online pictures	Researcher	Some drawing
Matthew	‘My home, my family at [name of his community agency’s home]’	Six family photographs, two online pictures	Researcher and Matthew	Some drawing
Mary	‘My life is a rainbow’	No photos or pictures	Mary	No drawing
Linda	No title	No photos or pictures	Linda	Some drawing
Zach	No title	No photos or pictures	Zach	Some drawing and shading

* PWD stands for ‘person with disability’.

11. **Institutional review board**

The Institutional Review Board of the Office of the Protection of Research Subjects at the University of Illinois at Chicago approved the study prior to the initiation of any research procedures. Approval was maintained throughout the course of the study. The approval notices can be found in Appendix E.

E. **Researcher Orientation**

In qualitative research, the researcher is intricately woven into the context of the study and functions as the research instrument. The background and the experiences of the researcher play an important role in the research process and need to be articulated to understand the study (Collins & Cooper, 2014; Patton, 2002).

My approach to this study has been shaped by my experiences in both clinical and research settings. I worked as professional in the field of intellectual disabilities and have worked as a researcher in the gerontology and disability studies fields. I have extensive interviewing experience with older people with intellectual disabilities. My research philosophy is influenced by the social model of disability and the notion that disability and impairment are social constructs.

I am an ‘outsider’ with respect to my research participants and there is a considerable experiential divide between me and my participants. A non-disabled researcher can be intimidating to persons with intellectual disabilities and it is important that the researcher be conscious of power issues. Emotional reflexivity is of importance to all qualitative researchers but particularly for those who do research with vulnerable populations.

I believe the experiential divide between me and the research participants did not challenge our work together as I aimed to position myself as equal to my participants and simply

as a fellow human being. Both the researcher and the research participants brought experiences to the table and those were mutually accepted and respected. My accent and my lack of shared cultural experiences or understanding (I am from a different country and a non-native English speaker), did not cause a distancing from the research participants but rather became a source of engagement and curiosity among the research participants. I have also lived in the United States long enough to understand cultural conventions.

Topics of a highly sensitive nature and negative life experiences were discussed during the interviews. They evoked strong emotions in the research participants. I tried to establish an atmosphere of safety and equity so that the participants would feel accepted and respected. I politely approached the participants, carefully listened to what they had to say, provided validation of their feelings and demonstrated a supportive, empathic and compassionate attitude. I was careful not to counsel as I am not a trained therapist, but I recognize that the nature of the work with some participants might have presented a therapeutic experience (Collins & Cooper, 2014) as they shared the emotional impact of life experiences with a skilled listener.

Some of the stories that my participants shared with me also evoked an emotional response in me. I was responsible for supporting the research participants during the interviews, so I supported myself after each interview. I took several hours to process my feelings, particularly after the interviews during the first half of the data collection. This process was the topic of several memoranda (that were reviewed during the writing of this dissertation). It is important that qualitative researchers be aware of their emotions throughout the research process and reflect on the source of their emotions as they might impact or illuminate their fieldwork (Collins & Cooper, 2014). I argue that being touched by individual stories and embracing

subjectivity are strengths as we, in our disability studies field, aim to advocate for people with disabilities and make steps towards a more socially just world.

The nature of life story research results in a number of considerations for the researcher. Gibson (2006) outlined necessary approaches for scholars when undertaking any kind of life story research. They should listen actively, by ‘noting what is said and what is not said’; emphasize, ‘by being able to share another’s world without losing their own’; attend, ‘by being available for people’; be nonjudgmental, ‘by accepting people as they are’; not be ‘frightened by expressions of painful emotions’; be able ‘to enjoy stories and be interested in the past’; be ‘disciplined, but be able to share their own thoughts if asked’; be able ‘to reflect on and critically evaluate their own work’; and be ‘able to accept feedback and offer feedback to others’. I tried to closely follow these requirements during the course of the study.

As my participants were sometimes unable to present detailed and elaborate anecdotes, I had the role of interpreter or biographer at times (Goodley, 1996). Because I met with the participants several times I got to know them, learned to understand their speech, and became familiar with how they presented themselves and their experiences. In the stories I drafted, I sought to articulate those lived realities and the life worlds of my participants as they presented them to me. It would be naïve to assume that I could just pass over ‘authority’ to my participants as researchers bring their own stories, meanings and values to the research (Braun & Clarke, 2006; Kenyon & Randall, 2001). A major source of bias in life history research stems from the researcher’s own preoccupations (Goodley, 1996). It was up to me as the researcher to be aware of my impact on the stories told, to acknowledge my input and interpretations of the events presented to me and to retain the voice of the participant during the research process (Goodley, 1996). I withheld my assumptions or presuppositions to allow participants to explain the full

range of their perceptions unless necessary to be forthright and honest. I balanced my need to listen and learn while anticipating the needs of the participants (Collins & Cooper, 2014). I articulated my reflections on the interactions with the research participants in extensive field notes, the drafting of detailed memoranda during data analysis and using direct quotes from my research participants in the presentation of the results.

F. **Data Analysis**

The interviews were transcribed verbatim. The literature suggests that researchers fix the grammatical concerns so narratives flow well (Carlson, 2010). I decided against this as I wanted to remain true to the voices of my participants and the word order they selected to describe their experiences and express their feelings.

The different stages of data collection resulted in interrelated, data pieces: interview transcripts, field notes, social network maps, lifelines and memoranda. I constructed twelve case records to organize the data (Patton, 2002). This involved the organization of the raw case data into manageable and accessible files. Table IV demonstrates the data generated in the study and the analytic methods applied to each set of data to answer the research questions.

Data analysis followed an inductive process and started with case-analysis (Patton, 2002). As Patton (1990, p. 449) stated, the researcher's "first and foremost responsibility consists of doing justice to each individual case. All else depends on that." I created readable narratives with careful thick descriptions of all participants' life stories. In thick descriptions, "the voices, feelings, actions, and meanings" of individuals are heard (Denzin, 1989, p. 83). The individual narratives were created by combining the social network maps, interview transcripts, field notes, lifelines and memoranda. The goal of writing the narratives was to make all the information accessible to readers that is necessary to understand each participant's life in all its uniqueness

(Patton, 2002). The narratives include backgrounds on the participants, descriptions of their present social convoys and chronological comprehensive life histories.

TABLE IV
OVERVIEW OF ANALYTIC METHODS

Research Questions	Data	Analytic Methods	Outcomes
Research questions 1-6 (Contextualization for subsequent analysis)	Social network maps, interview transcripts, field notes, lifelines and memoranda	Case-analysis (Patton, 2002)	Twelve individual stories
Research question 1-2	Social network maps and interview transcripts	Comprehensive summary of structural and characteristics of social convoys based on case-analysis (Patton, 2002)	Global description of structural characteristics of present social convoys
Research question 1-6	Interview transcripts	Inductive semantic thematic analysis (Braun & Clarke, 2006)	Themes related to social convoy experiences across the life course
Research question 1-2	Interview transcripts	Inductive semantic thematic analysis (Braun & Clarke, 2006)	Global description of functional characteristics of present social convoys

Even though I prioritized the perspectives of the participants in the stories, I included some representations of the distinctive views and experiences of the key support persons because of the important roles they hold in the lives of the participants. The individual stories provide context to the data useful which was useful for analysis and answering of all six research questions.

The second step of data analysis consisted of the creation of a comprehensive summary of the structural characteristics of the participants' present social convoys based on the case-analysis (Patton, 2002). Analysis of social network maps consists of the calculation of numbers as well as proportions of different aspects of social network functioning. The use of proportions allows for comparisons across social networks of different sizes (Tracy & Whittaker, 1990). I counted the numbers of relationships in the different circles of the participants' convoys. I calculated the number and percentages of family members, staff, peers with disabilities, friends, and others in all the convoys' circles. The percentages allowed me to compare convoy compositions across the participants. Furthermore, I included the numbers and percentages of male and female convoy members in each of the participants' circles. For each type of relationship in the convoys' circles I determined the most frequent in-person contact, the most frequent phone contact, the longest relationship duration, and the closest relation proximity. The global description of the present social convoys of the participants assisted in answering the first two research questions.

The third step of data analysis consisted of thematic analysis of the interview transcripts. Thematic analysis is an accessible form of analysis for those early in their qualitative research careers as it does not require the detailed theoretical and technological knowledge of grounded theory and discourse analysis. Thematic analysis was used to identify, analyze, and report themes

within the dataset. Themes capture important data elements “in relation to the research questions” and represent “a level of patterned responses or meanings within the data set” (Braun & Clarke, 2006, p. 82). I used thematic analysis as a technique to report and evaluate the experiences of the participants (Braun & Clarke, 2006).

The thematic analysis process commenced with a careful read of all interview transcripts. The next step involved coding the primary patterns in the raw data. My thematic analysis process was inductive in nature with hints of a deductive approach.³

I inductively established codes and identified themes by looking at the data “afresh for undiscovered patterns and emergent understandings” (Patton, 2002, p. 454). I examined the data in terms of the conceptual framework and the research questions of this study, which was deductive in nature. I was not wedded to the theoretical concepts underpinning this study (the supports-outcomes of aging well (Heller, 2004), life course perspectives (Dannefer, 2011; Elder & Giele, 2009; Heller & Parker Harris, 2012; Priestley, 2003) and the social convoy model (Kahn & Antonucci, 1980). These concepts combined served as a sensitizing framework that provided initial direction to the study and a starting point for the analysis (Patton, 2002).

ATLAS.ti was used to organize the transcripts. The use of ATLAS.ti helped in keeping track of and defining the codes, and allowed for advanced searches for codes in the transcripts. This was helpful as I coded for type of relationship (brother, sister, mother, father, etc.) to discover which convoy members related to participants’ particular life experiences. I kept an analytic journal throughout the process of coding. The journal assisted me to be more analytical

³ Hybrid forms of thematic analysis that combine inductive and deductive approaches have been reported in the literature (Fereday & Muir-Cochrane, 2006). With inductive analysis findings emerge out of the data. Deductive analysis on the other hand, is used to analyze data according to an existing framework (Patton, 2002). It is driven by the researcher’s theoretical or analytical interest in the area (Braun & Clarke, 2006).

and reflective and helped me to retain thoughts and ideas which assisted in the development of codes (Jeon, 2004). As the research questions aim to retrieve the experiences of the individuals with disabilities I only coded their statements and not those of the key support persons. The key support persons' perspectives provided background that I used in the case analysis. The context they provided assisted me in my work with the participants with disabilities.

I analyzed the codes and sorted them into potential themes (Braun & Clarke, 2006). I then refined the themes by judging how well the data within the themes cohered (internal homogeneity) and how well the themes could be distinguished from one another (external heterogeneity) (Braun & Clarke, 2006; Patton, 1990). Constructing the themes and theorizing about the significance of the findings and their broader implications in relation to previous literature required interpretation of the data (Braun & Clarke, 2006). Even though presented as a linear process, the thematic analysis was iterative and reflexive.

I drafted synopses for all participants with brief descriptions of how the themes applied to their data. This assisted with detecting patterns, and comparing findings between men and women, Caucasian and African-American participants, and participants with different residential histories. In the results chapters I present respondents in their own words and report the data that framed my interpretations. The aim of this approach was to not have my constructs dominate the analysis but to let the data tell their own story and to facilitate the reader's understanding of the concepts under study (Patton, 2002).

The thematic analysis provides insight into the patterns of experiences with social relations across the life course, including previous and current experiences with the social convoy. The present perception of social support is a functional characteristic of the social

convoy and hence is discussed along with the structural characteristics observed in the social network mapping process in the chapter on current social convoys.

Two colleagues conducted audits of the analysis process. They independently reviewed a selected number of individual stories, interview transcripts, the emergent themes, and a brief summary of the major findings. I asked them to compare their interpretations with mine. Their feedback helped me nuance and expand my analytic interpretations.

Lifelines have been analyzed by researchers like Hanks and Carr (2008) and Gramling and Carr (2004) using an approach of coding, categorizing, and clustering of themes. The goal of creating the lifelines in this study was to assist with the interviewing process. Discussions of the events presented on the lifelines are included in the interview transcripts. The aims of this study did not include an independent analysis of the produced lifelines which is, therefore, beyond the scope of this study.

IV. INDIVIDUAL LIFE STORIES

The data collection process resulted in rich information about the participants lives. This chapter presents the results of the case analysis (Patton, 2002) of the study's raw data. Each narrative includes a background on the participant and detailed descriptions of the participant's social convoy and life history. The narratives give insight into the unique experiences of each individual and provide background and context to the subsequent results chapters.

A. **Henry**

A barn. They had pigs. They scared me!

1. **Background**

Henry is a friendly and outgoing 59 year old Caucasian man with Down syndrome. Henry loves to collect pens and books even though he cannot read. He is a big fan of Elvis. Henry lives in a group home of a large service provider for people with intellectual and developmental disabilities in a suburb far northwest of Chicago. He has a moderate intellectual disability and a significant hearing loss. Henry is Catholic and church attendance has always been important to him. He does not attend mass regularly anymore but he watches television church each Sunday. The direct support staff at his group home arranges the community activities he partakes in such as going out to eat and bowling. He also goes to a camp two weekends a year. He is one of five children of his parents. Henry's sister and guardian Danielle was his key support person during the study. Danielle is a 62 year old Caucasian woman. She is a retired special education teacher. Danielle explained to me Henry was the reason she pursued the career she did. I completed the social network map and the life history with Danielle, Henry joined us at our the second meeting. It was challenging for me to work with Henry as he could

not give answers to direct questions and it was nearly impossible for me to understand his speech. Danielle assisted during the interview with Henry by engaging him in conversation.

2. **Social convoy**

In the first circle of Henry's convoy Danielle included herself and her husband, as well as their two daughters. In Henry's second circle she included their two sisters, their brother and sister-in-law, two of Henry's housemates, his case manager, and two of his direct support staff from his home. In the third circle she included five other housemates, both partners of her daughters, one friend from Henry's workshop, and one friend from his senior program. Henry sees his staff and housemates daily, Danielle and her husband and their daughters monthly, and his other siblings yearly. Henry speaks on the phone to Danielle and her husband daily. Danielle told me she encourages Henry to call their other siblings, but he does not call them. Henry has known the majority of his housemates and direct support staff longer than five years. He lives within a half hour drive from Danielle and her husband. About every three months Henry comes to stay with them for the weekend. He has a strong bond with both of them. When he comes over Danielle supervises his medications, helps him start a shower, and prepares his meals. Henry will ask her what clothes to wear. Danielle gives him a new pair of shoes each year and sometimes helps finance a trip for Henry to go on. She praises him for his work at the workshop, advises him to ignore his housemates' behavior when he has a temper, takes him shopping, out to eat and to concerts. Henry loves to trade books with his brother-in-law.

3. **Life history**

Henry grew up with his parents and his four older siblings in a house surrounded by farmland in a suburb north of Chicago. After Henry was born the church advised his parents to institutionalize him which they did not do: "*The truth, I don't know if it cause they had a*

strong emotional attachment to Henry, or if it was a financial thing. So, I, I don't know any of that.... So, he just became, you know, the family pet actually." Henry's father was a cement contractor and his mother a school teacher. Henry had a very close bond with his mother. Of his four siblings Danielle has always been closest to him: *"I remember the fact that he was kind of my playmate, because we were out in the country and there weren't very many people around."* Their paternal grandparents lived a quarter mile from the family's home and they saw them every Saturday night. Henry started going to school when he was six years old. Henry and another boy with Down syndrome were the first students in special education in their county. It was a separate school. Danielle said that once Henry was in school he came to have more friends. He was also in Boy Scouts and played sports in Special Olympics. He graduated from special education at age 21. Danielle told me Henry is very proud of his diploma. Henry also took art classes at a local university with a student in art therapy.

Henry lived at home for 33 years. Nine months after his father passed away, his mother unexpectedly passed away too, and Henry moved in with Danielle. Danielle told me that the loss of their mother was very hard on Henry: *"He would have many nights that he would be up, you know, crying and rocking, and being upset about the whole situation"*. According to Danielle, Henry was not prepared to leave the family home at some point in his life. Their mother started looking at placements after their father passed away, but she did not make the commitment to place him.

After living with Danielle for six months, Henry moved into a 94 bed facility where he lived for six years. Danielle said he looked forward to his new home. He viewed his move as going to college as his siblings had done before him. The family had a party for him with a cake that said *"Good luck in college"*. For Danielle his move was difficult: *"He had a single room*

when he first moved there, you know, and I took some of his personal effects and that is when I got my first introduction to group homes. The social worker said: "You know, I wouldn't leave those here. Because they will be stolen". So then we got him a locked cabinet." Indeed things got stolen from Henry, and Danielle thinks he picked up his habit of taking and gathering things during his time there. Danielle mentioned that the physical care was very poor at this facility: *"I will just tell you that he was released with the worst case of scabies that the dermatologist here ... had ever seen."* Henry is no longer in contact with any of the people he knew at the 94 bed facility.

Danielle explained that Henry also did not like this facility: *"When I would drive him there he would go: "I don't want to go", "You are breaking my heart here".*" Danielle found another group home where Henry has lived for the past twenty years. He moved with the group once into a new house. One of his housemates moved in the day before he did so he has known her the longest. Henry calls her *'his wife'*. Danielle mentioned that when Henry still lived at home he would spend time by himself and also took his own medication. At his current home is not allowed to do either.

Since his graduation from special education Henry has attended workshops to do piece work. Henry still does piece work one day a week and visits a senior program the other days. A recent event in his life he very much enjoyed was the wedding of his niece (Danielle's daughter) for which he was the ring bearer.

It was hard to pique Henry's interest during our interview, but he seemed much more engaged once we started with his lifeline. Danielle took out family photos and we looked at them during the interview. Henry picked a number of photos to put on his lifeline, one of him with his siblings, of the house he grew up in, of his graduation from special education, of him with his

parents, and of him with Danielle and her husband at their daughter's wedding. He asked me to write on his lifeline: his birth date, the name of the town he grew up in, the name of the first workshop he went to, "*graduation*", "*mom and dad passed away*", "*lived with Danielle and her husband*", the name of the 94 bed facility, the name of his current home and the organization he lives with, and "*wedding*". He picked different colored markers and drew circles around each life event. He titled his lifeline with his own name and added a smile face to it.

B. **William**

I used to have family; all my family is up in heaven now.... Now I ain't got nobody....It is a hard thing to say.

I don't know what is going on about that Dixon. Oh, that is a tough life out there.

1. **Background**

William is a 71 year old African-American man. He is partly bald with a short beard. He wears glasses, dress shirts and, when he goes out, a fanny pack. He lives in a group home run by a large community agency that supports people with intellectual and developmental disabilities on Chicago's north side. He has five housemates, two women and three men. William visits a day program run by the same community agency. He enjoys drawing, playing his harmonica and eating potato salad but hates sauerkraut. William is his own guardian. According to his records he has a mild intellectual disability, a 'schizoaffective disorder' and a seizure disorder. He also has a mild hearing loss, osteoarthritis and gastritis. William said he does not consider himself old. He mentioned he does not want to be old like his dad was, namely drinking whiskey: "*I am glad I don't drink that stuff. Not me. That is for the old men to drink, not for me, it ain't.... I don't want to be old like that.*"

William is not in the best health. The winter before our interviews he was hospitalized for a few weeks with a minor illness and shortly after our work together he spent some time in the hospital and in a rehabilitation facility.

Louise was William's key support person throughout the study. She is a 49 year old African-American woman who worked as a direct support person at William's home for the last five years but has known him for 14 years. Louise was involved and supportive throughout the research process. She seemed receptive of William's needs and supported his decisions in a way that promoted his self-determination. Louise came across to me as caring for William and involved in his life. Her respectful engagement with William made a positive impression on me. William is a very friendly and soft-spoken man. He is polite and somewhat shy, has a calm demeanor and startles easily. He does not like it when his surroundings are loud or chaotic. William was a pleasure for me to work with.

William seemed excited to see me and to participate in the study. At first I had some doubt whether he fully comprehended the informed consent process. I took additional time to go over the consent forms with him and Louise. I made sure to repeat that his participation was voluntary. During our different meetings I tried to ensure he felt comfortable. He repeatedly affirmed that he was having a good time. I asked questions that William would understand. He often jumped from one topic to another. It seemed his memories started to surface but he spoke slowly and it took some time to fully understand what he meant. From my perception I was able to build a good rapport with William and Louise. William's residential manager Andrew was recruited as a third informant. Andrew is a friendly middle aged Caucasian man.

2. Social convoy

I met four times with William. Louise was present during the first two meetings which were in a coffee shop close near William's home. During the first meeting we worked on William's social network map. Louise assisted William with filling out his social network map and giving examples of the types of support his relationships provide him with. According to William, he has no surviving relatives. He has no intimate relationships in the first circle of his convoy. Outside of his housemates and staff he does not have friends. In his second circle William included his housemates who he sees daily. He has known them between five and 10 years. The two overnight staff and the two staff from his day program were included in his second circle as well. He has known them for 5 to 14 years and sees them about four days a week. He also included the residential manager Andrew and Louise in his second circle. In the third circle he included three other direct support staff from his home. He has known these direct support staff members for five years. He sees each of them about five days a week. William also included one housemate in his third circle.

Only direct support staff advocate for William. He is dependent on formal support to meet his needs. Staff takes William home for the Fourth of July holiday, give him reminders to shower and change his clothes, help him purchase things he needs and compliment him when he looks nice. Louise explained that William is considered 'the elder' of the house. When others see something is wrong they will help him. One of his female housemates helps William prepare his lunch and fold his clothes. She can also be bossy with William. They watch TV and listen to music together and sometimes William plays his harmonica for her.

3. Life history

During the second meeting with William and Louise we talked about William's life history. With William's permission Louise brought the 'big black book' with William's records. We could find no information on William's life history in any of his records. He was able to tell us where he has lived, but it remained unclear when he lived where, for how long and in which order. Articulating various life events was challenging for him. Louise was not familiar with his life history. With William's permission I interviewed his residential manager Andrew to retrieve more information on William's life history. We went through William's records again and found some minimal information on his prior residences.

William was born in Chicago during the Second World War. At age nine he was admitted to Dixon state school in Dixon, Illinois.⁴ William mentioned he used to work in the central kitchen of Dixon where he swept and mopped the floors. William said there was a school there where he taught himself to write his name: *"I learned that my own self."* William was not able to share many specifics of his experience at Dixon state school. He did mention some names of people who lived and worked there. He told me: *"That is a tough neighborhood. I don't want to go back there no more.... They steal too much. I used to play the harmonica in Dixon, and then he said "William, how much do you want for that harmonica?", I said "get away from me, you!". I don't want to do that [sell his harmonica], because I am, I don't want to get myself in trouble by nobody.... Oh, that is nasty. It stinks there. Who wants to go back there? Oh no, not*

⁴ The 'Dixon State School for the Feeble-Minded' opened in 1918 and was located 100 miles west from Chicago. In 1970, the Chicago Sun Times published a series of articles by Jerome Watson and Jack Dykinga on the living conditions in the Lincoln and Dixon state schools in Illinois. Jack Dykinga won a Pulitzer Prize for his images of the neglected, naked individuals in these state schools. As a result the state enacted a number of reforms that lead to the closure of these institutions (Parsons, 2011).

me. I ain't doing that job no more.... God, I am glad I am out of that nasty place.... Oh. I don't know what is going on about that Dixon. Oh, that is a tough life out there.... Oh, I used to cry a whole lot out there in Dixon.... No, it is too many fights out there. I am so glad I am not hitting nobody, not me, oh no, not me. [first name other resident] used to be there. He didn't like it there neither.... He used to hit guys out there. I said "oh no [first name resident], you are not going to hit me though".... I had the right to stick up for my own life."

William moved out of Dixon in the early 1970s. After he left Dixon he moved into a nursing home in Chicago together with his mother. He lived there for six years. He mentioned he worked here in the kitchen as well. He said: *"Oh, it is bad there. I wouldn't go back there.... Too many begging, too much, for money all the time".*

He then lived in another nursing home in a Chicago suburb for 13 years. William told me the following about his experience of living with his mother in the nursing home: *"I did not like it, I used to buy my mother a brand new dress and she came in and told me that one of those girls stole it from my mother. I said "no, thank you, this is not your dress, this is for my mother, not for you, no thank you, goodbye".*" He also said a man stole his money when he lived at this nursing home.

From age 47, William lived in five different community integrated living arrangements (CILA's) for people with intellectual and developmental disabilities in Chicago. He lived at the first CILA for six years, in the second for four years, in the third for nine years, in the fourth for three years. And three years ago he moved to his current home. William did not like the CILA he lived at before his current home: *"I am so glad I am out of that place.... Oh, I didn't like it there. They beat me up too much there."*

William reported that his parents and a sister passed away. According to the community agency's records he was the youngest of four children. Supposedly he had a second sister but William has no recollection of this. Furthermore, he does not remember the name of his brother. At first William said his brother died, but at a later meeting he said he wasn't sure: *"Maybe he doesn't want to come see me anymore."* William told me that his father used to drink a lot. He liked his dad though: *"He used to give me some 50 cents and a radio, my dad did yeah."* According to William his father died of cancer while he was living in Dixon. William mentioned that eating sweets was bad for his mom and his sister and that they died because of it. It is unclear when his mother passed away, but William was able to tell me the following about this experience: *"I used to cry all the time when that girl told me, I said 'no, I am sorry, I don't want to hear about my mother dying, no, I don't want to hear that.' ... I didn't like for my mother to die like that. I wish I would have kept my mother. But now it is too late now".* William said he got along better with his mother than with anybody else. He mentioned his sister died after his mother did: *"Now I ain't got nobody."* William repeatedly mentioned the name of one girlfriend he used to have, but it remained unclear where and when he met her and he no longer has contact with her. William said: *"I don't know who I am going to have, I might as well find me a girlfriend if I can't find nobody else for mother."*

During the third and fourth meetings I met with William to work on his lifeline. We worked on his lifeline in the office of his home. William has no pictures of his family or of any events in his past. When asked for a picture of his mother he said: *"I used to have one, someone stole it."* Based on the addresses of the agency's homes William had lived at, I located photos of these locations and printed pictures of what the Chicago skyline and Chicago downtown looked like the year William was born, and a picture of Dixon state school. William recognized the

locations of each photo. The only house he did not recognize was the one he currently lives in as it was a photo of the front door and they always use the backdoor to enter. When Louise found out she told me she would also be taking him inside through the front door so he would recognize his own home. When he saw Lake Michigan on the photo he commented: "*I don't go swimming in that*". William wanted to draw a flower on his lifeline, he also wrote his name and drew a stoplight and a window. He also wrote a mirrored image of the number '3', representing the floor of the first nursing home he lived at with his mother.

William openly talked about sensitive issues with me but he did not cry during the interviews. He was engaged in the research process. Sometimes he would get tired which would signal it was time to finish our meeting. While working with William I sometimes felt like a detective, trying to find information about his life and fitting pieces of the puzzle together. Several months after my work with William, I decided to try to find more information on his family and to my surprise, I found a hand-written record of his family in the 1940 Census. As this Census was done three years before William was born, his name does not appear in the file. From the handwritten record it appears that in 1940, William already had three older sisters though William only mentioned one sister to me. The record shows that William's father was from Georgia and his mother from Oklahoma. William's maternal grandparents were from Oklahoma. William's father was 55 when William was born and his mother 22 when she married William's father. The records state that William's dad was a 'common laborer' and worked at WPA road construction. His mother was a house wife.

C. **Lucy**

Look when I had my Cuddly Dudley.

1. **Background**

Lucy is a 51 year old Caucasian woman. She is small, with short brown hair and lives in a one-bedroom apartment in a large Chicago suburb. She receives a section 8 voucher.⁵ She has a mild intellectual disability and no additional disabilities. Once a week, a staff member from a large agency that serves persons with intellectual and developmental disabilities visits her to check in with her and provide any support she might need. Lucy is her own guardian. Lucy holds a job as a bagger at a grocery store close to her home. She likes her independence, but feels she is alone too much of the time. She would like to be able to participate in more activities such as going to museums, shopping and going on overnight trips, and would like to have more friends to do these activities with.

Lucy told me she is Catholic and believes in God. She would like to go to church but her work schedule prevents her from doing so. She has never dated, but would like to. Lucy stated does not consider herself as having a disability and says if she had a disability she would not know what it was: *“See, I don’t have a disability. I don’t know how I wound up on social security. I still don’t know.”* Lucy said she did not feel any different from other children growing up and that she does not feel she was ever treated any differently. She connects the idea of having a disability with having a physical limitation.

Lucy is open and friendly and seemed excited to participate in the study. She asked Robert, her residential manager from the agency to be her key support person for the study.

⁵ The housing choice voucher program is the federal government's program for assisting low-income families, older adults and people with disabilities to afford housing in the private market (U. S. Department of Housing and Urban Development, 2015).

Robert is a 42 year old Caucasian male. Lucy has known him for six years. Lucy decided she wanted Robert present for our meetings. He was supportive of Lucy's needs and helpful to her throughout the research process. Lucy is very independent and was able to talk to me by herself. However, she felt more comfortable with Robert present so I respected her preference.

2. **Social convoy**

Our first meeting took place at a conference room in the office building of the agency through which Lucy receives services. It took one hour. With Robert's assistance she was able to answer the questions establishing her social network map. Lucy values the relationships with her family members. She is the youngest of her "*siblings*". The three persons Lucy calls her siblings are not technically related to her as they are children of the ex-husband of Lucy's mother and his wife. Lucy was the only child of her mother and father.

Lucy's paid support staff from the agency and her neighbors are important to her as well, but she did not mention any other friends until prompted. She did not include any work colleagues in her social network map.

In her first circle Lucy included her three siblings and two of their spouses as well as two nephews and their significant others. In her second circle she also included family members: a cousin, two additional nephews and their combined nine children and a niece. Lucy also placed her residential manager Robert, her case manager, and one of her direct support staff in the second circle. She also included two neighbors, one friend who also lives with the agency that supports her as well as two former housemates. In her third circle Lucy included her special recreation coach.

Lucy sees one sibling yearly at Christmas time and the other family members even less frequently. She sees her neighbors daily. Lucy speaks to one sibling weekly by phone. She

speaks with all other relatives less than yearly by phone. Lucy said: *“I have local calling so I can’t call her. She can call me but I can’t call her. Cause I don’t have long distance on my phone. I have local calling.”*

She sees and speaks with her formal support staff by phone on a weekly basis. She has known two of her formal support staff and her two neighbors less than five years. She has known all others in her social network map longer than five years. Her formal support staff are located within a half hour drive from her apartment. Two siblings, one sibling in law and her cousin live within a one hour drive, and all other relatives live more than three hours away.

Lucy picked her sister and her sister’s husband as the two persons most important to her. She views them both as providing her with similar levels of support. Lucy considers herself as very independent and stated *“I usually do everything on my own”*. Her sister and her brother-in-law therefore do not provide any instrumental support⁶. Lucy mentions that she gets Christmas gifts from them but they do not provide her with any other material support. Lucy feels that they do provide her with informational support, giving her advice weekly by phone. Lucy provided the following example: *“If you had an argument with your other brother they would give you advice on how to handle the argument. How we could settle this.”* When speaking about emotional support Lucy stated that her sister and her brother-in-law would comfort her when she was upset. For example they came over to tell her their cousin was very sick. When talking about this she mentioned that she was unable to see her cousin before she died even though she wanted to: *“And I really wanted to be at the hospital to see her, I didn’t even get a chance to see her. They were all there, and I guess they were not going to drive all the way up here just for an hour*

⁶ See Chapter II, section D, page 22 for an explanation of instrumental support.

to pick me up and having to turn all the way back around to take me back home because they knew I would probably get upset.”

Lucy’s grandparents died before she was born and when she was very young. She spoke about the death of her parents, aunts and uncles. *“Most, most everybody is gone, except for my brothers and sisters. Thank God ... that I still have some.”* Lucy stated the following about her sister and her brother-in-law: *“They mean a lot to me, they help me, they really do. They are about the only ones. Well, Robert, and [names two other formal support staff].”* Lucy feels she receives enough support.

3. **Life history**

The second meeting with Lucy and Robert took place in the living room of Lucy’s apartment and mostly centered on information about the most important events in her life. Lucy was waiting for me outside and pointed out where I could park. She gave me a short tour of her very tidy and clean apartment. Lucy brought photo books out of her bedroom to the living room. Robert brought information on Lucy’s intake at the agency with him as well as her vocational history since 1990. Lucy has a very good memory and independently provided most details on her life history. Robert assisted only minimally and was able to use the agency’s documents to confirm and supplement Lucy’s information.

Lucy was born in 1962 in a hospital in Chicago. She lived with her parents who moved from Chicago to a west suburb of Chicago. Her father worked as a mechanic for a major American airline. When they had a fire in their house they moved to a trailer park in another west suburb of Chicago. Lucy was about seven years old at that time. Lucy described the entire floor plan of their trailer home in exhaustive detail. Throughout her childhood she was always in special education class rooms in mainstream schools. Lucy cannot remember her experiences at

primary school. She started high school but since the school was too far from home, she changed schools. However, she had bad experiences at this school. She shared how other students set her locker on fire. *“All my books were in it, everything was in it, I couldn’t get into it because the lock was melted. So, I called my dad and said “get me out of the school”, I think I was the only white student in the whole school. It was all black.”*

When she was 15 years old, her father passed away at age 50 from a heart attack. Together with her mom she temporarily moved in with one of her siblings and her brother-in-law. Lucy said she was very lonely without her dad as they had done many things together. After her father’s death she changed schools and graduated high school when she was 18 years old. She had good experiences at this school. She mentioned she sometimes still runs into people from high school at the local grocery store where she works. After high school Lucy received a food service degree from a two-year community college. Her first job was at a hospital where she worked in *“dietary”* and *“purchasing”*. Her mother worked there also and they commuted there together from the trailer park. After a few years the hospital closed and Lucy lost her job.

When Lucy was 22 years old she moved to the campus of a large private ICF/DD. This transition was hard for her: *“Moving away from home was not good.”* Once she moved she was sad: *“Sad, not being able to be with my mom and dad like I wanted to be. After a little while I was able to come out of it.”* Lucy lived at two different homes on the campus of the large private integrated care facility (ICF/DD). Six years after she moved out of the family home her mother passed away at age 66. Lucy was 28 at that time. Four years later she moved to a group home in the community where she lived with three other housemates instead of 12 others. She lived in this home for 10 years until she moved into her own apartment in 2003.

Once she moved to the large private ICF/DD she started working in a restaurant on campus. After that she held a series of short-lived community jobs. She worked in a number of large retail stores and fast food restaurants. She did not hold a steady job until 2007 when she started working at the grocery store where she still works.

When I asked Lucy about the most important positive events in her life she mentioned how she loved the weddings of family members she attended. She said: *“The most important part of the night is when they toss the flowers!”* Furthermore, Lucy speaks fondly of high school reunions she attends with her brother. The most recent one took place three years ago and was the 30 year reunion. When asking Lucy about the negative life events that impacted her the most, she mentioned without hesitation the loss of her job in the hospital, her move out of the family home and her first roommate’s death from cancer.

Based on the information Lucy and Robert provided during the second meeting I prepared Lucy’s lifeline. During the third meeting, which also took place in Lucy’s home, she worked on her lifeline and provided her perspectives on the events in her life. She showed many pictures during the interview. She mentioned she has many pictures and stated: *“Oh, yeah, every day I take them out and I go through them and I am like, “hey look at that”, “look when I had my Cuddly Dudley”.”* Cuddly Dudley was a stuffed animal used as a subscription sales promotional item by the Chicago Tribune in the mid-1960s. The animal was a recurring character on Chicago children's TV for many years ("Cuddly Dudley,").

Lucy did not write anything on her lifeline but asked me to write for her. On her lifeline she included short descriptions of her family home, the death of her parents, the year she lived with her sister and her brother-in-law, her graduation from high school, her first job in the hospital, her move to the campus of the ICF/DD, her move to a group home in the community,

her move to her own apartment, the start of her current job at the grocery store and her last high school reunion. Lucy did not draw on her lifeline but selected pictures to place on it. She decided to include a photo of the family's trailer home that I found on google street view, a picture of a cap portraying her high school graduation, a picture of herself when she was a teenager, and a picture of her father in his army uniform.

Once completed, she asked for the lifeline to be placed on her wall. During the last meeting with Lucy member-checking took place and she received her gift card. During the member-checking Robert was not present.

D. **Charlotte**

My mom called me Schätze.

1. **Background**

Charlotte is a 58 year old Caucasian woman. She is small and has short grey hair. She loved my audio recorder and operated it during our meetings. Charlotte has a mild intellectual disability and said she has been diagnosed with depression for which she takes medication. She lives in a home on the campus of a large private ICF/DD in a suburb far north of Chicago. She attends a workshop on the campus daily. She is not a member of any community groups and all her activities are organized by the staff of her home. Charlotte is Catholic and has attended church her whole life. She said the following about her disability: "*So I have one brain on this side, and not on this side.*" When I asked her whether she felt any different from her sisters growing up she said: "*I mean, I am not that, like them*". When I asked her what that was like she said "*Pretty bad. A bad feeling. I wish I could have done more.... Like driving cars.*" About growing older Charlotte said: "*I am scared that something will happen.... Uh, maybe, it's a drug or a heart attack. I don't know.*"

Charlotte asked Lauren to be her key support person. Lauren works as direct support staff at Charlotte's home. She is African American and 55 years of age. Both Charlotte and Lauren were friendly and easy to talk to. Charlotte independently answered my questions and asked Lauren for help when needed. I met with Charlotte four times in total. Lauren was present for the first two meetings.

2. **Social convoy**

We completed Charlotte's social network map during the first meeting in a meeting room of the administration building of the ICF/DD. Charlotte included her sister and her brother-in-law, their son and his wife and their two children, Lauren, and her best friend in her inner circle. Charlotte's best friend lives in another home on the campus. Her sister helps clean Charlotte's room, takes her shopping and out to eat. Her son and his wife come pick Charlotte up and take her home with them for a visit; they shower her with gifts for her birthday and at Christmas time. Lauren supports Charlotte with her finances and with meal preparation. She encourages Charlotte to eat well, to participate in activities and discusses with her how to avoid conflicts with her housemates. They like to play card games together.

In her second circle Charlotte included her other sister and that sister's daughter, her first sister's second son and his wife and another staff member. Charlotte said the sister in her second circle became an alcoholic and that they have a distant relationship. In her third circle she included her mother (who has Alzheimer's disease and lives in a nursing home), two housemates, and her support staff at work.

Charlotte sees her staff, housemates and her best friend on a daily basis. She sees the sister she is close to between weekly and monthly and speaks to her by phone twice a week. She sees her other sister a few times a year and does not speak to her by phone. Charlotte no longer

sees her mother. She sees her nieces and nephews and their children a few times a year at family events and speaks to them by phone with similar frequency. All Charlotte's family members live about an hour away. She feels she receives the support she needs. At the end of our first meeting Charlotte gave me a hug.

3. **Life history**

During our second meeting we talked about Charlotte's life history. Lauren brought a book containing Charlotte's case files. Upon her return she was accompanied by a member of management. The manager told me that only Lauren could look into the files. I assured her I would not look in the files⁷. Charlotte could tell me about the places she had lived, but not the dates or how long she lived where. Lauren could not find very much information on Charlotte's life history in her case files. What she did find confirmed what Charlotte told me.

Charlotte was born on Chicago's south side. She said she lived with her parents and two sisters in a bad neighborhood: *"There was a lot of fighting going on, the police always came."* Her father was a butcher and her mother worked as a banker. A friend cared for the girls while their parents were at work: *"She would drive us around and go to different places, a restaurant"*. Charlotte's parents were both born in Europe. Her mother was from Germany and her father from Poland. Her father called her *"cookie"* and her mother used the German word of endearment *"Schätze"* which means 'sweetheart' or 'mother's darling'. When Charlotte was a child her mother took her on three trips to Berlin. Charlotte still knows some German and got very excited when I told her I speak German as well. She enthusiastically shared her German vocabulary with me. Charlotte had a good relationship with her father growing up: *"Back in the garden I helped him collect the grass and talked with him, you know. He was funny."* Charlotte

⁷ As Charlotte is her own guardian, I felt she should be the one deciding who could take a look at her files. Hence, I considered the response of the manager inappropriate.

said she did not know her grandparents but that she was close to her mother's sister and to her father's brother. Charlotte played the piano and won a recital once in grammar school. None of her staff knew about this. After living on the south side the family moved to the north side of the city. Charlotte does not remember participating in any community activities growing up except for attending church.

When Charlotte was 15 years old her parents were divorced and her father remarried. After the divorce Charlotte lived with her mother and two sisters. They moved to another home on the north side of Chicago. She lived together with her mother when her sisters moved out. Graduating from school was one of the most positive events in her life. After graduation she volunteered at a hospital for many years. She also attended Jewish vocational services. Charlotte then lived independently in an apartment in a suburb northwest of Chicago. She moved there when her mother went into a nursing home. She only visited her mother a few times after that. Her mother's illness progressed to the point where it became too difficult for Charlotte to see her. Charlotte did not work when she lived in her own apartment.

Eight years ago she moved to the home on campus of the ICF/DD on the initiative of the sister she is close to. Charlotte said it was hard to move here as she could not bring her cat with her. She said she has more friends where she lives now as there are more people she has regular contact with. Her father passed away a half year before our work together. She said she was unable to say goodbye to him: *"I had wanted to see him, but it wasn't a good time."* It did not become clear to me why it was not a good time for her to see her father.

Charlotte said she has had two boyfriends. She shared: *"I always wanted to get married, but it hasn't happened either."* During one of the interviews Lauren told me that Charlotte had had a crush on a staff member. Charlotte told me she can now only say *"hello"* to this person.

During our third meeting Charlotte and I worked on her lifeline for about an hour. She seemed to enjoy the process. She wrote “*Chicago*”, the name of three streets she lived on, “*graduation*”, “*mom and dad divorce*” and “*dad died*” on her lifeline. She included a photo of two children in her family on her lifeline. She also included three photos of homes she lived in that I had located. With my assistance she also drew a picture of a German flag and a graduation hat on her lifeline. She chose the title “*Picture of my life*” for her lifeline and asked me to write it for her.

When we were done Charlotte asked me my phone number and said she would like to call me “*as we are friends now*”. I gave her my business card. I met with Charlotte a last time to do member checking and provide her with her gift card. Several months after our last meeting, one of the managers of the organization contacted me as Charlotte had been asking about me.

E. **Barbara**

You are not a disability and you are person second, no, it is the other way around.

1. **Background**

Barbara is a 55 year old Caucasian woman. She is tall and has short light colored hair. She has a pleasant personality, is sassy and energetic. Barbara is very direct and can be a little blunt. She will tell you what she thinks and be frank with you. Sometimes she is somewhat insecure, but when you provide her with support, it instills confidence in her. Barbara has a mild intellectual disability and has been diagnosed with depression for which medication has been discontinued. She has tardive dyskinesia caused by medication. Furthermore, she told me that she is impacted by TMJ and has severe pain in her jaw. Barbara lives in a group home in a suburb north of Chicago run by a large private ICF/DD. During the day she does mail runs on the

campus of the ICF/DD. Barbara loves cats but said she is not allowed to have one in her home. Barbara told me she is not religious and that she does not go to church.

Barbara selected Diana as her key support person. Diana is a 54 year old Caucasian woman who, in her role as direct support staff and management of the ICF/DD, has known Barbara for 19 years. I met with Barbara five times and Diana was present for the first four meetings. These took place in Diana's office and the last was in an empty room of the administrative building of the ICF/DD. Barbara was always drinking a can or bottle of soda during our meetings. She asked Diana to help her during the completion of her social network map and during the life history interview. Diana drew on Barbara's case files to assist during the interviews.

2. **Social convoy**

We completed Barbara's social network map during the first meeting. Diana helped where needed but it was Barbara's perspective that was captured in her social network map. Barbara placed her two half-sisters and her best friend in the inner circle of her convoy. One half-sister has the same father as Barbara and the other has the same mother. Her best friend used to work with her. In her second circle she included two direct support staff, her horseback riding instructor, three of her housemates, one former housemate, her niece, two friends who also have a disability, and the receptionist of the administration building of the ICF/DD. In her third circle she included her stepmother (her father's widow), her stepsister, her brother, and two other housemates.

Barbara sees the three women in her first circle less than yearly as they all live out of state. She has not seen one of her half-sisters for four years. Barbara said she misses her terribly. She sees her niece and her brother less than yearly as well. She sees all her other relations

between daily and monthly. She speaks to one half-sister on the phone weekly. The other she speaks with only a few times a year. Barbara mentioned she cannot call this sister as she lives out of the country and her home will not let her call out of the country. Barbara speaks to her friend in her first circle and to her brother monthly by phone. Barbara said it is hard for her to get a hold of her brother. She visits her stepmother and stepsister (who live together) every other weekend and speaks to them by phone weekly. Except for one housemate and one friend with a disability she has known everyone in her social convoy longer than five years.

Barbara is closest to the half-sister she speaks to most frequently. Barbara explained her best friend supported her when her parents died: *“She was good when my mom passed away and she was good when my dad passed away.... I don’t know exactly what she said word by word but she just talked to me.”* Barbara said that it is hard for her friend to support her in other ways since she lives out of state.

3. **Life history**

Barbara was born on the East Coast. When she was born, her mother, father, brother and one of her half-sisters were part of the household. Her grandmother used to babysit her. Her father was a very well-known writer. When she was 13 years old, Barbara enrolled in a private boarding school for children with disabilities on the East Coast near where her family lived. She attended for four years, though she came home regularly. Barbara said going to boarding school was a difficult transition for her: *“I was homesick the first day, they dropped me off, because I wasn’t used to my parents, you know, just taking, dropping me off and then leaving me there.... And when my mom first took off, I was upset, I went to the ladies room and I was crying because it was the first time I had ever been away from home.”* During her time at the boarding school her parents divorced which was also difficult for Barbara. After leaving the

boarding school she lived at another boarding school for a year. Barbara said she and her dad did not like the woman who ran this school: *“My dad couldn’t, could not stand her. I don’t know why he put me there when he didn’t like the lady who ran it! That doesn’t make any sense. But my dad and my mom did try other programs, they would not put me in. They didn’t think they would be the right programs for me. There were other programs they looked at and they said “I am not putting Barbara there”. ”*

When I asked Barbara how she experienced her disability growing up she said: *“It was hard because people used to make fun of me.... People used to call me terrible names, they called, me “there is that retard”, and I didn’t like it. I think that is why I don’t like the word.”* When asking about who supported her most growing up, she said the following about her family: *“They didn’t really help me, I was mostly in programs most of my life.... So they really didn’t help me much, I had programs that helped me.”*

After leaving the second school she attended Barbara lived on the campus of an organization supporting people with disabilities for seven years. Barbara said she did not like living there at all: *“I wasn’t there for very long, I didn’t like it because I had to be with these old folks, and they had more disabilities than I did”*. During this time she volunteered at a child development center as a teacher’s aide. She also worked at a flower shop during this time period, and that is where she met her best friend whom she is still in contact with. Barbara made one more friend there too; she died from breast cancer several years ago.

After leaving the campus Barbara lived in her own apartment for about nine years. Then when her father moved to Illinois 20 years ago she moved to the group home of the ICF/DD: *“And I came and I was really homesick cause my, I didn’t, it was hard for me to say goodbye to my dad and to my mom at the time.”*

In the past twenty years she has held various jobs, both on and off campus. In the community she worked at a fast food restaurant, at a school to prepare lunches, and at a library. Barbara refers to all the places she lived as “*programs*” not “*homes*”. Barbara once traveled out of state to attend a meeting of People First. She mentioned the following about this: “*I spoke because, they had the thing called People First, you are a person before your disability.*”

Barbara has had boyfriends even though she does not currently date. She told me about some negative experiences she had had dating.

Barbara’s mother died about ten years ago. Her father passed away about nine months before our meetings: “*It is still hard for me to go to my stepmother and my stepsister’s house to visit them for the weekend or whenever I go there because I am so used to seeing my dad being there and I know that sounds crazy but it is hard, you miss a loved one, and they are not there anymore.*”

Barbara told me about the difficult relationship she had with her father. According to her he did not have much patience with her: “*I still, I still love him even though he did those nasty things to me, I mean, I felt embarrassed when he called me stupid, because you are not used to having you one of your own parents calling you stupid, I am not stupid. I might have a learning disability, yes, but that does not make me stupid.*” Barbara told me that her father used her name in one of his books, she also repeatedly mentioned the memorial service that was planned for her father in the near future.

When we worked on Barbara’s lifeline she brought a large number of photos. Diana started going over them with her. Barbara was able to name everyone on the pictures, even the ones that were 40 years old. She seemed to have fun with the process. She selected 10 pictures of herself with family and friends she wanted on her lifeline. Diana also photocopied Barbara’s

convoy to include on her lifeline. Barbara wrote the names of the six places she has lived on her lifeline in purple and shaded it with a purple pastel. She also wrote the name of her horse and her trainer on her lifeline. She titled her lifeline “*The wonderful purple life of Barbara*”. Barbara picked a gift card for McDonalds.

F. **Philip**

I would rather be in heaven with mom and dad.

1. **Background**

Philip is a 52 year old Caucasian man with Down syndrome. He has a mild intellectual disability and some hearing loss. He is a resident of a large private ICF/DD in a suburb north of Chicago. Charlotte is one of his housemates. Philip has a sense of humor, he impersonates those he has had conversations with. He will also wish you a Merry Christmas in the middle of summer.

Philip selected Andrea to be his key support person. Andrea is a 29 year old Caucasian woman who has known Philip for two years as his case manager. I met with Philip and Andrea four times. All meetings took place in Philip’s rooms in the nursing home where he was recovering from foot surgery. During the course of four weeks Philip changed rooms three times. Since his leg was in a cast he was temporarily using a wheelchair.

It was challenging for Philip to answer questions about his day-to-day life because it was interrupted by his stay in the nursing home. He also was distracted very easily and had trouble staying focused on topics at hand. Andrea regularly redirected him to our conversations. I was worried as to whether Philip was enjoying our work together, but Andrea told me that Philip asked about me every day and inquired when I would come see him again. Sometimes I had trouble understanding Philip because of his unclear speech or would simply not understand him.

Andrea was able to facilitate our communication. When I explained to Philip that I was interested in speaking to people with disabilities, he was very adamant that he does not have a disability. Andrea explained to him that I meant Down syndrome, but Philip said that is not a disability.

2. **Social convoy**

Andrea's assistance was needed to complete Philip's social network map during our initial meeting. Philip has no contact with any surviving relatives. One remaining aunt (his mother's sister) passed recently away. In his first circle he included Andrea and one other direct support staff (Lauren, who is also Charlotte's key support person), as well as a good friend of his deceased aunt. In his second circle Philip included four direct support staff. In his third circle he included one additional direct support staff and his seven housemates. His aunt's good friend is the only person Philip has contact with outside of his direct support staff and housemates with disabilities. He has known her for about 20 years and sees and speaks to her on the phone monthly. Even though Philip is his own guardian, she helps him make financial and medical decisions. She also gives him birthday and Christmas presents.

Philip has known most of his direct support staff between five and 10 years. With the exception of the period of his stay in the nursing home, Philip sees his direct support staff between two and five days a week and his housemates daily. Andrea and Lauren provide most support to Philip. They help him with cleaning, cooking, bathing and other activities of daily living. They also provide him with emotional support, motivate him to eat healthier and go on weekly outings with him.

3. Life history

During the second meeting we discussed Philip's life history. Philip was able to tell me some details of his life. Andrea had Philip's casefiles to access additional information. Philip was born in a suburb north of Chicago and was his parents' only child. He grew up with his mother, father and a dog. He attended a local elementary school, junior high school, and high school, where the field trips were his favorite activity. He said that schoolmates made fun of him: *"They called me retarded.... My parents were pissed."* Growing up, Philip was an Eagle Scout and a member of a local church youth group (he was raised Catholic). Philip got excited when speaking about his parents being excommunicated from the church. He kept repeating it over and over: *"They wanted to change something we got very upset and we were discommunicated because they didn't agree with my parents... My parents were troublemakers, they wouldn't do what they were told from the church."*

Philip was close to his father. They attended the Thanksgiving Day Parade together each year and kept albums with pictures of the parade floats. Philip did not like at all that his father smoked. Philip said both his mother and her sister were *"a bowl of fun"*. His maternal grandparents died during his junior year in high school. His paternal grandparents as well as the other relatives on father's side of the family lived on the East Coast and Philip did not have much contact with them outside of visits during summer vacations.

After high school Philip stayed at home with his mother. According to his files he was not expected to do any chores around the home. A few years before his mother died he began with vocational training. Over the years he has worked at restaurants. Now he works at a day program on the campus of the ICF/DD which he does not like very much: *"Well when there is nothing to do we are just sitting there falling asleep.... It is irritating."* According to Andrea he

does not want to do the work because he does not like it. When talking about retirement Philip kept mentioning that he cannot retire because *“they keep raising the age limit”*.

Five years after his mother’s death, his father passed away and Philip moved to a house on the campus of the large ICF/DD. He moved homes once on campus. His parents’ deaths and his move to the ICF/DD were very upsetting to him: *“They are gone.... That is why I am so upset. Because, your parents are dead, you must live at [name ICF/DD] for the rest of your life. I would not accept it.... I would rather be in heaven with my parents.... I had a cherished life and then when it was taken away from me when my parents died.... When my parents died I had to go to a whole new life here.... I was angry.”* When I asked Philip if his parents had ever talked to him about the future he said: *“Because they were told ... that your child has to go away from you forever.... They did not have a choice. I did not have a choice. My parents did not have a choice.”* Philip told me that the house he grew up in is no longer there: *“My house is destroyed.... When my parents died, they, they got rid of my house.”*

Creating the lifeline did not appeal to Philip. He was not sure what to write or draw. Even though I rolled it out during our last two meetings, he did not use it. His direct support staff had not been able to find his photos in his room at the ICF/DD. Maybe the use of pictures would have made the process appeal to him more. At the last meeting Philip started to repeat things he had said before. In a way this functioned as a member check.

G. **Betty**

What Amanda means to me? Love. Happiness. We had good times growing up. And I thank her for when she came back to be here with my parents, when they passed away.... And I am very happy with her. She, we do things together. We are happy, we have a happy life here.

1. **Background**

Betty is a 66 year old Caucasian woman. She has a mild intellectual disability caused by her premature birth. Betty was diagnosed with bipolar disorder 10 years ago. She lives in her family home with her sister Amanda who is five years her junior. Betty and Amanda are both very friendly. The two sisters have a very close mutually supportive and respectful relationship. Amanda is Betty's guardian and was her key support person during the study. She was at all four meetings, all of which were at the kitchen table of their home. Amanda was very hospitable and made me feel at home. I have known Betty and Amanda for several years. They were research participants in a previous study I worked on, and I had interviewed Betty twice before.

Betty is extremely talkative and has a very good memory. She recalled the names of all the children she used to play with in her neighborhood in the fifties. It was interesting to observe Betty remembering events that Amanda did not. In those instances our conversation would turn into a family reminiscence session. Sometimes Betty would mention two events that happened decades apart in the same sentence. Amanda would clarify the chronologies for me. When Betty could not find a word she was looking for she turned to Amanda for assistance. They finished each other's sentences on several occasions. Amanda helped Betty answer questions, but when I asked Betty a direct question regarding how she felt about something, Amanda gave Betty all the room needed to provide me her answer independently. Amanda was involved in the process without being overbearing.

Betty works in the restaurant of a large private ICF/DD in a suburb north of Chicago five days a week. Betty participates in special recreation activities at the park district and goes on

weekend trips. When Amanda travels by herself Betty stays in a group home. Amanda and Betty have always loved pets and they have two cats.

Amanda said their neighborhood has changed drastically over the years. The population used to be primarily Caucasian and the family knew all the neighbors. Currently there are large Hispanic and African American populations and Betty and Amanda no longer have relationships with any of the neighbors.

In recent years Betty had a boyfriend but she is no longer in touch with him. Betty said she does not have interest in dating again: *“I am happy with my life, I am single.... I don’t have to worry about babies and things like that, because I know I couldn’t have one. And, I have my freedom, I have my friends.”*

When I asked Betty about what it means to grow older she said: *“You feel older, in your bones and someday I will be old, but I still have got my youth! I am still going.... Think about all the times that you did many things, and you are getting older and you slow down a little bit more.... Your body. It changes. You get wrinkles. Of pictures of older people how long they lived, and your face changes a little bit, you get a little, and I hope I will always have this look but I won’t, I will be old, get older and change and everything. My face, and I am happy. When I change, I am still happy.”*

2. **Social convoy**

I completed Betty’s social network map with Amanda. In Betty’s first circle Amanda included herself and her son who lives on the East Coast. In her second circle Amanda included their aunt and uncle, 10 of their cousins, three direct support staff from the large private ICF/DD, four of Amanda’s old childhood friends who are Betty’s friends too, five peers with

disabilities who work at the ICF/DD, and two friends who work at the local park district. In Betty's third circle Amanda included Betty's social worker and two old family friends.

Betty sees Amanda's son yearly and speaks to him by phone once a month. She sees all other relatives less than yearly and speaks to them by phone a few times a year. She sees the old childhood friends and family friends once to a few times a year and speaks to them with similar frequency. Betty sees her social worker once a week, her friends from the park district two to three times a week, and her peers with disabilities and direct support staff five days a week. Betty has known her social worker for a year and everyone else in her network for five years or longer.

Amanda provides the most support to Betty. She selects her clothes to wear and prompts her verbally to dress, shower and prepare food. Amanda also supports Betty financially. Betty always tells Amanda about her day when she comes home. The sisters do most things together, including grocery shopping, going to the mall, seeing movies and going to concerts. Betty is also close to Amanda's son. He buys her presents and helps her when he visits. He also helps Betty pick out Christmas presents for Amanda.

3. **Life history**

Betty was born in a suburb north of Chicago. Amanda told me that her parents were in an auto accident caused by a drunk driver. This sent her mother, who was pregnant with Betty at the time, into premature labor. Betty spent the first months of her life in an incubator. When she was three or four years old her parents bought the house they still live in today. Shortly after, Amanda was born.

Betty's father had a doctoral degree in biochemistry and was a research scientist at a local laboratory. Her mother completed some college coursework and became a housewife after the

children were born. The family took road trips each summer and visited all of the continental United States. Betty told me the following about one trip to Yellow Stone Park: *"We stayed at a cabin. And we saw the bears and they tell them 'don't feed the bears' because they will tear up your car. They were walking down the road.... Don't feed them! Don't feed them."*

Growing up Betty was in church groups (she grew up Presbyterian) and was in Brownies and Girl Scouts: *"I like camping with the Girl Scouts. We had a tent, and a park up here. My mother was a Girl Scout leader. And helped out."* Betty played with the children in the neighborhood: *"I had friends around here that I played with."* She also had a number of boyfriends growing up.

Betty was close to her father. He taught her how to tie her shoes and ride a bicycle. They also worked in the garden. Betty said: *"'And he planted tomato plants, and was showing me how to do it when I was a little girl."* Before Betty went to school he taught her to write her name, address and phone number. Amanda told me that when it became clear Betty was not able to keep up with school work, her father invested time supporting her: *"He had reading books that she had in grade school and he would sit and work with her to try to teach her to read. Well, that did not work very well, because she just couldn't learn that."* Amanda said that Betty's disability became apparent at this time: *"I think it was a big blow to both of my parents. Because they didn't understand initially, how it happened.... And then they did finally figure out what caused it. But they never discussed Betty's disability to their relatives."*

Betty told me she attended special education classes: *"And I was slow and we had special classes.... I could not read the stuff so the principal found down this school, and they had children like me, slow, and would I like to go there? Make it more easy on me. So we went there."* When I asked Betty what her disability was like for her parents she said: *"I think it was*

hard for them for a while. My dad tried to teach me to read and write.... I tried and I couldn't do it. And my dad and mother understood."

Betty said the following about how her childhood friends viewed her disability: *"They knew it that I was slow, but that didn't bother them."* When I asked Betty whether her disability ever bothered her she said: *"Maybe when I got a little older. I realized that I couldn't read or write. And I'd say, I would always think, "why couldn't I read and write like those other children?"."* This question and Betty's answer evoked an emotional response in Amanda.

Betty was very close to both her grandmothers. Her paternal grandparents owned a lake cottage over in Indiana and the family spent time there. Betty said she had a good time there: *"And then my grandfather and my dad would go out fishing, and ice fish on the dock. Showing me how to fish. And they put the worm in my hand."* Betty and Amanda also visited their other grandmother for several weeks at a time. Both grandmothers died when Betty was in high school. Betty said the following about one grandmother: *"It was very sad, because I missed her, when we did things together"* and this about the other grandmother: *"She died first and she was nice too."* Betty and Amanda were also close to several aunts and uncles.

When Betty was sixteen years old she attended to school part-time and worked at a nursery school part-time where she assisted with child care. According to Amanda, Betty loved her work there and became close friends with the women who worked there. Betty worked at the nursery school for about 10 to 15 years. She started working there full-time after graduating from high school. Betty told me the following about her graduation: *"My cap was blue, and yellow, and orange. And my dress was blue and my shoes were blue. And my uncle [name uncle] came to my graduation."* Amanda got married a few years later and moved across the country. Amanda had one son and her marriage ended in divorce.

Amanda told me what happened after the director of the nursery school passed away: *“The College of Lake County took over the nursery school and they didn’t want anybody like Betty there. So they let her go. And that was very crushing for her. And for my parents.... I often think, I wonder, if they had any idea what they did. I don’t think so.”* There was no longer a place for Betty. For the next several decades Betty lived at home with her parents without another job or daytime activity. She went on several trips to Europe with her father. She enjoyed that travel.

When their mother developed Alzheimer’s disease their father became a caregiver for both his wife and daughter. When their father was in a serious auto accident, Amanda came back home for three months to support Betty and their mother. When their father was released from the rehabilitation facility Amanda left and arranged for a live-in caregiver. Over the course of several years a number of caregivers lived with the family. Amanda and Betty told me long stories about several negative experiences they had with these caregivers. One of them was constantly using the family’s home phone which increased the phone bill. Another one stole from the family. Amanda said the severe stress from this situation caused her to develop Crohn’s disease. When their father had to undergo surgery, Amanda came back home for another three months. Their father then also started to develop dementia. Amanda still lived across the country and this situation started to weigh on her: *“I felt terribly guilty but I thought you know, what am I going to do? I have my job over here, I have, I own a condominium....I have a son in college. I have to maintain my life too.”* Betty also had a hard time with the aging of her parents: *“Both my parents got real ill.... I was sheltered a lot. I didn’t go anyplace or do anything. Because they couldn’t get out of the home.”* Their mother passed away ten years ago and their father a few months later. Betty said the funeral was *“very sad”* but that *“there were beautiful flowers”*.

Amanda came home after their mother died and stayed until three months after their father died. Amanda told me: *“And then I went back [to her home on the other side of the country] for three months, thinking that I could stay there and just have these caregivers and I came back and I realized, you can’t do this, you know Betty needs too much, and you can’t leave the house in the hands of a caregiver.... So, I, it dawned on me, this isn’t gonna work. You are going to have to go back there and stay.”* Amanda decided to permanently move in with Betty and gave up her job as a nurse. Amanda decided it would be good for Betty to have activities during the day so Betty started attending a day program. It was a difficult transition for Betty at first: *“I was scared”*, but now she thoroughly enjoys it: *“I have a lot of friends.”*

We looked at some pictures but Betty decided to draw on her lifeline. She drew her house, the lake cottage, their boat, her mother and father, one grandmother playing the piano, one grandmother playing cards, her graduation cap, herself at her sister’s wedding, her three friends (who are her sister’s friends too), herself as a Girl Scout, the family car, and their two cats. She also wrote the name of the nursery school where she had worked on her lifeline. We included an image of the map of Europe as a representation of the trips she took there with her father and an image of the logo of the ICF/DD where she works. We completed the lifeline by shading the paper so the end result looked very colorful.

H. **Roger**

Why did they send me away?

1. **Background**

Roger is a 67 year old Caucasian man. He lives in a group home run by a large community agency that supports people with intellectual and developmental disabilities on Chicago’s north side. Roger is one of William’s housemates. He has a mild disability with no

additional disabilities. Like William, Roger also selected Louise as his key support person.

Louise has known Roger for nine years.

Roger has a great sense of humor, is positive and optimistic. His personality is endearing. He was always cheerful and liked to joke with me by saying something like: *"You work hard. You should, you should get a raise."* He also regularly gave me compliments about my appearance. I met with Roger a total of five times. Louise was present during the first two meetings. As with William, we met in a coffee shop for the first interviews and worked on the lifeline in an office of the group home. Roger has no teeth which sometimes made it a little difficult for me to understand him. After one of the meetings I played back the recording for Roger and he heard his voice for the first time in his life. This made for a good laugh as it made Roger realize the extent of the monotony of his voice.

During the course of our meetings I developed a good rapport with Roger. He greeted me with enthusiasm and told me *"I made his day"*. Roger told me that I would be a good counselor because *"I ask good questions"* and, according to him, listen to what he has to say. During our last meeting he asked me if I could be his case manager and I had to explain to him again the purpose of my presence.

Louise told me that Roger sometimes solicits and has a history of prostituting himself. When I asked Roger about dating his former girlfriend, he told me the following and gestured to his crotch: *"I don't like it, it's sick you know. It's sickening, you know, what she does to you. I am not used to it."* When I asked him if he does not like to be touched he said: *"I never did."* He then proceeded by telling me about a sexual encounter in a car with a man he did not know. Roger said he has a girlfriend who lives outside of the city, but that he has not seen her for a long time. I could not get him to elaborate on this.

At his previous home Roger was not allowed to leave the house. He is now allowed to walk independently through the neighborhood and go out for coffee or a beer: *"They let me go out more.... I have more freedom."* He agrees in advance with the direct support staff on a time that he needs to be back home from his walks. Louise told me that the direct support staff tries to educate Roger on acceptable behavior. They also try to protect him, as Roger has been harassed on the street. Louise said: *"He said some guy hit him across the face with a tennis racket ... people ... think that the disability population, that they are some kind of circus or whatever."* Louise told me the direct support staff also needs to make sure Roger comes home regularly to change his clothes as he has limited continence. Roger is Catholic and attends church regularly.

2. **Social convoy**

We completed the social network map during the first meeting. Louise assisted and checked with Roger on certain questions. Roger included his two living brothers, his case manager, a former direct support staff member, and a female housemate (who he used to date) in his first circle. In his second circle he included three other housemates and three direct support staff (including Louise). In his third circle he included four more housemates and one direct support staff.

Roger sees his housemates daily and each of his direct support staff five days a week. Every few months he sees the former direct support staff member in his first circle. He does not see his brothers regularly. Before a recent visit he had not seen either one of them for over six months. He talks on the phone twice a week with one of his brothers. This brother will talk to Roger when the staff tells him about problems. He also sends Roger pocket money twice a month. Louise feels his brothers do not provide enough support to Roger. Roger has known the direct support staff since he moved to the group home seven years ago. He has known his

housemates for twelve years as they used to work in a workshop together before they became housemates. The female housemate Roger is close to helps him fold his clothes, gives him a hug when he needs one, makes him coffee and listens to music with him. They also go to McDonalds or Dunkin Donuts together.

3. **Life history**

Roger was able to share many details on his life history and gave me permission to look into his casefiles to confirm these and find additional background information on him. Roger was born on the south side of Chicago as one of four sons of the family. He has a surviving older and younger brother. His twin brother who also had a disability lived in an institution downstate but passed away decades ago. Roger used to visit him.

His father was a truck driver and his mother worked at a factory that produced electric home appliances. They were divorced when he was young. Roger told me his father used to drink and hit his mother but never hit the children. His mother later remarried. Roger told me his aunt used to take care of him. When I asked him why his aunt took care of him and not his parents, he said: *“Because mom and dad got divorced and they got into a fight, and the police came, and they took them to jail and all that.... It bothered me when I was a little kid.”* When he was nine years old Roger went to what he called *“the Kennedy school”*.⁸ Roger told me the following about moving there: *“I felt kind of bad.... Yeah, I thought kind of “what’s going on”, you know.... In my mind you know.... Yeah, why did they send me away, you know.”*

⁸ The St. Coletta School of Chicago was established by Catholic Charities in 1948. A former barn in a suburb southwest of Chicago was reconstructed into a camp lodge known as ‘Tormey hall’ and converted into chapel, classrooms, dining hall, kitchen, and dormitory for 60 boys. By 1950, three new buildings for 131 boys were ready for occupancy. In the early 1950s the Joseph P. Kennedy Jr. Foundation offered the school \$1,250,000 dollars in memory of navy pilot, Lt. Joseph P. Kennedy Jr., who died in World War II. Two additional cottages and a service building were constructed to house a total of 180 boys and the school was renamed the ‘Lt. Joseph P. Kennedy, Jr. School for Exceptional Children’ (Wissuchek, 1965).

Roger lived at the Kennedy school for 10 years even though his mother took him home on some weekends and during the summer. Roger told me the following about his time there: *“We used to go to church every day.... Every day! ... Every single day! ... Weekends too!”* He said he did not like it at the school and was glad to leave as they were very strict.

After leaving the Kennedy school, Roger lived at a nursing home in a suburb north of Chicago for 30 years where he worked in the laundry. When he was let go, a waitress from a restaurant he used to frequent took him in temporarily. Roger and a roommate then moved into an apartment supervised by a local agency for people with intellectual and developmental disabilities. When his roommate passed away Roger had trouble living on his own despite his brother providing food and spending money. He then lived in two group homes run by the agency that currently supports him. Roger does not remember much about the passing of his parents but told me: *“It is kind of sad you know.... I can’t believe that happened.... So fast.”*

Roger does not have any pictures of his family and said he was sad not to have a photo of his deceased twin brother. He decided he wanted to draw a picture of his family on his lifeline. He asked me to write the names of his brothers on his lifeline and the following message to his deceased twin: *“Write uh, tell him that I am doing fine where I am at.”* He asked me to write a similar message on his lifeline to his parents. Based on the addresses he gave me, I printed four pictures of the places he used to live that we put on his lifeline. He did not want a title for his lifeline or any pastel colorings. Louise said she would ask Roger’s brother for a picture of his deceased twin as Roger wanted to add one to his lifeline. Furthermore, Roger expressed a desire to visit the places he used to live and started making plans for that with Louise.

I. **Matthew**

They had teepees, and we eat out there.

1. **Background**

Matthew is a 69 year old African-American man. He wears his hair relatively short and has glasses. Matthew is friendly and positive despite the challenges he has endured. He is helpful and giving to others. Matthew has a mild intellectual disability and he reported he has arthritis and high blood pressure. He lives in a home run by a faith based non-for-profit agency that supports people with intellectual and developmental disabilities in communities of friendship and mutuality between people of differing abilities. Matthew is his own guardian. He works at a small private liberal arts college in a suburb west of Chicago. His faith is important to him; he has attended church his whole life. When I asked him about his disability, the only thing he said about it is that he cannot read but that it does not bother him.

Matthew asked his friend Sandra to be his key support person. Sandra is a 35 year old Caucasian woman who used to work as staff in Matthew's home still has regular contact with him. They have known each other for 13 years. At first I had some trouble understanding Matthew but Sandra was able to help me understand him.

Matthew was not always particularly talkative but he was very engaged and attentive during conversation. He needed time to respond to questions and carefully crafted his responses. When Matthew got in the swing of telling a story, he shared it in such an engaging manner that I felt as though I had witnessed the event myself. I met with Matthew four times. Sandra was present for the first two meetings. The first two meetings took place in Sandra's office. The other two meetings with Matthew took place in a class room at UIC.

2. **Social convoy**

During the first meeting we prepared Matthew's social network map. Sandra assisted Matthew. In his first circle Matthew included his two half-sisters in Georgia, a staff member at his home, two housemates with disabilities, and two friends who are sisters involved with his faith-based community. Even though Matthew included his two half-sisters in his first circle, he has not seen them in years and never speaks to them. The two sisters from his faith based community live out of state and he sees them a few times a year. He has known them for about fifteen years. He has known the housemates for about five years and the staff member for about one year.

In his second circle he included Sandra, a friend from a local band for people with disabilities, two former staff members, five other housemates, his community coordinator, two current staff members, his accompanier (a friend who accompanies him for community activities) and the former regional coordinator of his community. One of these former staff members he sees on a monthly basis. Matthew only uses the telephone to speak to the other former staff member and to his accompanier. In his outer circle Matthew included one more friend, his reverend, his supervisor from work, a married couple that is involved in his community and one work colleague. He has known the relations in his second and third circle between two and 15 years.

Matthew receives most support from the staff member in his inner circle. She helps him track his health, takes him to the doctor and takes him shopping. She helps him schedule his activities and they go bowling together. She suggests Matthew take a walk when one of his housemates annoys him. Matthew calls her "*his friend*". About one of the two sisters from his

faith based community he said *“that’s my heart right there”*. Matthew feels he receives the support he needs.

3. **Life history**

During the second interview we finished Matthew’s social network map and discussed his life history. Matthew agreed to my contacting his community coordinator to ask whether the community agency had any information on his life history. This source had no information on his life history and there were no other sources of information so it was not possible to cross check any of the information Matthew gave me.

Matthew was born on a Cherokee Indian reservation in Georgia. His father was married twice. Matthew’s mother was his second wife. Matthew said the following about his parents: *“My father he was no good.... I hate that I have his first name, I hate that. My momma she was alright.”* In addition to his two half-sisters, Matthew also had a full sister and a full brother. Matthew was called *“bubba”*, and he still refers to himself by that name. Growing up Matthew picked cotton and played in the woods with his brother. He attended only primary school. He remembered the name of his teacher. Matthew’s maternal grandmother also lived with his family when Matthew was a child. They sat on the porch together and she taught him how to chew tobacco.

Matthew remembers that his grandmother once sent him to a farm to get butter for her to bake cornbread. On the way back he ran into a girl from school he liked and started talking to her. By the time his grandmother yelled that he should come home, the butter had melted. Matthew told her: *“Grandmamma, you saw that girl here? ... That girl got me in trouble....Grandmamma, she was so pretty.”* Once home, she gave him a beating with some sort

of wooden whip: *"She wet it. I couldn't sit down for a week"*. When he saw the girl again, he told her: *"I don't have time for you now"*.

Matthew's father was abusive: *"He beat me up sometimes.... He hit my momma, she would, when was pregnant with me, she, uh, he put my mom down the steps."* When he was nine or ten years old he shot his father: *"He was drunk. And he jumped my momma, he beat her up real bad, he pushed me in the hot pan. I told him what I was saying, "Don't hit my momma no more". I went there and I got that gun and I shot his shoulder."*

Matthew also spoke about his grandmother's death: *"She passed away, see what happened was, my father, they were uh, there were uh, it was snowing, it was very cold outside.... He was so, he were drunk, my grandma she was outside, you know, he wouldn't let her in and she froze to death.... She went outside to get some wood for the fire place.... She banged on the door.... He wouldn't let me let her in."*

Matthew moved to California with his sister and his mother for a short period of time but soon returned to Georgia. Later he moved to Chicago with his sister and lived with her. Around that time Matthew's 17 year old brother was murdered: *"The white boy pushed him on the railroad track. When the train was coming"*. His half-sister in Georgia wrote to Matthew and his sister about what happened. His father died when Matthew lived in Chicago: *"My sister told me he died sitting on a toilet in the bathroom."* Matthew's mother died when she was visiting him and his sister in Chicago. She had a heart attack: *"She fell right into my arms"*.

Matthew said he worked at a food truck at the Dixon state school. When I asked him what Dixon was like, he said *"terrible"*. When I asked him whether he lived there, he said he did not.⁹ Matthew said his sister would take him there. When I asked him whether his sister would

⁹ However, it seems to me that Dixon would have been too far of a daily commute from Chicago.

pick him up after work he said: *“No, I would stay there.... They came to see me on the weekend”*. Matthew said he does not remember much about Dixon. When I asked him why it was terrible, he said: *“The people, you know, they were no good.”*

About fifteen years ago Matthew moved to his current home where he is supported by the agency. His sister passed away a few years after he moved in. She had two adopted children but Matthew does not have contact with them. For years, Matthew worked as a janitor at a school for children with disabilities.

During the third interview Matthew and I started to work on his lifeline. The first 20 minutes Matthew asked me to write and draw and for him but after becoming acquainted with the lifeline process he started to draw himself. We included the name of his hometown, the name of his primary school teacher, an image of the state of California, the name of his deceased brother, the word *“grandma”* for his grandmother, the name of his sister who passed away, the word *“mom”* for his mother and a smiley face *“because she smiled a lot”* and a print-out of the logo of the community organization he lives with. He also drew the sun and the moon and a big ball to portray the city of Chicago. Matthew decided to include six recent photos that we cut from his individual support plan. These photos included Matthew during community activities and with his friends. He asked me to write next to one picture that he misses his work friends¹⁰.

Our last meeting only took a half an hour. Matthew picked a title for his lifeline: *“My home, my family, at [name of his community agency’s home]”*. William said he liked his lifeline and that he would like to be on television. His community coordinator later showed me a photo of a party at William’s house during which he had put his lifeline up in the living room for everyone to see.

¹⁰ As it was summer time during our work together, he was not working his regular job at the college.

J. **Mary**

My advice to you, if you have a friend, any friend, teach them well.

1. **Background**

Mary is a friendly 54 year old African American woman with what she calls a “very mild” intellectual disability. She said that when she was retested she was found to be dyslexic. Her mild depression is treated with medication and counseling. She has arthritis. Mary has an average height and short hair. She recently lost a lot of weight.

Mary asked Rhonda to be her key support person. Rhonda is a 37 year old African American woman who has worked in Mary’s group home as direct support staff for the past three years. Rhonda was not present at any of the interviews since Mary wanted to participate independently. Rhonda functioned as my contact person in the home.

Mary was excited to participate and very talkative. She told me stories about her life with intricate detail. All six meetings took place in the basement of Mary’s group home. Whenever a direct support staff or a housemate walked by, Mary stopped talking and continued when the person had left. It was clear that she valued having her conversations privately with me. We could regularly hear one of Mary’s housemates upstairs scream while having a temper tantrum. This would make Mary feel uncomfortable and put our conversation on hold.

Mary works as a fitting room attendant at a thrift store run by Goodwill Industries five days a week. She enjoys her work but told me that she needs to spend half her salary on her transportation to and from her job. Mary also works for an electrical company and participates in community events that create awareness among the general public on ways to save energy.

Mary identifies as a self-advocate and is part of People First Illinois.¹¹ She showed me a folder with her many certificates and individual achievement awards from disability organizations. This folder is important to Mary: *“You know if I feel like I am in a blue mood, you know, like that, I get out the book and look at my achievements.... Instead of getting upset.... When somebody, you know, teases me or puts me down at work.... Especially this one coworker ... he was calling me the R-word constantly.... I am not taking it very well. It is difficult for me.”*

Mary has a boyfriend who also has an intellectual disability. They have been together for three years. Mary told me the following about intimacy and sexuality at her home: *“Everybody is so used to the taboo quote on sexuality where people with disabilities, just they say “They just know how to hold hands or kiss” and I say “I don’t think so.” They don’t allow us to have sex.... They know there is a lot of boyfriends and girlfriends, except, it is very hard for them to have their privacy, because usually there is a chaperone within 50 to 60 feet.... We try, you know we have to cool our jets and say, because when we try to kiss each other, and we say, “can we have time alone, you know without the staff, can we have a private time?” Except there is a chaperone within a yard’s distance, and that is when I get nervous with him.... It’s complicated. It’s frustrating for me.”* Mary would like to live in her own apartment with her boyfriend with support: *“And don’t worry about anybody says “You cannot do this, you cannot do that”.”* Mary was raised Baptist and even though she does not go to church regularly her faith is important to her.

2. **Social convoy**

In her first circle Mary included her divorced parents, her uncle, her two sisters and her brother-in-law. In the second circle she included a close non-disabled colleague from her

¹¹ People First of Illinois is a group of self-advocates.

work at Goodwill, Rhonda, her three nieces, her two housemates, and her boyfriend. In her third circle she included her uncle's granddaughter.

Mary's mother, sister and niece live together in the Great Plains: *"I call it a generational womanhood house."* Mary sees them once a year. She speaks to them on the phone occasionally. She travels independently by airplane for visits, but her father takes her to airport and helps her to the gate. Mary told me her mother is very sick at the moment, but is expected to recover. Mary sees her father every other week and speaks to him by phone every day. Mary proudly told me that her father made a large donation in her name to the agency that supports her. He provides her material support, appraisal,¹² and informational support: *"He gives me advice almost every other day on how to be careful with men.... And he goes..., "this is all new to me, I don't know how to talk to you about dating". You know this is all new to him."*

Mary sees her other sister and her brother-in-law who live locally a little less than once a month. She speaks to them by phone every other day. Mary told me she speaks to her sister about sexuality. Two of her nieces live with her sister and brother-in-law and Mary sees them when she visits the house. She rarely speaks to them on the phone. Mary sees her uncle twice a year. He travels across country in his RV. She does not speak with him on the phone. Mary sees her uncle's granddaughter about twice a year as well. Mary said she is like a niece to her. Mary sees her colleague, whom she is very close to, five days a week. She has known her for two years. They do not speak by phone. Mary said the following about their relationship: *"We talk a lot She cheers me up.... One time I was crying at work because [name of the colleague] came to my rescue, that is how good of a friend she was."*

¹² See Chapter II, section D, page 21 for an explanation appraisal.

Mary sees Rhonda five days a week. She does not speak to her by phone. Rhonda helps Mary with banking and budgeting and supports her emotionally: *“She says: “Don’t let a bad day make your joy turn sour.”* Mary can also speak to Rhonda about dating and sexuality. Mary sees her housemates daily. She sees her boyfriend every two weeks and speaks to him by phone almost every other day: *“It is part of our arrangement of dating each other.... You know we have to check with our coordinators and our finances in between, and they set up the transportation and where we want to go from going out to dinner to going to movies.”* Even though Mary did not include her boyfriend in her inner circle, he is very important to her: *“The moral of the story is [name boyfriend] has been on my side forever. You know through bad times and good times with my family.”* He provides her with emotional support: *“When I feel I am being crummy or depressed he knows. I said “I don’t want to talk, right now am upset.” Then he says “who are you upset with?” And I said “I am upset with myself”. Then he says, “okay, talk to me”. And I feel a bit better when I talk to him.”* Mary said that she was having some problems with her boyfriend because she saw him talking to other girls: *“I took my pride I got angry with him.... I need to clear my head for a while because I am trying to control that green eyed monster before it gets out of hand.”*

3. **Life history**

Mary was born in a state south of Illinois. Her parents met in college: *“My parents were very young when they had me.... They were sort of scared of me.”* Mary told me she was born full term but was sick with pneumonia and a kidney infection. Mary’s paternal grandparents who lived in a rural area, took care of her until she was 18 months old: *“My dad was still in school, my mom had to be with my dad until she had her second baby, and then when she had her second baby she was okay with having me.”* A third daughter was born shortly after.

When Mary's father graduated from college he had trouble finding a job and the family moved to Illinois where he worked as an engineer. Every summer the girls visited their grandparents in the Great Plains: *"One neighbor had a plum tree.... We would pick them and she [grandmother] made plum jelly"*. Mary's uncle also lived at the house.

Mary said her father did not accept her disability right away: *"He said: 'You should be like everybody else in the family' when I was growing up."* Mary's mother had stopped working to take care of the girls. Mary shared the following about the relationship with her mother: *"I am grateful for her.... She wanted me to get an education.... At that timeframe, they were living, ... you see, in certain states, they don't teach people with disabilities life skills."*

Mary went to special education classes in mainstream schools. She said that the other children did not want to be friends with her because she was in special education: *"I couldn't have friends because of the mental retardation ... I was so different, because I went to special classrooms throughout my life."* She said that her two sisters protected her growing up.

When the girls were between 10 and 13 years old their parents divorced. Their father told them: *"He took us aside and told us that it was hard for my mom to tell us than him.... Because you know here is my mum crying in the room and we thought what's wrong with mommy?... We heard mommy crying all day long."* The divorce was difficult for Mary: *"We didn't really want to leave dad.... Us three girls, you know, we started crying in the car literally."*

Mary's mother took the children back to the state they came from while their father stayed in Illinois. The girls would visit him for three months each summer. Mary had to change schools. It was very upsetting to her that she could no longer go to the same school as her sisters. Her father got full custody of Mary when she was 17 years old and Mary moved back to Illinois permanently. This was another difficult transition for her: *"I never had the friends I used to know"*

in my childhood, they were going to one school and here I am going to a different school.... And my stepmother¹³ didn't really accept me at all.... She had her daughter to take care of and, it got worse as it came along.... It was hard to share my dad with a wife.... And here you are being isolated from the world."

After graduating from high school Mary attended a day program and had a series of jobs, mostly in food service. Her father toured various agencies with her and introduced her to the agency that supports her. About 10 years after graduating from high school she moved out of her father's house: *"It was heartbreaking, because my dad and I became very close."* Mary moved into an apartment with female roommates: *"We always had to go the Laundrymat outside.... And that was scary, you know. You never knew when it was gonna be dark."*

A few years later she moved into the group home. When her group moved to a new house, Mary was told she had to change day programs. This meant that she could no longer see her boyfriend at the day program: *"I was devastated, I said "No!", inside my heart. And I took it very hard."* Mary's boyfriend comforted her by telling her the new house would be nice and that he would call her.

Mary's second stepmother recently passed away. She was her father's third wife whom he had divorced. This divorce and her stepmothers passing were difficult for Mary. She was close to her: *"When she died, it really hit me hard because I didn't have a chance to say goodbye to her.... I am slowly getting over that."* It was upsetting to Mary that no one told her about her stepmother's passing until she found out from her sister nine days later.

¹³ This was Mary's father's second wife, not the stepmother that Mary was close to and who recently passed away.

As her father's family was like immediate family to Mary, it was also hard when her paternal grandfather passed away: *"You know when he died it threw my heart away.... Except that staff was really very, very supportive."*

Mary showed me pictures of her family members. She did not want to use photos on her lifeline or draw, instead choosing to write. She wrote about the year she was born, the move to Illinois, the move back to the south with her mother, her move back to Illinois, the start of her time with the community agency and her current home. She titled her lifeline: *"My life is a rainbow."*

K. **Linda**

Every time I look at them [her pictures], I just cry.

1. **Background**

Linda is a 55 year old African American woman. She lives in a group home run by an agency that supports people with intellectual and developmental disabilities in a suburb west of Chicago. Linda has a mild intellectual disability and a history of mental illness (schizophrenia). She also has a controlled seizure disorder and diabetes. Linda is soft-spoken and came across to me as timid. She also seemed to have a low affect. It was difficult for me to determine whether she enjoyed participating in the project, as she did not say anything positive about her experience working with me as did other participants.

Martha, a 33 year old Caucasian woman, was Linda's key support person. She is Linda's direct support staff and has known her for two years. Martha takes care of Linda's dog. One day a week Linda works at a dog daycare and has her dog with her for the day. Linda would like to live in her own apartment with a roommate so she can have her dog live with her again.

I met with Linda three times in the office of the community agency. Martha assisted during the first two meetings. Throughout our meetings I repeated the elements of informed consent, reassured her that everything she told me is confidential, told her I wanted her to have fun, and explained to her that she did not have to talk about anything she did not want to. The meetings took place in the afternoon, after Linda returned from work, when she was tired. I therefore took the initiative to set up a meeting with her earlier in the day. However, in between the third and the scheduled fourth meeting, one of Linda's direct support staff contacted me to say that Linda had expressed concern about talking any more about her past. I had asked Linda if she wanted to bring some pictures of her life to our meetings. Linda said she wanted to do that but that her staff did not want her to look at them because it would upset her.¹⁴ Linda's direct support staff mentioned in the email that talking about her past brings back bad memories that can "*trigger her schizophrenia*". Also, she told me her pictures are placed in her closet on a shelf where Linda cannot reach them: "*If we bring those pictures out, it will be like Linda taking 7 steps backwards when she has made significant progress with coping with the loss of her mother¹⁵ and daughter.*" In the email exchange with staff I gave Linda the option of meeting with me and talking about something else, but she preferred to end our work together.

2. **Social convoy**

In her first circle Linda included her sister, two brothers, mother and stepfather. In her second circle she included two coworkers, her supervisor at work, and three direct support staff (including Martha). In her third circle she included six female housemates. Linda's mother and stepfather live in a southern US state and visit for family reunions or other special occasions

¹⁴ I interpreted this as a conflict between what Linda wanted and what her staff wanted for her. I wanted to be respectful of Linda's preferences without being overbearing by pushing for her to bring the picture against the wishes of her staff.

¹⁵ Linda's mother did not actually pass away.

about once a year. Linda used to take Amtrak to go visit them. She rarely speaks to her brothers and sees them less than yearly. She sees and speaks her sister to by phone a few times a month. She sees her coworkers and her supervisor at work weekly and has known them for a year. She sees her direct support staff and housemates daily and has known them for two years. She has known One of her housemates for five years. Linda is very independent and does not need support with (instrumental) activities of daily living. She only needs occasional reminders, for example, to do her laundry. Linda said her sister gives her advice and shows that she cares for her by spending time with her. They go out to eat and to see movies. In turn, Linda helps clean her sister's home.

3. **Life history**

Linda was late for our second meeting and gave Martha and me permission to start on the life history interview. Martha looked up the files on Linda. We had to piece together the available information to construct a chronological timeline of events in Linda's life. When Linda came in, we asked her some follow-up questions to fill in the gaps.

Linda was born on the west side of Chicago as one of five siblings. Linda said the following about the neighborhood she grew up in: *"We used to live in the projects... There was violence and gangs."* Her dad died when she was very young: *"I would like to know more about when I was born and about my parents. My father died when I was a baby."* Linda seemed pained by not having had the opportunity to get to know her father and asked me whether I knew my father. When she was a child Linda moved out of state with her aunt and uncle. They lived in a small town in a rural area. Linda said she loved her aunt and uncle and that she loved the country. She told me that her uncle had diabetes, had his legs amputated and passed away: *"I think about him too a lot."*

Linda got married shortly before graduating from special education. She told me that her husband abused her and she left him. She had two children with her husband, a daughter and a son. Her son was raised by her aunt and her daughter was raised by Linda's mother. Linda's son lives in a southern state. She has very limited contact with him and last visited him a few years ago. After her children were born, Linda moved back to Illinois where she lived with her aunt for two years. She then lived in a mental health facility for an unknown period of time. Next, she lived in her own apartment in a west suburb of Chicago for two years. Fifteen years ago she moved to a group home for people with intellectual and developmental disabilities. Three years ago she moved into a second group home which she left almost immediately since she injured her knee and had to spend some time in a nursing home for rehabilitation. After her recovery she moved into the group home where she now lives.

Linda spoke a lot about the passing of relatives which she is clearly tormented by: "*A lot of my family is dead*". In addition to her father and several uncles, one of her sisters passed away as well: "*It is so sad. In two days it would have been her birthday.*" Her daughter passed away a few years ago at age 29: "*I wanted to go see her in the hospital, but I couldn't get a ride. I wanted to go to my sister when she died, but I couldn't get a ride.*"

During our last meeting together we started to work on Linda's lifeline. She seemed to enjoy the process. For her childhood she wrote "*I love the country*" and drew a flower. She also wrote: "*About my father. I didn't know him much. I love him so very much. His name was [name father]*". Furthermore she wrote the names of her son and her daughter on her lifeline. About her daughter she wrote: "*She was a very sweet young daughter. I love you so much*" and "*Why did you have to die so young. I shall miss you. Love your mom. Linda.*" She also drew a picture of her daughter. We were not able to finish the lifeline.

L. **Zach**

They always say 'I love you'. They always say it. All the time.

1. **Background**

Zach is a tall 59 year old Caucasian man with a moderate intellectual disability.

Zach was born with his umbilical cord around his neck. He has cerebral palsy with right side paralysis and epilepsy that is controlled by medication. He lives in a group home for people with intellectual and developmental disabilities in a suburb west of Chicago and has five housemates. He visits a day program four days a week and one day a week he works at a local McDonalds. Zach cleans his room and does his laundry independently. He helps the direct support staff with grocery shopping and putting the groceries away. He loves to swim. Zach is Catholic and his faith is important to him. He has always attended church. He still attends every week together with his housemates.

Zach wanted his sister Doris to be his key support person: *"Doris and I, we always have fun together."* Doris is a friendly 76 year old Caucasian woman. She was present during the second and third meeting. I could observe the reciprocity in their relationship as Zach sometimes depended on Doris' input and Doris on Zach's memory.

Zach likes to look at *"pretty girls"* and talks about his *"girlfriends"* but does not refer to these relationships as sexual or romantic. When asked, Zach confirmed he does not know the difference between being friends with a girl, and dating a girl. Doris said he has never had interest in sexuality and does not like to look at nudity. Furthermore, Doris mentioned this as a topic of awareness to her and their other siblings, as Zach played a lot with their children when their children were growing up.

Zach is polite, sociable, personable, disarming and smiles a lot. Our conversation was smooth as Zach is very talkative and would instinctively start talking about the next topic before I breached it. Zach has a very large extended family. When I asked him what is good about growing older he said: *“I know I like to take care... I always like to see the kids. See my great-nieces, great-niece, great-great niece, and my great-great nephew.”* He said he does not need more support because he is getting older: *“I am not 90 yet!”*. When I asked him what advice he had for me being thirty years my senior he said: *“You could be my third sister. Or my, or my, one of my other nieces.”*

Zach’s grandmother was German and he still knows some German. As with Charlotte, I built rapport with Zach by exchanging our German vocabularies. Zach was very comfortable around me. When I asked him to bring his photos, he asked me to bring cookies. When he shared the mischief he had been up to as a child we both laughed. Whenever Zach said something, he always repeated the same sentence at least once. I met with Zach five times. The first time I met Zach was at his home to go over the informed consent. The other four meetings took place at an office at Zach’s day program.

2. **Social convoy**

In his first circle Zach included his aunt, his sister, his sister-in-law (Zach’s brother passed away about seven years ago), Doris and her husband and their two daughters. In his second circle he included his five housemates, two cousins, two friends with disabilities, and three of his direct support staff. In his third circle Zach included his 26 nieces, nephews, great-nieces, and great-nephews. He also included three colleagues from his work at McDonalds, 11 peers with disabilities from his day program, and four of his sister Doris’ neighbors in his third circle.

Doris, her husband and his other sister provide most support to Zach. Doris helps him shop for new clothes. Zach and Doris told me that Zach recently lost a lot of weight and that Doris encouraged his healthy eating habits. Zach sees Doris and her husband every other week and speaks to them by phone every day. Doris or her husband will pick up Zach at his home so he can spend the weekend with them at their home. In summer, he loves to swim in their pool and play in the pool with his nieces and nephews. Zach sees his other sister every couple of months and speaks to her by phone a few times each week. She occasionally takes him out to dinner. Zach has his driver's license so whenever he spends time with family they let him drive the car.

Zach sees his sister-in-law once a year and speaks to her by phone every week. The last time Zach saw his aunt was two years ago. She lives on the other side of the country. They speak by phone every couple of months. Zach sees his nieces, nephews, great-nieces, and great-nephews about twice a year. He has known his two friends with disabilities in his second circle since he was twelve years old, but he has not seen them for a long time. The three of them used to square dance together: *"Then they say: "swing your partner around, around, Dosado and Allemande left, and corner, around, around"."* Doris told me that the parents and the children would go for cake and coffee after the dances. Even after the dance events no longer took place the parents still brought the children together. Zach is now able to independently stay in contact with his friends even though they do not see each other frequently.

Zach sees his housemates, peers with disabilities from his day program, and his direct support staff daily and he has known them over five years. Zach sees his colleagues from McDonalds weekly and has known them for about five years. He sees Doris' neighbors every time he visits her, which is every other week. He likes to talk with them.

3. **Life history**

During the third meeting Doris provided information on Zach's life history. Zach provided clarification when Doris was unsure about the timing of events.

Zach was born on the south side of Chicago as the youngest of four children. According to Doris they lived in a good neighborhood with friendly neighbors. Zach was born the year Doris graduated from high school. Doris recalled: *"We were very excited ... about this baby ... and then when we found out that ... he had the injury and stuff, that was really devastating.... But we all worked with it, we all worked with him. With my mom and dad, helping them, and stuff, he was our guy, he was like, I felt like he was my baby."*

Zach's disability became apparent when he was an infant as he developed constant seizures. He received some therapy and medication at a local hospital but the doctors told his mother they could not do very much for him: *"They thought I would never be able to walk ... let go of the coffee table and walk right into the bedroom by myself.... Here, I am walking already."* Zach's mother was very involved with his development and took him to be seen by a chiropractor. The adjustments the chiropractor provided him with helped him significantly, and aided by medication, his seizures finally stopped.

In addition to his mother and father, his grandmother also lived in the family home. The family was always very close. Zach's parents and siblings all cared for him. When Zach was 12 years old the family moved to the west side of Chicago. Zach loved to ride his bicycle around that neighborhood. Zach and his brother were always up to mischief: *"Now we had the Magnolia bush in the front, when I, I said, 'the thing ain't gonna grow', so I went up downstairs and I got the saw, and I went out and started cutting it down.... My mother, she started swearing at me.... She is standing at the window, then she went to the back door, she said 'What the hell are you*

doing!” ... “Zach, I told you, don’t cut the three down!” My mother almost murdered me.” Zach loved his brother very much. He used to tease Zach: “He would come to the bathroom and he would say, “Will you get off the toilet? You are like an old woman”.... Then he used to put my, put my cereal in the microwave, he gave me dog food instead of cereal.”

Zach’s father was a butcher and his mother worked in their store. When Zach was born, his father got seriously ill with Addison’s disease. Zach’s parents sold their store, Zach’s father started to work as a production manager for a printing company, and Zach’s mother became a cook manager for the public schools in Chicago.

The first school Zach attended was for children with disabilities. His mother used prepared the meals there. Zach then attended three more elementary schools and two mainstream high schools. Zach told me why he changed high schools: *“The teacher was giving me a hard time.... Then after a while my dad took me out of there.... If I had no pencil or pen, he would tell me to sit under the desk. I said “you are nuts”.”* Zach used to deliver newspapers. He has also worked at a warehouse, at a grocery store and at two fast food restaurants.

Zach got along very well with his father. After his father’s death Zach moved with his mother into a condominium in a suburb southwest of Chicago. Zach was in his early thirties at the time. Doris said: *“Zach was my mother’s chauffeur. He drove her all the time, I mean she could drive but he would uh, she would let him drive and he would drive her wherever they were going.... And he would go shopping with her... he would take her to bingo and of course he used to help with bingo.”* The complex had a swimming pool that Zach frequented every day. Zach completed little chores at the complex. He was friendly with a neighbor there who passed away. When his mother became ill about fifteen years ago, she moved in with Doris, and Zach moved into a group home for people with intellectual and developmental disabilities. Doris said of

Zach's transition out of the home: *"He did make the transition all right, but ... he had a little bit of homesickness ... they were very good with him, consoling him and stuff ... being supportive ... but then if he was having a hard time we would go and get him.... He adjusted and now he is really good with it."*

Zach loves to visit Doris and her husband for the weekends and would like to live with them. Doris said: *"Of course he would love to come live with us, but under the circumstances, we feel that he has to be on his own like everybody else.... But he can still come home anytime, he can come and be with us.... I made my mother a promise that I would always take care of him."*

During the fourth and fifth meeting Zach and I worked on his lifeline. Zach started drawing and writing immediately, so it seemed to be a process that resonated with him. He brought his many pictures during our last meeting. Zach picked out a couple and showed them to me. We put these on his lifeline but he was most comfortable with writing short anecdotes on his lifeline. He included the name of his chiropractor and drew a bicycle, included the names of two of his colleagues at McDonalds and wrote the nickname his aunt had for him. He also wrote *"Ma said what the hell are you doing I told you don't cut down the tree"*, *"Ma and Dad, Zach still loves you"*, *"my brother was a pain in the neck"*, *"at [name agency] to get acquainted it took a while"*, and *"I still like going to Doris so I can jump in the pool."*

V. SOCIAL CONVOYS

This chapter explores the structural and functional characteristics of the current social convoys of the participants based on the social network maps and the interview data. This chapter's section on structural characteristics discusses the types of relationships and relationship contacts in the inner, middle and outer circles of the participants' convoys. The section on the structural characteristics of the participants' convoys also includes a summary of the structural characteristics of the overall convoys and concludes with an exploration of the differences in social convoys between male and female participants.

The Table in Appendix F, provides an overview of these structural characteristics and reports on the numbers, types and genders of the participants' relations in their inner, middle and outer convoy circles. I aimed to gain understanding of the extent to which the participants have relations inside and outside of their immediate disability communities.¹⁶

The coding process of the thematic analysis resulted in a number of findings related to the participants' perceptions of their social relations and the social support they receive and provide. These can be found in this chapter's section on functional characteristics.

A. **Structural Characteristics**

1. **The inner circles**

The participants reported having between zero and nine intimate relations. Eight of the 12 participants have primarily family members in their inner circle. These family members tend to be siblings or siblings-in-law. Three participants have at least one surviving parent but only

¹⁶ When participants identified peers with disabilities as friends, I included those under the category 'peers with disabilities' rather than the friendship category. This decision is by no means intended as a statement on the meaningfulness of these relations to the participants. 'Five days a week' was reported as daily contact, 'biweekly' as monthly contact, and 'a few times a year' as yearly contact.

one is in regular close contact with a parent. Seven of the 12 participants speak daily or weekly to a family member by phone and have family members who live within an hour drive from them. The family relations are characterized by their long duration in comparison with other types of relations.

Five of the 12 participants have no family in their inner convoy circles or see family members less than yearly. In their inner circles four participants have direct support staff, three have peers with disabilities, and three have friends. Eight of the 12 participants have more females than males in their inner circles.

2. **The middle and outer circles**

The participants reported between four and 26 relations in their middle circles and between one and 44 relations in their outer circles. One was an outlier as he has a very large extended family and included all his (great) nieces and (great) nephews in his outer circle.

Seven of the 12 participants have family members in their middle circle and/or outer circle. These participants see and speak to these family members yearly or less than yearly. They tend to be siblings the participants are not close to, cousins, and nieces and nephews. All participants have at least one direct support staff in their combined middle and outer circles. Ten participants have at least one peer with a disability in their middle circle and eight have at least one peer with a disability in their outer circle. Participants tend to have known direct support staff and peers with disabilities (most often housemates) in their convoys for at least five years and see them on a daily basis. They do not tend to speak to them by phone.

Only two participants have friends without disabilities in their middle and outer circles. Four participants have relations other than family, direct support staff, peers with disabilities and

friends in their middle and outer circles. These are, for example, neighbors and colleagues from community employment.

3. **Summary of convoys**

As demonstrated in Table V, the participants' convoys consist of between 14 and 63 relationships. The convoys are comprised of family relations (0 to 70.9%), relations with direct support staff (4.8 to 64.3%), relations with peers with disabilities (9.7 to 50%), friends (0 to 22.2%), and other relations (0 to 17.6%).

A distinction can be made between convoys with significant bonds with family members and convoys that lack strong bonds with family members. Close bonds exist primarily with siblings. For most participants bonds with siblings are the participants' only lifelong relations. The participants do not tend to be close to or have frequent contact with extended family members such as nieces and nephews. Also, most convoys do not include romantic relationships. Only one participant reported being in a romantic relationship.

The participants' convoys lack diversity in types of relations. Few have friends without disabilities. Furthermore, it seems the participants have most frequent contact with the individuals in their outer convoy circles. They often have daily contact with peers with disabilities and direct support staff. The majority of the participants did not tend to have intimate relationships with peers with disabilities (housemates particularly). Even though relationships with direct support staff are of a formal nature, the participants often included them in their inner and middle circles. Ten of the 12 participants have more females in their convoys than males.

TABLE V
AVERAGE NUMBER AND PERCENTAGE OF RELATION TYPES IN THE PARTICIPANTS' SOCIAL CONVOYS

PWD* Pseudonym		Betty	Roger	Matthew	Mary	Linda	Zach
Family	Total Number	14	2	2	10	5	35
	Percentage Total	45.2%	12.5%	7.4%	66.7%	29.4%	55.6%
Staff	Total Number	4	6	7	1	3	3
	Percentage Total	12.9%	37.5%	25.9%	6.7%	17.7%	4.8%
Peers**	Total Number	7	8	8	3	6	18
	Percentage Total	22.6%	50%	29.6%	20%	35.3%	28.6%
Friends	Total Number	6	0	6	0	0	0
	Percentage Total	19.4%	0%	22.2%	0%	0%	0%
Others	Total Number	0	0	4	1	3	7
	Percentage Total	0%	0%	14.8%	6.7%	17.6%	11.1%
Female Relations	Total Number	20	6	11	11	13	36
	Percentage Total	64.5%	37.5%	40.7%	73.3%	76.5%	57.1%
Male Relations	Total Number	11	10	16	4	4	27
	Percentage Total	35.5%	62.5%	59.3%	26.7%	23.5%	42.9%
Total Number of Relations		31	16	27	15	17	63

* PWD stands for 'person with disability'.

** Peers stands for 'peers with disabilities'.

TABLE V (continued)
AVERAGE NUMBER AND PERCENTAGE OF RELATION TYPES IN THE PARTICIPANTS' SOCIAL CONVOYS

PWD* Pseudonym		Henry	William	Lucy	Charlotte	Barbara	Philip
Family	Total Number	10	0	22	11	6	0
	Percentage Total	45.5%	0%	70.9%	64.7%	31.6%	0%
Staff	Total Number	3	9	4	3	4	7
	Percentage Total	13.6%	64.3%	12.9%	17.6%	21.1%	46.7%
Peers**	Total Number	9	5	3	3	8	7
	Percentage Total	40.9%	35.7%	9.7%	17.6%	42.1%	46.7%
Friend	Total Number	0	0	0	0	1	1
	Percentage Total	0%	0%	0%	0%	5.3%	6.7%
Others	Total Number	0	0	2	0	0	0
	Percentage Total	0%	0%	6.5%	0%	0%	0%
Female Relations	Total Number	13	8	16	12	17	8
	Percentage Total	59.1%	57.1%	51.6%	70.6%	89.5%	53.3%
Male Relations	Total Number	9	6	15	5	2	7
	Percentage Total	40.1%	42.9%	48.4%	29.4%	10.5%	46.7%
Total Number of Relations		22	14	31	17	19	15

* PWD stands for 'person with disability'.

** Peers stands for 'peers with disabilities'.

4. Convoys of women versus men

As demonstrated in Table VI, the female participants reported a slightly higher average number of relations (5.5) in their inner circles than their male counterparts (4.3). What stands out is that the female participants have twice as many family relations in their inner circle as male participants (90.3% versus 44.8%). The men reported having more direct support staff in their convoys than did the women (20.2% versus 2%). The dominance of females in the participants' convoys is not explained by the participants' gender. There is no clear difference between the female and male participants in the number of female (57.3% versus 50.8%) and male (42.2% versus 49.1%) individuals in their convoys.

TABLE VI
AVERAGE NUMBER AND PERCENTAGE OF RELATION TYPES IN INNER CIRCLES
OF WOMEN VERSUS MEN

		Gender	
		Women (n=6)	Men (n=6)
Average Total Number of Relations Inner Circle		5.5	4.3
Percentage Relations Inner Circle of Total Convoy		28%	17.7%
Family	Number	5	2.5
	Percentage	90.3%	44.8%
Staff	Number	0.16	0.83
	Percentage	2%	20.2%
Peers*	Number	0.16	0.5
	Percentage	2%	8.1%
Friends	Number	0.16	0.5
	Percentage	5.55%	10.3%
Other	Number	0	0
	Percentage	0%	0%
Female Relations	Number	3	3.2
	Percentage	57.8%	50.8%
Male Relations	Number	2.5	1.2
	Percentage	42.2%	49.1%

* Peers stands for 'peers with disabilities'.

B. **Functional Characteristics**

The structural characteristics of the participants' convoys do not provide insight into the perceived quality of these convoys. Below a discussion follows on how the participants experience their social relations and the social support they receive.

1. **Experience of social relations**

The participants were mostly positive about their convoy members and said they like them. Charlotte said the following about her sister: *"I think she is a really nice person."* Roger said about his siblings: *"He is a good brother, you know. They both are."* Lucy was also positive about her siblings: *"They mean a lot to me, they help me, they really do."* Some participants spoke fondly about a housemate. Zach said about his housemate: *"He is funny. A nice man too"*. Barbara mentioned: *"I would say [he] is one of my closest friends, he makes me laugh."*

Many participants stated that they feel close to their direct support staff and consider them friends or family. Philip said the following about a female staff member: *"I call her cute cod."* William expressed himself as follows: *"The staff, I think, it is alright here."* Barbara said the following about a female direct support staff member: *"She is staff but she is a friend of mine..."* Similarly, Charlotte stated: *"I am friends with the staff too...She [Lauren] is nice, she is loveable. She cheers me up."* Mary said the following about her key support person: *"I would say we are good friends....And the house staff is like family too."* She dismissed the formal nature of her relationship with her direct support staff: *"You know they say: "It is my job" and I say "No, you're family"."* Zach said the following about a direct support staff at his day program: *"He is real nice, like when we had a snow day, he came to our house."*

The participants also stated that they did not like certain convoy members, particularly their housemates. Barbara is not too fond of any of her housemates: *“Some of them I don’t even like, two of them in my house I don’t like.”* Matthew said the following about his housemate: *“[She] is hard to live with. She doesn’t do anything wrong, I don’t hate her or nothing.... But sometimes she gets on my nerve.”* Philip said the following about his housemate: *“She always yells at me....I can’t stand her. I never liked [name female housemate]. [Name female housemate] always gets to me.”* Roger is also not too fond of one of his female housemates: *“She gets too bossy....I don’t like her.”*

Most participants need support to facilitate and maintain their relations. In these cases convoy members need to be proactive to maintain their relationships with the participants. Linda’s experience provides an example of this type of support: *“I talked to my mom and ... she says she is going to see if I can go see her on Amtrak.”* A few participants provided examples of convoy members facilitating relations with other convoy members. Mary explained that she needs support from her direct support to maintain her relationship with her boyfriend who she sees every two weeks:

You know we have to check with our coordinators and our finances in between, and they set up the transportation and where we want to go from going out to dinner to going to movies.

Zach’s sister takes him to see his nieces and nephews and to see their aunt in Las Vegas.

Only a few participants stated that they independently maintain contact with their relatives. Linda said she calls her brother for his birthday. Zach actively maintains the relationships with his family members: *“I keep in touch with Doris almost every week.... I check on the family.... I try to see [them] as much as possible.”* He also maintains a lifelong friendship: *“I keep in touch with him and see how he is.”* Mary independently telephones her sister and brother-in-law. When asked about making friends, Mary said you need *“a lot of skills”* and that

she was “*taught each day*” by her father. Barbara said the following about making friends:

“Sometimes people help me but a lot of the time I do it out of my own.”

A few participants identified communication barriers with their convoy members. Lucy and Barbara have relatives who live out of state, and their residences do not let them make long distance phone calls. Barbara said: *“I can’t call her [Barbara’s sister] because the phone won’t let me call out of the country.”* A few participants said they do not have phone numbers of convoy members. Linda said: *“I don’t know my brother’s number.”* Barbara cannot call a former staff member: *“I don’t have her number so I can’t speak to her on the phone.”*

Difficulties with transportation are another barrier to maintaining relationships for some of the participants. Charlotte and Linda said they were not able to say goodbye to loved ones who passed away because they did not have transportation. Linda shared: *“I wanted to go see her [her daughter] in the hospital, but I couldn’t get a ride. I wanted to go to my sister when she died, but I couldn’t get a ride.”* Even though Mary’s direct support staff helps her with transportation to see her boyfriend, this is not without difficulties. She told me what happened when she went to see her boyfriend and had to go back home:

They didn’t,..., okay, we have certifications around here you know, and one of the staff who is being, you know like a part time staff here, she doesn’t have certification of driving me back, you know picking me up....And they aren’t qualified to take me home, that is what Rhonda told me....And they [staff of Mary’s boyfriend] were saying: “Do we have to?” You know they were giving me a hard time, period. ... “Hey, you know if you want to pay for my cab fare you are welcome to”. So they said: “Yeah, will take you home.” So they had an attitude.

Mary identified other barriers she encounters in her relationship with her boyfriend. She mentioned she lacks privacy at her group home: *“When I try to talk to him [her boyfriend] in*

private, it's hard. I have to go to my room... You see these walls are very thin." She also is prevented from being sexually intimate:

They don't allow us to have sex at [name supporting agency]....It's harder for me and him to, I, you know I want to get intimate with them, except it is harder. ...we want to have that quality time, and we are talking about the issue at hand, except it's all talk right now, and like we have to get approval from all different levels of [name supporting agency]. Should we or should we not, and...?... It's very hard and it's very difficult.... That's when, you see [name supporting agency] frowns on everything about sexual manners with people, they know there is a lot of boyfriends and girlfriends, except, it is very hard for them to have their privacy, because usually there is a chaperone within 50 to 60 feet.... He [Mary's boyfriend] has to be in the living room.... You know we have to cool our jets and say, because when we try to kiss each other, and we say, "can we have time alone, you know without the staff, can we have a private time?" Except there is a chaperone within a yard's distance, and that is when I get nervous ... It's frustrating.

2. **Social support**

The participants perceive social supports to be available to them and value these supports. Supportive relations are often sisters and female direct support staff. Lucy said the following about the support from her siblings: *"They would give me a lot of help, you know."* Betty said the following about her sister's support to her: *"I love her doing the help."* Charlotte said her direct support staff Lauren helps her *"a lot"*. Roger put the support of his direct support staff as follows: *"They pay attention to you"*.

The participants identified a range of supports provided by their social convoy members. They most often mentioned that they receive emotional support. Sisters play an important role in providing this type of support. When asked who helps her when she is upset Barbara said: *"My sister ... is very good about that."* Henry also said that his sister helps him when he is upset about something. Betty said about her sister Amanda: *"She helps me, she asks, we talk about work, and how I am doing. And I tell her what happens."* Linda also feels emotionally supported

by her sister: *“She said that I could talk to her anytime.”* Roger does not have a sister but said the following about his brother: *“He gives me a hug every time he comes.... He tells me not to worry so much.”*

Most participants also feel supported emotionally by their direct support staff. Linda said the staff advises her when she is upset: *“Don’t stay in my room too much, come out and talk to staff, if I have a problem.”* Mary said the following about her direct support staff Rhonda:

She still checks on me and says: “How are you feeling?” And I go: “I am angry, you know, I was frustrated”. She says:... “Don’t let your joy turn into sorrow”. She says: “Just brush it off. Don’t let a bad day make your joy turn sorrow. You gotta move on. You gotta share that joy”.

Mary, Philip and Matthew said their direct support staff help them when they get upset or frustrated with a housemate. Matthew said: *“Yeah me and her [female direct support staff],... down in the basement, we sit down and talk about it.”*

Mary said the following about her good female friend at work:

She keeps me going at work.... She, how do you explain it, she and I, you know, even for our ages apart, we, she helps me, she motivates me you know if, she says: “Don’t give up, don’t give up.” She is my cheerleader.... She cheers me up.... She says: “You are doing good”, you know she gives me applause. Every day.

Her friend’s support is instrumental in Mary’s success in her community employment.

The participants also told me their convoy members provide them with companionship. When I asked Linda how her sister shows she cares for her, she said: *“With spending more time together.... Sometimes we go out to see a movie.”* Betty also spends time with her sister: *“We go places together in the car.”* Zach’s sisters regularly take him out to eat. Roger spends some time with his brothers: *“That was good, they took to me out to eat ... We had a good time, they brought me back and they will come again next month.”* Matthew said he goes out with his accompanier sometimes and goes for walks with one of his housemates.

The participants also spoke about receiving instrumental support¹⁷. Most are relatively independent with activities of daily living and they receive most support with instrumental activities of daily living. Betty said about her sister: *“She cooks the supper for me because I can’t do it. And she does the washing for me.”* Henry told me his sister helps him shower when he visits her. Zach’s sister Doris helps him shopping for new clothes. She also helps him cut his meat at dinner. Linda and Mary said their direct support staff help them with their finances. Mary: *“She helps me budget out the money that I need.”* Matthew’s direct support staff makes sure he takes his phone with him when he goes out. Zach said his direct support staff helps him clean his glasses.

The participants said their convoy members help them take care of their health and take them to see the doctor. Charlotte said her direct support staff Lauren helped her by telling her not to smoke. Matthew said his direct support staff helps him keep track of his blood pressure. Zach’s sister helps him eat healthy and lose weight:

When I get to Doris’s I bring my stuff up to the room right where I sleep. And then I get the scale, I take my shoes off, my watch. I take that off, give my arm a rest. Then I bring the scale down, step on that, [name brother-in-law] says: “You are doing good”. He said: “you are doing all right”...I have a cookie, once, every now and then, that is alright once in a while.

William mentioned Louise took him to see the doctor:

She took me to go to the hospital last Thursday, that’s what....They told me, lay down, I am gonna check up on you. She [the doctor] said, hold still....Make sure I am not sick or nothing.... I hope I am still better.

Mary told me her direct support staff Rhonda helps her when Mary gets her mammogram:

I said, I, like when I had a mammogram for the umpteenth time, I said, “Rhonda, you are gonna be there?”. She said, “Yeah, I am going be there, I will see you afterwards”. I said: “no, I need

¹⁷ See Chapter II, section D, page 22 for an explanation of instrumental support.

somebody to hold my hand.”....And she helped me, when the doctor made a call, she says: “How did it go?” And you know, she is there to answer the phone, and then she will tell me before I get a notice, you know, she says “Mary, come over here, you are okay”.

The participants shared instances of receiving appraisal support¹⁸. Linda said her brother and sister give her compliments on her appearance: *“Sometimes if I go to their house, they like the clothes I wear.... How I look.”* Linda and Matthew also get compliments from direct support staff for helping clean the house. Mary told me about her father’s response after she received recognition from the state of Illinois for her self-advocacy:

So, he says: “I am proud of you”. Then he says: “Have you told anybody else?” I said: “no”. And he said: “We will celebrate, I promise.” You know just because his third wife and him went to Florida and they made a family announcement you know, he made a family announcement and he says: “I am proud of you, I am proud of you”, right in front of the family. And my family ... went: “Wow!” He gave me long stem roses...! ...Inside the card he says: “We are very proud of my daughter.”... Then I start crying because I got the long stem roses. Now, given all these awards... I am turning the clocks on my dad. You see my dad got all these achievements in his study, in his office at where he lives. Now, it is the other way around, I can’t keep track of it..... He said, “I can’t keep up with you”. I said, “oh well”.

The participants also provide support to their convoy members. Barbara mentioned she helped her friend who lost a loved one: *“I just told her I felt sorry.”* Betty asks her nephew how he is doing when she talks to him by telephone. Mary said she helps her direct support staff by giving her personal space: *“Rhonda has tons and tons of paper work. And then I say: “Do you need anything?” And she says: “No”. ... Then I leave her alone.”* Mary said she also gives her father and sister their personal space when they need it. Similarly, Matthew also gives his direct support staff space: *“I let her be, she goes to her room, I let her be.”* Linda helps clean her sister’s house when she is there for a visit. She also helps direct support staff to bring in

¹⁸ See Chapter II, section D, page 21 for an explanation of appraisal.

groceries and helps clean the kitchen. Matthew and Zach also help their direct support staff with the groceries. Zach helps his sister with unloading the dish washer, taking out the trash, and setting the table.

C. **Conclusion**

The participants were mostly positive about their convoy members and said they liked them. Those they disliked were most often housemates with disabilities. The participants perceive social supports to be available to them and value these supports.

Two thirds of the participants' inner circles are dominated by family members, mostly sisters, who provide the bulk of support to these participants. The supports provided to the participants include emotional support, companionship, instrumental support¹⁹, health related support and appraisal²⁰. Those participants who lack close bonds with family members depend for support on mostly female direct support staff members. The participants reported they also provide support to their convoy members.

Many participants feel close to their direct support staff. The participants are rarely close to extended family members and most are not in romantic relationships. They have few relationships with people without disabilities other than staff and relatives. The participants have the most regular in-person contact with those they are least closely related to. Only a few participants independently maintain contact with their relatives. Communication and transportation barriers hinder participants' ability to maintain their relationships.

Two gender based differences were observed. First, the participants' convoys are dominated by females. Second, female participants have twice as many family relations in their inner circles as do male participants.

¹⁹ See Chapter II, section D, page 22 for an explanation of instrumental support.

²⁰ See Chapter 2, section D, page 21 for an explanation of appraisal.

VI. SOCIAL CONVOYS ACROSS THE LIFE COURSE

In this chapter I present the four common themes that emerged from the participants' experiences with social convoys across their life courses. The first theme, 'Positive Impact of Social Convoys in Early and Mid-Life', discusses the ways in which the participants' convoys facilitated positive experiences in the first parts of their lives. Parents and siblings were the most important members of the participants' convoys in their first life stages. The second theme, 'Emotional Impact of Early and Mid-Life Transitions', discusses that the participants felt their lives were disrupted by several convoy related transitions as they reached young and middle adulthood. Moving out of family homes and the deaths of parents were the most poignant transitions in the participants' lives. The third theme 'Interpersonal Conflict across the Life Course' addresses the challenging encounters with convoy members that caused distress and negatively impacted the participants' well-being at various points in their lives. The fourth theme '(Be)Longing in Late Life' addresses the parallel sentiments of longing and belonging that were in the foreground in the participants' experiences.

A. Positive Impact of Social Convoys in Early and Mid-Life

The participants shared positive childhood and young adulthood experiences with convoy members, particularly parents and siblings. These relations enabled positive life experiences in the first half of the participants' lives. To a lesser extent the participants identified the important roles of extended family members, such as grandparents, aunts and uncles in their early lives. The participants rarely identified the positive impact of relations with childhood friends or others outside their families on their early life experiences.

1. Support from parents

Many participants had strong bonds with their parents in childhood and young adulthood and felt supported by them. They mentioned that their parents tried to teach them skills. Betty's father tried to teach her to read and write and showed her how to plant tomato plants in their garden. Mary recalled a similar experience:

You know, my mom ... gave up teaching to be with me, to teach me, reading and writing and music.... I was taught each day by my dad.

Zach's father taught him how to drive a car:

He [Zach's father] taught me, took me to [name park] and took me around and then I started going out on the street. After a while I started going on the expressway.

Parents also provided emotional support to the participants. Betty said she tried very hard to learn to read and write but that she could not do it. She said her parents '*understood*'. Barbara recalled how her mother was supportive of her after a challenging experience:

And I had to cross the street because I was working at a daycare center I think at the time, and I was trying to cross the street, and I think I was so tired that I wasn't watching what I was doing, I don't remember what happened. But the last thing I remember, I woke up and I was in the hospital and I said "What am I doing here?" "You got hit by a car". And they said my mom was coming to visit me and I knew, I knew my mom told me that she was gonna be out of town for a while, but no, she wasn't out of town that time, she bought me, a huge teddy bear.

Parents were also a source of companionship to the participants. Betty traveled all over the world with her father. Charlotte and Zach liked to play bingo with their mothers. Roger went "*barhopping*" with his father. William's father visited him in the Dixon state school and the nursing home where he lived with his mother. Lucy worked with her mother and they drove to work together. She also spoke about the activities she enjoyed with her father:

We used to go to the bank, and we used to go get the car washed or we would go grocery shopping, we would take the dogs for a walk because we had the two dogs, the cat, the parakeet, five gold fish, we had quite a filled schedule.

A number of participants said they were members of community groups when they were children and young adults. They were, for example, in scouts, in church groups and sports clubs. Only Betty and Zach explicitly mentioned that their parents helped facilitate their participation in these community activities. Betty said: *"I like camping with the girl scouts. We had a tent, and a park up here. My mother was a girl scout leader."* Zach's parents helped facilitate friendships with two other children with disabilities. The families would meet each week for coffee after the children finished their square dancing lessons. Zach stayed in contact with the other children as an adult and also had good bonds with their parents. He used to spent time with the father of one of the girls:

I used to go to her house and, see them, and then, when she was working, he'd take me with to pick her up and then I'd go back to the house while she got dressed, take a bath, then we would go out and have supper.

Betty, Lucy, and Charlotte spoke about the particularly good bonds they had with their fathers. Betty said: *"Then in the backyard my dad had this, he made this sandbox, where we could play in the sand."* A number of men had particularly close bonds with their mothers and were quite fond of them. Matthew said about his mother: *"She smiles, she had, my momma she was real nice.... Every day she had a big smile on her face."* Zach and Henry lived with their mothers for years until these mothers were no longer able to provide support to them.

The participants moved out of their family homes during childhood and early adulthood, stayed in touch with their parents. For Barbara, going to boarding schools did not result in discontinued contact with her parents. She was quite adamant though that it was not her parents

who supported her most: *“They didn’t really help me, I was mostly in programs most of my life.”*

Roger and William, who were also institutionalized before adulthood, remained at least in some contact with their parents. Even though William was institutionalized at a young age, he also ended up sharing a residence with his mother: *“I got along with my mother good.... Better than anybody else.”*

The participants who left the family home in young adulthood, before their parents became unable to provide support, also remained in contact with their parents. Lucy’s mother used to come visit her at the ICF/DD:

She would take me out to lunch, we would go to the pet shop, and see the farm was all old at the time, it wasn’t remodeled like it is now.

2. **Bond with siblings**

All but one participant had siblings who played important roles in their lives²¹. As children the participants liked to play with their siblings. Betty explained:

I would play with her [Amanda], and we would play together and we had a play, we had plastic bowling balls and we played down in the basement. We played school down there.... And we had a swing and we swung in the back.

Henry played football with his brother, Matthew played in the woods with his brother and sister, and Zach and his brother got in mischief around the home and teased one another relentlessly.

Roger visited his disabled twin brother who lived in a state institution: *“I used to buy him a bottle a pop. He used to drink it real fast.... He gobbled it down in one time.”*

The participants also spoke of how their siblings provided them support. Roger and William said their siblings visited them at their institutions. Mary said her sisters have protected

²¹ Philip is an only child. Lucy is also the only child of her parents, but as her parents’ ex-spouses had children, she has step-siblings.

her throughout her life. Similarly, Roger said his brother advocated for him when Roger did not like his residential placements:

It was too strict, you know.....I don't like it. My brother took me out of there: "Why are you so hard on my brother?"....My brother got on them, he said: "Don't be rude to my brother".

Some of the participants said their siblings supported them during important positive life events. Lucy shared a memory of her sister attending her primary school graduation: *"I remember my 8th grade graduation, my sister came over and did all my hair and my make-up and everything."* Lucy's brother accompanies her to each high school reunion.

Weddings of siblings (and other family members) also triggered positive memories for a number of participants. Betty vividly remembers her sister's wedding:

Amanda got married and it was here. She had a white dress, white sleeves and her hat was down like this....She had a belt in the back with a hook up....I was in green with green shoes with flowers in my hair.

Lucy said weddings are very important to her. She smiled when she shared the following anecdote of her niece's wedding:

The most important part of the night is when they toss the flowers! And I got a story to tell you. My godniece Michelle when her flowers got thrown, there was a chandelier in the middle of the hall, the bartender had to come out with the ladder trying to get this ribbon to untangle from the chandelier because it wound up so high in the chandelier and it was going back and forth and the people were like: "I think I am going to leave this hall" because they just couldn't trust the chandelier. Because they were afraid it might drop on them....It was ribbon, and the ribbon tied around the chandelier. What happened was [name family friend] was drunk, he was going to try to get it down. And he was drunk, laying on the floor, so they got the bartender out from behind the bar, he couldn't get it out. Because it was a set-up, they had everybody leave the floor they told everybody: "I am sorry, we are not throwing them tonight, they are stuck in the chandelier". It was a set-up so I couldn't get them. See what I am saying? Can you picture?... And it was ribbon, it was wound around the chandelier. So they wound up taking a pair of scissors to get it down. A pair,

you know, one of those weed trimmers. To get it down because they couldn't get it down.

A few participants mentioned receiving support from their siblings after the deaths of parents. After her father died, Lucy and her mother temporarily moved in with Lucy's sister and brother-in-law. Barbara said her sister was of support to her when her mother died:

When I, when my mom first passed away, when my mom first passed away she was there because she was the only one there, she did my help me when my mom passed away.

In families with both daughters and sons, sisters tended to be most involved in the lives of their disabled siblings. Matthew lived with his sister for a period of time. Linda, Henry, William, Lucy, Barbara, and Zach were closest to their sisters even though they each also had at least one brother. Each of the participants also remained in touch with at least one sibling after the children left the family home. Betty and Mary described their sisters as being liaisons with other children when they were growing up.

3. **Involvement of other relations**

A number of participants had the opportunity to have relationships with their grandparents. Barbara recalled that her grandmother used to babysit her. Matthew spent a lot of time with his grandmother as a child. Betty's grandfather gave her a dog and taught her how to fish. Betty spent time at both of her grandmothers' homes: *"I stayed with her [one of the grandmothers] and she liked to watch soap operas"*. Mary was raised by her grandparents for the first 18 months of her life and frequently spent time visiting with them throughout her childhood: *"And if it wasn't for my grandmother..., my mom would go panicking."* Her grandmother brought Mary and her sisters to choir rehearsals at the church and they cooked plum jelly together. Zach also had fond memories of his grandmother:

My grandma she, when I was little, took me to the school yard across the street and then she said "I'll put you in the baby"

swings”, that is what she used to do, put me in the baby swing.... And then she would say “you can go play in the sandbox”. With my boyfriend. She used to do that to me.

A few participants recalled memories of extended family members, particularly aunts and uncles. Betty talked fondly about her uncle who attended her high school graduation. Zach said the following about his aunts and uncles: *“They were all good to me, I’ll tell you, they were all great.”* He recalled his uncle used to have *“all these watches on his wrist, from here all the way back to here* (gesturing from his wrist to his elbow)*”*. He gave Zach what Zach describes as a Rolex watch.

In some instances, aunts and uncles stepped in to support the participants when their parents were no longer able to. Roger said his aunt took care of him before he went to the Kennedy school. Linda lived with her aunt and uncle both as a child and after she left her husband. Linda’s aunt also raised Linda’s son. Philip was close to his aunt who was his only surviving relative after his parents died.

Betty spoke in much more detail about her childhood than any of the other participants. She remembered playing with the children in her neighborhood growing up:

She [girlfriend] was fine to be with, we went, she went to school with me, and we went to the school down here and, she was a nice girl, we played, and we played in her house. And the mother was a housekeeper and I don’t remember what the dad did.

Mary said she and her sisters used to play with a group of children in her neighborhood:

We had those friends you know, everybody hanged out with everybody in this one area. Like they all said, they all said: “can you come out and play?”.

The other participants rarely spoke about close childhood friends. This might be due to the fact that they do not remember their childhoods in much detail. Lucy put it as follows: *“I don’t remember when I was a kid, I really don’t.”* Charlotte said she does not remember the

names of the friends she grew up with. Roger and William could recall the names of peers with disabilities they lived with as children, but could not articulate any details about these relationships. Charlotte said she was close to people outside of her family but she did not remember their names or any details about them.

A few participants said they did not have friends growing up. Philip stated: *“I had no friends at all....When I was young, it never came up.”* Mary said that once she was in school other children did not want to be her friends:

I couldn't have friends because of the mental retardation, you know, the picking of the friends, and what not..... Because I was so different, because I went to special classrooms throughout my life.

B. Emotional Impact of Early and Mid-Life Transitions

The second common theme concerns convoy related transitions that affected participants in their early and mid-lives. These transitions include moving out of family homes, parental divorces and the deaths of parents. For some participants these transitions continue to adversely impact their emotional well-being as they age.

1. Move out of the family home

All but one of the participants moved out of their family homes. The emotional difficulty of this transition was dominant in the life experiences of all of them, regardless when it occurred. Betty did not move out of the family home but also faced significant transitions with the aging and passing of her parents.

Barbara, William, and Roger moved out of their family homes as children. Barbara was 13 years old, and William and Roger were both nine years old. Barbara and Roger were vocal about how difficult it was for them to leave their family homes. They vividly recalled these events that happened 42 and 58 years ago, respectively. Barbara felt her parents just left her. She told me:

My parents wasn't taking me anywhere. They just dropped me off and left. This does not sound right.... It was the first time I was ever dropped off at a program, or a school, whatever. And it was the first time I had ever been dropped off and my mom and my dad just dropped me off and left me and I, because the other times when they took me somewhere I was always with them and they didn't drop me off anywhere. While the first time I went to [name school], they just dropped me off.... And when my mom first took off, I was upset, I went to the ladies room and I was crying because it was the first time I had ever been away from home. If you have never been away from home, of course you are going to be upset.... Well, when, next time I saw my mom she said, "Don't feel bad Barbara, I cried all the way home." My mom said she was crying all the way home....

Roger felt he was being sent away by his parents:

We had to go, we couldn't stay with them, you know.... I felt kind of bad.... Yeah, I thought kind of "what's going on", you know.... In my mind you know.... Yeah, why did they send me away, you know.

William said more about what he endured while he was at Dixon state school and less about his transition into that institution.

A few participants moved out of their family homes while their parents were still alive.

Lucy had a difficult time with her transition. She wanted to stay with her mother and felt it was not her choice to move out:

I'd rather be with my family, you know.... It just, it wasn't what I expected it was going to be, because I expected to live at home.... Because I felt more comfortable and my mother wanted me to go to [name ICF/DD], I kept trying to tell them: "No, I am not going to [name ICF/DD], I am staying right here. I live here.".... My mother and dad said "This is the way it is going to be, we are your guardians, that is the reason we are here. If something happens to you, there has to be someone responsible".

Mary was more involved in the planning and decision making process of moving out of her father's home, but the new situation was initially still challenging for her: *"It was heartbreaking, because my dad and I became very close."* Charlotte lived in her own apartment

after leaving her mother's household. She said her sister made the decision for Charlotte to move into the ICF/DD. This experience was challenging for Charlotte: *"It was kind of hard for me, because I had to leave [name of her cat]."* Barbara also missed the cat she was not allowed to bring with her when she moved into the ICF/DD.

A number of participants did not leave their family homes until their parents became unable to provide care or passed away. For Philip it was very difficult to move away from his family home after his parents died. He felt he did not have a choice in where he lived and felt restricted in his freedom:

I didn't ask to come to [name ICF/DD]. I was told to....I have to do what I am told....I am trying to say to you, every time I watch television they would say turn it off and go to bed.... Here are the rules and regulations. And my aunt and I didn't do that.

Zach said he needed some time to get used to his new living arrangement after he moved into a group home: *"I know it took a while to get acquainted over there."*

Clearly, a number of participants felt they were not involved in the planning of their moves out of the family homes and felt excluded from the decision making processes of where they would live. Lucy said this continued after her first move out of the family home. She was moved to another home on the campus of the ICF/DD: *"I transferred to another house.... They wanted me to try it or something.... It was the staff's choice. I think, I think that is how they did it."*

2. **Parental divorce**

Charlotte, Barbara, Roger and Mary experienced the divorces of their parents. Each described the emotional impact this event had on their lives. Roger said: *"It bothered me when I was a little kid.... I was scared, you know."* Both Barbara and Mary remembered their

parents' divorces coming as a shock to them. They both remember the moment one of their parents told them about the divorce. Barbara said:

There was a lot of fighting because my dad and my real mom weren't getting along....It was right at Christmas time so we went to see Christmas lights and we went back to where my dad was living at the time and my dad and my mom wanted to be left alone because they wanted to talk, so, they came back and my mom was really upset and I said "Mom, what is wrong?", and she said: "Me and dad are getting a divorce".... It was a shock.

Mary remembered the following:

He [Mary's father] took us [Mary and her two sisters] aside and told us that it was hard[er] for my mom to tell us than him... Because you know here is my mum crying in the room and we thought what's wrong with mommy?...And the he says: "your mom and I are gonna get a divorce", and we heard mommy crying all day long....We [Mary and her two sisters] are trying ... to control our tears because you know we didn't ... want to leave dad.... And when that rainy day hit us, us three girls, you know, we started crying in the car literally, all four of us. ... And my dad was trying to look in the side..... Because he didn't want to say goodbye to us because he was used to us girls in the house or whatever.... It was sort of a complete shock to our system.

The compositions of the participants' households changed as a result of parental divorces.

Charlotte was relieved she still got to see her father after the divorce: *"I was upset about it but..., but then I got over it.... I was happy because I got to see my dad."*

3. **Death of parents**

Mary is the only participant with two surviving parents. The mothers of Charlotte and Linda are still alive but these mothers no longer play active roles in their lives. Most participants lost their last surviving parent between 10 and 30 years ago. Even though these events took place a considerable length of time ago, the participants clearly articulated what they experienced at these times in their lives. The passing away of their parents was prominent in their self-representations.

Most participants remember when, where and how their parents died and whether they were with their parents at the time of their passing. Lucy vividly remembered the morning of her father's passing:

And he [Lucy's father] went to bed one night and something happened about five o'clock in the morning, something happened, he woke my mother up, and [she] said "[name Lucy's father], lay still", and when she got up at six o'clock, he was gone and she came running to my room and said: "Call the fire department, I think dad has had a heart attack", because they couldn't wake him up.... Every fire department we called was out on call, they didn't have one ambulance.... They said: "We will be there in three hours". Well then my mother got on the type writer and she wrote a letter to the chief of the police department to tell him how dissatisfied things had rolled that morning. When somebody died you expect the fire department to have an extra ambulance available to take somebody to the morgue.... We had to wait like for three hours before they finally picked him up. They came over, they worked on him, they couldn't get anything out of him, there was no movement, he didn't move his hands, they put the, the, pacemaker machine on him... they hooked it up, they had an outlet in the wall, and they were getting a flat line and they knew if he wasn't moving, that he was gone.... They had a police officer that was a friend of ours, came over and we had a paramedic that lives behind us, those were the only two people that came over to work on my dad. ...I said, if we would have been there sooner we could have saved him, they called it, what they call "a massive heart attack".

Most participants were not present at the time of their parents' deaths, and were told about them by family members. Barbara, for example, recalled a message from her brother when she came back from dinner with her house manager:

My brother leaves a message and says "call me". So I called...him back. "Your mom just passed away". I was in tears.... I knew she had cancer. I knew she was gonna die. But I didn't know when.... She went to sleep and never woke up.

William was told about his father's death by his mother:

My mother said: "William, your dad is dead", "Oh no! No", I said: "Don't ask me that question anymore", I used to cry a whole lot about it. But I am trying not to start crying about it. That is not good.

Zach's sister told him when his mother passed away:

I said, if something is happening to my mom, I said: "don't wake me up." It was almost morning, and I said: "let me sleep", and then when I got up she [Doris] told me that ma passed away.... Then I felt kind of sad.

Lucy was also with her sister when her mother died:

I was with my sister when my mother died. I was, I had gone to their house for something. There was something going on.... And I stayed overnight and the phone rang and my, it was in the middle of the night, one o'clock in the morning and my sister answered the phone and she came run out of the living room: "Get up, get up, get up, we gotta go to mom's, they can't wake mom up. They think she had a heart attack in bed during the night"Because she had emphysema.... And we all jumped in the car, went out to [name town] and by the time we got there the rescue squad was already gone, they were down, I don't know if they went to the morgue or to a hospital, I don't know where they went.So we did not get a chance to see her.

Barbara's and Charlotte's fathers passed away recently, hence their grief is fresh. Barbara told me the following:

Because Father's day is going to be the first day without him. It will be my first Father's day without him. So it is not gonna be a great, a good Father's day. I was at home in tears last night thinking about it.

Charlotte's sister told her about their father's recent passing: "I started crying. ... My sister had him, you know, burned." Charlotte said she felt bad she could not say goodbye to her father:

I had wanted to see him, but ... my sister... said it wasn't a good time, said.... he wasn't feeling good,.... he was sitting on a chair, trying to die.... And... no way I could have gotten up there.

She did not see him after he died either: *“My sister... says he looked disfigured.... No point going.”*

Most participants identify as Christian. A number of participants expressed their religious beliefs with statements relating to their parents being ‘in heaven’. William said:

My mom, my mom, she passed away, she is up in heaven ...with God.... My dad... passed away too, he is up in heaven with God.

Zach shared the following with me:

They [his deceased family members] are watching over me....Making sure that I am alright....They want to make sure I am alright.

Betty formulated it as follows:

I love God, and I know God is up there and I know Jesus, and I know my parents are up there. And I know everybody goes up there someday and meets God. Like that.

C. **Interpersonal Conflict across the Life Course**

The third theme found in the participants’ experiences concerns their negative encounters with convoy members. The participants spoke about challenging relational experiences in their early lives within their families and their schools. In several instances they attributed these experiences to others’ responses to their disabilities. In mid-life, negative encounters took place primarily with peers with disabilities and direct support staff in residential facilities. A number of participants also spoke about negative experiences in their past in romantic relationships.

1. **Conflict in early life**

Even though the participants had good bonds with their parents growing up, several participants disclosed physical and emotional abuse taking place within their families. A number of participants said they were occasionally maltreated by their fathers. Matthew told me about the systematic physical abuse he and his mother endured from his father. Matthew and

Mary stated that they underwent corporal punishment. Matthew was physically disciplined by his grandmother. Mary was disciplined by her father: *“As it progressed he couldn’t discipline me anymore. Because you know, you can’t spank your own daughter who gets older than you.”*

Other participants might have been disciplined by physical correction as well, but they did not share this with me and I did not specifically ask them.

Three men said their fathers drank. According to Matthew, his father was drunk when he abused him and his mother. William’s father drank too, but William said he liked his father: *“My dad, he was, he was good. My dad....he is okay with me.”* Roger also remembered his father drank and was abusive to his mother. Like William, he did not speak about being treated poorly by his father himself.

Barbara and Mary said their disabilities were a source of frustration to their fathers, with negative interactions as a consequence. Mary told me:

My dad ... he said: “you should be like everybody else in the family” when I was growing up. You know, here I had my share of discipline. Except it was harder on him too. My mum was laid back and easy. My dad was, you know, he was, say: “You gonna be like everybody else in the room”.

Mary’s father can still be impatient with her. Nevertheless, they have a close relationship and Mary feels supported by him. Similarly, Barbara loved her father even though he treated her poorly:

And oh, I don’t remember what place it was but he wanted me to get, he told me to go get him something and he got mad because I told him that that place, I don’t remember exactly what happened but something happened and I couldn’t get it or something and I said: “that place doesn’t exist anymore” and he said: “yes it does”, and he got mad at me, but the second time, I remember that, because he wanted me to get him breakfast or something, and I got, and he says: “bring it here”, but I got lost and he got upset with me and he called me “stupid” because I got lost and he said it in front of a whole bunch of people and I felt very embarrassed and I am not so used to having my own dad calling me stupid....

But I still love him, you know, even though people do things that made you upset at the time, you forgive them, you forgive them.

None of the participants shared any memories of their mothers or siblings maltreating them.

Most participants lived at home with their families during their childhoods and attended mainstream primary schools and special education classes at mainstream high schools. Several participants recalled instances of being bullied by other children. Mary said the students in her high school were “*rude and crude*”. Philip was made fun of by students at his school: “*they called me retarded*”. Barbara underwent the same treatment: “*Kids when I was growing up... used to call me names that I didn’t like. Retarded. I hated that word. I am glad they don’t use that word ... anymore.*” Betty’s experience with other children in her neighborhood was not this negative: “*They knew it that I was slow, but that didn’t bother them.*”

2. **Conflict in mid-life**

Both male and female participants shared memories of conflicts and tension with direct support staff at residential facilities. Roger said he did not like the way the direct support staff at his group home spoke to him: “*They were rude to me.*” William said his group homes’ direct support staff was “*very strict*”. Mary shared the following about direct support staff at her group home:

They always said it was our fault all the time....They always put the blame on the individuals in this house. That made it really uncomfortable for all of us....You know like “you cannot eat this, cannot eat that.” Or, you know simple criticisms and that’s when we said, “enough”. You know, it got me upset on certain things.

William was particularly vocal about many instances throughout his life in which he experienced conflict with direct support staff. At times it was difficult for me to determine where and when these events took place. William seemed to confuse different settings in conversation, but it

became clear that he has many memories of negative interactions with direct support staff. One of the first took place at Dixon state school:

The nurse she used to holler at me a whole lot.... She is just kind of too crabby out there... She got too upset with me.... I said: "Goodbye ..., I don't feel like being bothered and touched by you, goodbye".

William also had a negative experience with a nurse at the nursing home he used to live: "*She gets everybody upset too much.*" About another instance of conflict with direct support staff he said: "*That colored guy he used to argue with me. I said "I don't like to be in no fight like that".*" Even Betty, who has lived in her family home her entire life, was not spared conflict with support staff during a community outing:

She cussed, she yelled, she got mad at everybody, I was with the girl with the wheelchair, getting off the boat, she grabbed me and said: "You are not supposed to go with that girl, you go with me", I said: "No, I am with the girl, I am walking with her, helping the boy walk the wheelchair". And I was very upset, I was about in tears. Because I couldn't believe she'd act like that.

The participants also shared instances of tension and conflict with their housemates with disabilities. Despite his limited expressive verbal skills, Henry said about his experience in a 94-bed facility: "*They hollered at me...I don't like him....Hit me in the head...*" Lucy did not get along with one of her female housemates in the ICF/DD: "*[T]here was one girl there I didn't get along with.... And then she started fighting with me constantly, every night we were fighting.*" Philip said his housemates at the ICF/DD got annoyed with him: "*I would say 'Merry Christmas', and they got tired of it.... That is what my father said, repeat and repeat and repeat and repeat.*" Zach shared the following about his housemates:

The one guy, he was kind of messy. He did a lot of peeing on the, in the bathroom, and then one woman, ... she thought I was playing with myself when I had to use the bathroom....Every time she was

looking at me when I was using the bathroom....That is what I didn't like.

William repeatedly said that peers with disabilities stole from him and begged him for money.

He also said there were fights in the Dixon state school and in one of the group homes. About one of the group homes he said: *"I didn't like it there. They beat me up too much there."*

Several women who had romantic relationships earlier in their lives recalled instances of abuse. Linda endured both physical and sexual abuse by her husband:

Soon after we were married, we were with my mom and he told me to cook him something to eat, and he told me I wasn't doing it right, he balled up his fist and he hit me in the head.... He raped me.

Her aunt and uncle helped Linda to leave her husband. Barbara shared the following about a former boyfriend: *"He told me to do stuff that I didn't want to do."* Betty found out about her boyfriend's temper after they started dating: *"That was a mistake to date him.... I didn't know anything about his temper or anything."*

Even though it was mostly women who shared examples of maltreatment in romantic relationships, Roger also told me about unwanted sexual advances by a former girlfriend: *"I don't like it, it's sick you know. It's sickening, you know, what she does to you. I am not used to it."* Furthermore, he recalled an unsolicited homosexual encounter:

I had a, I had a man do it once....In the car.... Yes, it was sick. I told him, get outta here....A strange man....He was driving around you know.... Something wrong with him, you know.

D. **(Be)Longing in Late Life**

The last theme relates to the ways participants expressed their social well-being in late life. They simultaneously expressed feelings of belonging and of longing. Their experiences are characterized by a tension between sentiments of fulfillment and nonfulfillment.

1. **Belonging**

The participants' sense of belonging was demonstrated by their satisfaction with their friendships, by the roles they hold in the lives of others, and by their relational understandings of self. Furthermore, they expressed continued affinity with relationships that impacted them positively earlier in their lives.

Barbara, Betty, Charlotte, Matthew and Mary feel they have more friends in late life than they had in the past. For Betty, the aging of her parents restricted her ability to be socially active: *"I was sheltered a lot. I didn't go anyplace or do anything.... Because they couldn't get out of the home.... I would barely go any place."* Her community engagement after the death of her parents has enabled her to build friendships. Charlotte feels she has more friends now because there are more people around at her current home in the ICF/DD than there were at the apartment where she used to live independently.

Participants regularly described themselves by their social roles. When shown a photograph of himself with his parents, Henry said: *"Their son."* Similarly, when speaking about his parents Philip said: *"I was their son. You know, I was living with them."* Linda said her sibling cares for her because they are *"sisters"*. Mary identifies strongly as an aunt to her sister's children as well as to her uncle's granddaughter, and reflected on the impact of her disability on that relationship. She told me she questioned her sister:

"Okay, how do you explain [her disability] ... your new family, you know, your daughters?", and they didn't know. And then, as time progressed, you know, we slowly told them. You know, they were the protectors, and that's, you know, we eased into it.... Okay, like, my nieces, you know, they were too little to understand why aunt Mary couldn't drive.

Zach also strongly identifies with his role as an uncle to his siblings' children and their children and calls himself: *"Uncle Zach"*.

A number of participants' statements revealed perceptions of convoy members that shape participants' understandings of self. Barbara frequently talked about her daily physical discomfort caused by her TMJ. She said her stepmother thinks Barbara might have arthritis in her jaw. Linda said her sister wants her to live with a roommate: "*She doesn't think it is a good idea for me to be on my own.*" When I talked to Zach about aging, he quoted his sister Doris: "*She says I am starting to get grey up, a little bit of grey*".

The participants demonstrated clear understanding of the difference between the past and the present. Overall, they understood themselves more in terms of their past and present than in terms of their future. They defined themselves by what happened to them in the past and by their present experiences and less by their wishes for the future.

The participants' sense of belonging in late life was impacted by their previous positive life experiences. Some of the participants' convoy members had a lasting impact on their emotional experiences as they aged which created feelings of belonging. Betty still speaks fondly about her childhood and the supportive roles her parents played in her life: "*They were good parents.*" Matthew's experiences provide an additional example of the continuing impact of his relationships on his feeling of belonging. He identified his two half-sisters as intimate friends even though he has not seen them in years and never speaks to them. The two sisters from his faith based community who he feels very close made a big impact on his life when he first moved into his community. He said the following about one of them: "*Me and her go way back.*" These sisters now live out of state and he sees them only a few times a year.

2. **Longing**

The lasting impact of relationships with convoy members on participants' experiences as they aged also created feelings of longing. In many of the participants' stories,

experiences of loss were dominant. They often referred to the passing of their parents and other family members. For Philip, his experience of aging is directly tied to the deaths of his parents:

“Things change....I lost my parents....It wasn’t fun....Seeing your parents die.” Lucy clearly expressed her sense of loss: *“Most, most everybody is gone, except for my brothers and sisters..... Thank God that I still have some.”* And so did Linda: *“A lot of my family is dead.... I only have my uncle and two aunts left.”*, and William: *“Now I ain’t got nobody....I ain’t got no family or nobody. Oh, it is a hard thing to say....It is all you think about.”* Roger expressed disbelief about his parents’ passing which happened at least 15 years ago: *“It is kind of sad you know.... I can’t believe that happened.... So fast.”* William expressed a sentiment of wishing his mother had not passed: *“I didn’t like for my mother to die like that. I wish I would have kept my mother. But now it is too late now.”* Philip expressed himself similarly: *“I want to forget... I wish it never happened.... I could have saved all of them.”* Zach said: *“I think about my mother and dad. I think about them every day.”* He wrote on his lifeline that he still loves his parents. When looking at her family photos, Barbara told me the following:

That is me and my mom. My real mom. Who I miss terrible.... I don’t know when my mom died, I just know she died in January, that is all I know. And I can’t ask my brother because he gets cranky when I ask him questions like that I think. I think it hurts because he misses his mom too.

She also imagined what her mother would have thought about her current health problems:

I don’t have my real mom or my real dad. I think if my real mom was still alive, she would not like to see her daughter have TMJ. Because I didn’t have TMJ when my mom was still alive.

Matthew said he misses his grandmother, Mary still thinks a lot about her deceased uncle and Roger misses his twin brother.

The participants also talked about the deaths of people outside of their families. Barbara was close to a direct support staff member:

I was really upset when she died because she was like another mother figure. ... She was a sweetheart. And then we are trying to go to her memorial service or her funeral, I don't remember what it was, we, somebody was taking us there but we couldn't find the place to go, where her memorial, her funeral was, so we never got there.

Barbara also told me that her friend from a previous residence died from breast cancer and that her godmother died from lung cancer. Roger lost a close roommate which was difficult for him.

Lucy had a close friend from the ICF/DD who passed away:

We were like one month apart of each other in move dates...And [name friend] had breast cancer and they did not want to tell anybody because they were afraid if she got sick they would have to move her and a couple of years after I was gone [name friend] got real, real sick and they decided her parents made the decision, it will be better off to move her back home where they could watch her.... Well, then I got a phone call of house [number house] to tell me that [name friend] had passed away. That they just, there was nothing else they could do for her.... We were roommates, we were, we were sisters.

The participants also mentioned that with aging some of their relationships changed and others discontinued. Barbara mentioned she is no longer close to her friend. Charlotte said that her sister became an alcoholic and that they became “distant” from one another. Likewise, Charlotte’s relationship to her mother who developed Alzheimer’s disease changed: “*I can’t even see her, because she is that bad now.*” Matthew said the following about his relationship with one of the sisters from his faith-based community: “*I don’t see her that much. Not anymore.*” Roger no longer goes for walks with his female housemate: “*I walk by myself.... I don’t want her to walk with me, I am so used to being by myself.*”

The participants do not always remember the names of those they were close to and do not know where they live or if they are still alive. Barbara said of her aunts and uncles: “*I don’t know if they are still alive.*” Linda said: “*I don’t know where my brother [name brother] lives.*”

Matthew and William forgot the names of their siblings. Matthew said: *“And the other one sister, I can’t tell her name, I forgot her name.”* A few participants also told me they had been unaware people passed away until told much later.

Most participants changed residential facilities many times. Rarely are they still in contact with peers with disabilities or direct support staff from previous residences. Barbara said: *“My friend who had Down syndrome,... I had her as a roommate. She was great.”* She said about another former housemate: *“I don’t know whatever happened to her.”* One of Barbara’s direct support staff members moved away: *“I had a very close friend but then she moved to Georgia, and she came to visit not that long ago, but I still miss her.”* Mary spoke about a former direct support staff member she was close to:

I had a supervisor was practically like my best friend to me. And she still is, I have to keep in touch with her, so it is hard you know, she lives at the, apartment building where I lived, back then.

William said about a former direct support staff at his group home: *“She quit from here. She used to be staff with Louise here. Not no more.”* He also said of a man he lived with at Dixon state school: *“He used to be there, not no more. Not no more.”* and about a man he lived with at the nursing home: *“I don’t see him no more, no.”*

Participants’ expressions of loss of relationships and changing relationships were more prevalent than sentiments of loneliness. Only a few participants said that they feel alone at times. William expressed himself: *“I am all by my own self. I am on my own.”* Roger feels he has fewer friends than earlier in his life. He said it was easier for him to make contact with others in the town he used to live in. A number of participants expressed a desire to see their relationships more frequently. Lucy said she would like to have more friends to do activities with: *“We could do anything really, go out to the mall, go to museums.... I would like to start joining a church or*

something.” Similarly, Charlotte expresses a desire for more contact with convoy members: *“I wish I see more of my nephew’s kids.”* Linda, Barbara and Lucy said they would like to have more contact with their brothers. Barbara spoke of her unsuccessful attempts to get in touch with her brother: *“My brother used to tease the heck out of me. He doesn’t do that anymore. Well, know, I can’t even get a hold of him when I want to.”*

On occasion the participants said they would like to have a romantic relationship. Lucy said she would like to date. Charlotte expressed her nonfulfillment: *“I always wanted to get married, but it hasn’t happened”*. Zach said: *“he probably could have a girlfriend”*. William’s desire for a girlfriend was linked to his missing his mother:

I don’t know who I am going to have, I might as well find me a girlfriend if I can’t find nobody else for mother....I wish I had myself a girlfriend so I could go on, but I am afraid to have one, but I have nothing to be afraid of though. I can always have a girlfriend.

Philip and William have no surviving relatives. They expressed the strongest sentiments of longing. For participants like Zach, Betty, Roger, and Linda, who also experienced considerable loss, surviving relatives, particularly siblings, ease their sense of longing.

E. **Conclusion**

A tension between attachment and detachment can be recognized in the themes. The early lives of the participants were characterized by strong attachments to their intimate convoy members. The transitions the participants underwent as they aged resulted in a sense of separation from what was familiar and meaningful to them in their lives. Existing attachments to intimate convoy members such as parents and siblings changed, and new attachments with convoy members such as direct support staff and peers with disabilities were formed. Negative encounters with convoy members across their lives caused ambivalence in participants towards these relationships and in other cases, dissociation from them. The participants’ experiences in

late life are characterized by a tension between feelings of connection and disconnection to convoy members.

VII. DISCUSSION

This chapter discusses the major findings of the study. It addresses each research question and situates the findings in the literature on social relations of people with intellectual disabilities. Considering the limited research on social relations of older people with intellectual disabilities, I discuss the various ways this study's results confirm and expand previous research. I consider implications of this study for the development of research methods for application with those aging with intellectual disabilities. The final question is addressed in the section of suggestions for practices and policies. The chapter concludes with a discussion of the limitations of this study and recommendations for future research.

A. Research Questions

1. What are the structural and the functional characteristics of the social relations of older adults with intellectual disabilities?

There is evidence that people with intellectual disabilities have ranges of positive relationships in their lives (Kersh et al., 2013). The same is true for the participants in this study. They appreciate most of their convoy members and feel supported. These perceptions positively impact their subjective well-being.

The participants had between zero and nine intimate relationships and between 14 and 63 relationships in their convoys. It is difficult to compare the sizes of the social networks of people with intellectual disabilities across studies due to the use of different instruments (van Asselt-Goverts, Embregts, & Hendriks, 2013). More informative are comparisons between the types of relationships in the social networks and their functional characteristics.

Two thirds of the participants' inner circles were dominated by immediate family members. Sisters tended to be the most supportive relatives, a trend consistent with the literature.

Generally, women are more involved than men in the lives of their disabled siblings (Bigby, 1997a; Orsmond & Seltzer, 2000). Sisters rather than brothers tend to become primary caregivers after parental death (Prosser & Moss, 1996). As Bigby (2002) concluded, adults with intellectual disabilities who have a brother as their only sibling may be at the highest risk for receiving only limited family support after parental death. Orsmond and Seltzer (2000) found that brothers of brothers with an intellectual disability had better relationships than brothers of sisters with an intellectual disability. Based on this finding, Bigby's (2002) conclusion might be particularly salient for women with intellectual disabilities who have a brother as their only sibling.

Many participants felt close to their mostly female direct support staff. Bigby (2000b, 2002) found that direct support staff members become an integral part of the support networks of many older people with intellectual disabilities. The same was true for the participants in this study. This finding resembles Krauss and Erickson's study (1988) that found that direct support staff provides the majority of support and companionship to older adults with intellectual disabilities in residential settings.

A number of participants relied on formal supports for their needs to be met. It has been argued that formal services cannot replace the affective support that characterizes informal support from relatives and friends (Bigby, 2000a, 2005). Between 1980 and 2005, turnover rates of direct support staff in community residential settings in the U.S. have ranged from 45 to 70 percent (Hewitt & Larson, 2007). As suggested by Lippold and Burns (2009), turnover is likely to disrupt the close bonds between direct support staff members and older people with intellectual disabilities. These disruptions in the convoys are likely to have the greatest impacts

on those without close bonds with family members, as they do not tend to have other close relationships to provide them with social supports.

The participants' convoys were dominated by women. This is not a surprise, as in the U.S. women have been found to dominate the pool of informal caregivers (Grant, 1993) and direct support staff are typically women (The Lewin Group, 2008). The participants had few close bonds with men.

The participants stated their convoy members provided them with companionship. The appreciation of shared interests and common activities with others by adults with intellectual disabilities is one of the prevalent themes found in qualitative research with this population (Kersh et al., 2013; Knox & Hickson, 2001). Consistent with previous research, the participants stated they receive instrumental²² and emotional support from their convoy members. Additionally, they said they received health related support and appraisal²³.

The participants had few friendships with people without disabilities other than relatives and staff. Much previous research on social relations of people with intellectual disabilities has found the same pattern (Bigby, 2002; Lippold & Burns, 2009; Robertson et al., 2001; van Asselt-Goverts et al., 2014; Verdonchot et al., 2009). This lack in diversity in types of relationships in the convoys is reason for concern. Social inclusion requires connections to others in the community (Bigby, 2005). A lack of community inclusion jeopardizes this populations' ability to age well (Heller, 2004).

The participants had the most regular in-person contact with those with whom they had more distant bonds. This means there is an element of superficiality to these individuals' everyday networks. Relationships they deem to be of the best quality were not as accessible to

²² See Chapter II, section D, page 22 for an explanation of instrumental support.

²³ See Chapter II, section D, page 21 for an explanation of appraisal.

them. Additionally, those the participants disliked were most often housemates with disabilities. Again, these are people with whom the participants were likely to have most contact. The participants were rarely close to extended family members and most were not in romantic relationships.

An important gender difference was observed in the participants' convoys. The female participants in this study had twice as many family relations in their inner circles as did male participants. This finding seems consistent with previous observations in the literature. In a study by Lunskey and Benson (1999) family caregivers reported women with intellectual disabilities in residential setting had larger networks and received more support than their male counterparts.

No clear differences were found between the convoys of the Caucasian and African-American participants and those in different residential settings.

2. **How do the social relations of older adults with intellectual disabilities develop and change throughout their life courses?**

The participants retrospectively described their convoys in early life as dominated by close bonds with parents and siblings. The participants in this study who were institutionalized in childhood remained in contact with their families. This is unusual because during the first half of the last century, many institutionalized children with disabilities often had little or no contact with their families (Leiter, 2012). The participants who left their family homes later in life also remained in contact with their living relatives.

The participants remembered their parents as teaching them skills and providing them with emotional support. As the participants grew into young adults, their parents provided them with companionship. There is little research on the implications of family support on the psychological adjustment of individuals with intellectual disabilities (Widmer, Kempf, Sapin, &

Galli-Carminati, 2013). However, closeness with mothers and fathers is associated with better psychological adjustment in children in the general population (Rothon, Goodwin, & Stansfeld, 2012).

Even though participants had numerous positive memories of support from their parents, a number of them indicated they were maltreated and even abused by their fathers.

Unfortunately, this finding is not surprising, as children with disabilities are three to four times more likely to be abused or neglected than their peers without disabilities (Murphy, 2011). The first government sponsored child protective services in the U.S. stem from the 1960s, but it was not until the end of the 1970s that a nationwide system of government-sponsored child protection was established.²⁴ Abuse can cause long-term trauma in people with intellectual disabilities (Mitchell & Clegg, 2005). Unfortunately, symptoms of trauma are under-recognized in practice (Hollins & Sinason, 2000).

Earlier studies have shown that adults with intellectual disabilities tend to have long-lasting close relationships with their siblings (Bigby, 1997a; Heller & Arnold, 2010). This study confirms this finding. Siblings held permanent membership in most participants' convoys. Sisters in particular were positive constants in many of the participants' lives. Conforming with the findings of previous research (Bigby, 1997a), even when there were multiple siblings, one of them usually had the most involvement in the lives of the participants. For example, Henry was closest to his sister Danielle, Zach to his sister Doris, Lucy to her brother, and Charlotte to one of her sisters.

²⁴ The Child Abuse Prevention and Treatment Act (CAPTA) Pub.L 93-247, January 1, 1974, 88 Stat. 4., authorized federal funds to improve the state response to physical abuse, neglect, and sexual abuse. Child abuse reporting laws and enhanced awareness of child abuse produced an increase in intervention (J. E. B. Myers, 2008).

Research has yet to give sufficient attention to the roles of extended family members in supporting individuals with intellectual disabilities and the impact of this support on the well-being of these individuals. As family contexts have become more heterogeneous, the exclusive focus on support from the nuclear family should be reconsidered (Widmer et al., 2013). The majority of participants reported at least one extended family member being involved in their early and mid-lives, for example, a grandparent or aunt or uncle. On occasion these family members supported the participants when their immediate families were unable. Widmer and colleagues (2013), exploring the family configurations of young adults with mild intellectual disabilities, found they cited mothers fathers and siblings first as significant family members. Other family roles that were cited less often but nevertheless were represented in significant numbers, included grandparents, uncles, and aunts. Walmsley (1996) also found that adults with intellectual disabilities identified parents, siblings, aunts, and uncles as their most important family members. The participants in this study retrospectively identified the same family members as the participants in both of those studies.

The participants made few mentions of close childhood friends. This might be due partly to the fact that the participants did not have close friends and partly to the fact they might not remember childhood friends. However, it seems that childhood friends did not play significant roles in their lives as they did remember details about relationships with family members from childhood. Support from friendships with peers, who usually provide some form of companionship, is functionally distinct from parental support (Widmer et al., 2013).

A relatively high number of participants in this study reported attending at least some special education classes. By one estimate, only 15% of children with intellectual disabilities in the 1960s who were living with their families received special education in public schools.

However, children in urban areas were more likely to receive special education than those in rural areas (Mackie, 1969).

Students with intellectual disabilities are more likely to be rejected socially than their nondisabled peers (Kersh et al., 2013). A number of participants in this study reported being bullied in school by other students. Bullying can have serious long-term consequences for victims. Children who are bullied have been found to remain at risk for a range of poor outcomes decades after exposure (Takizawa, Maughan, & Arseneault, 2014).

The participants left their family homes at different ages. They each remembered how they felt at the time of separation, even when it had been decades since leaving their family homes. A number of participants experienced resentment against their parents, emotional distress and an overall lack of self-determination related to their moves. It is unclear to what extent the participants were involved in any future planning activities as young adults. Even if they were involved in decision-making processes, they did not share that with me. A number of participants did state that decisions about their lives were made for them. Research previously found older adults with intellectual disabilities typically have had few opportunities to exercise self-determination in their lives (Heller, Sterns, Sutton, & Factor, 1996).

Because the participants were very close to their parents, losing their parents was particularly difficult for them. Parental bereavement has been found to be a source of trauma for people with intellectual disabilities. Distressing bereavements after death of parents have been observed in the literature, particularly when adults with intellectual disabilities witnessed the parent dying or found them dead (Mitchell & Clegg, 2005). People with intellectual disabilities are more likely to develop mental health problems following bereavement than those in the general population (Bonell-Pascual et al., 1999).

The participants did not speak about their mid-lives with the same fond memories as their childhoods. Adulthood for people with intellectual disabilities is often regarded as an undifferentiated period of time. Little is known about the challenges of middle age for those with intellectual disabilities (Bigby, 2004; Knox & Bigby, 2007). This study demonstrates that moving away from the family home and parental death are challenging transitions that often take place when adults with intellectual disabilities are in their middle age.

After moving out of family homes, the participants lived in a range of residential settings. The participants shared memories of conflicts with peers and tension with direct support staff at residential facilities. The participants were not always close friends with their housemates. Several women who earlier in their lives were in romantic relationships recalled instances of abuse. A qualitative study with nine women with intellectual disabilities in Australia found most of the women reported unwanted or abusive sexual experiences. The authors of this study suggested General practitioners need to be aware of the possibility of sexual abuse of women with intellectual disability, and offer interventions (Eastgate, Van Driel, Lennox, & Scheermeyer, 2011).

Most participants changed residential facilities many times. Rarely did they stay in contact with disabled peers or direct support staff from previous residences. Most of their relationships other than relatives seemed to be specific to their residences. Knox and Hickson (2001), who solicited the meaning of friendship from a number of individuals with intellectual disabilities, found their subjects described longevity, particularly a sense of shared history, as a significant characteristic of a good relationship. In the present study, the participants clearly shared their sense of shared history with their siblings but not with other convoy members.

3. **How does the social convoy model apply to the experiences of older adults with intellectual disabilities?**

Based on the study's results a number of statements can be made regarding the applicability and usefulness of the social convoy model in research with people with intellectual disabilities. The first concerns the use of the model as a data collection instrument. The social network mapping instrument (Tracy & Whittaker, 1990) that is based on the social convoy model can be used effectively with people with intellectual disabilities. The visual nature of the three concentric circles makes the abstract concept of the social convoy tangible to those with mild and moderate intellectual disabilities. The participants made clear distinctions between relations in the model's first and second circles. It was more difficult for them to conceptualize their relations in the third circle.

Research using the social convoy model in the general population resulted in the creation of social network typologies (Fiori et al., 2006). These typologies are then used as a variable to measure differences in mental health. The social networks of this study's participants cannot effectively be compared to the typologies found by Fiori and colleagues (2006) since three of the six variables they used in creating their typologies do not usually apply to people with intellectual disabilities (married, number of children, contact with children). The convoys of the present study's participants would most likely fall into one of the 'restricted networks' conceptualized by Fiori and colleagues (2006).

This study's participants seemed to have convoys that fall into one of the three following categories: 1) family dominated; 2) direct support staff dominated; and 3) diverse. Those with family dominated convoys have most close bonds with relatives. Examples are the convoys of Zach, Betty, Mary, Henry, Lucy, and Charlotte. Those with convoys dominated by direct support

staff lack close bonds with family. Examples are the convoys of Roger, William, and Philip. Those with diverse convoys have a more equal balance of convoy members including family, direct support staff, and peers with disabilities. Examples are the convoys of Barbara, Linda, and Matthew.

The social convoy model assumes a curvilinear pattern in convoy membership across the life span (Antonucci et al., 2004). It predicts young children have few but growing numbers of close relations. It assumes that convoys expand through young and middle adulthood as roles and family size increase, and that convoys decrease in late life as roles and families become more limited. Based on the retrospective accounts of the study's participants, it seems they had few close relations in childhood. Their convoys expanded with direct support staff and peers with disabilities as they left the family home. They did not tend to assume social roles such as those in the general population do, for example of becoming a college student, spouse, parent, or employee. New convoy members did not replace the loss of older relatives such as grandparents, parents, aunts and uncles. It therefore seems the participants' convoys decreased in size earlier in life than in the general population.

The social convoy model predicts relative stability in convoy membership across the life courses of people in the general population. The convoy model also acknowledges that changes in personal and situational factors can lead to important transitions in social convoys (Antonucci et al., 2004). A lack of continuity and stability in the participants' convoys across their lives was dominant in most of their experiences. Most participants did not have a stable convoy that moved with them through life. It seems participants with close bonds with family members and who lived at home with family for most of their lives had the most stable convoys. For those who left

the family in childhood or young adulthood, changes in residential settings caused constant changes to convoys.

The social convoy model allows investigating influences of convoys on individuals' experiences through life transitions. The lifespan focus of the model proved helpful in conceptualizing social networks of people with intellectual disabilities since life transitions were the most poignant elements in the participants' aging experiences. Investigating the roles and influences of convoys on these transitions is valuable for research in the intellectual disability field.

The social convoy model posits that convoy members can benefit and hinder individuals' developments. The present study clearly identified positive and negative influences of social relations on the development and experiences of the participants as they aged. Convoy members positively influenced participants' well-being by providing support. Abuse and conflict were characteristics of social relations that negatively influenced participants' well-being.

The social convoy model presumes individual autonomy in acquiring, developing and breaking off social relationships. Many people with intellectual disabilities depend on supportive others to help them make relationships (Bigby, 2002; McConkey, 2005). Only a small number of this study's participants mentioned they independently maintain their social relations.

A model that conceptualizes social relations of individuals with intellectual disabilities from a life course perspective needs to take into account these individuals' needs for externally provided supports to develop and maintain their social networks, particularly through life transitions that tend to disrupt their convoys.

4. **What are the main facilitators and barriers experienced by older adults with intellectual disabilities to the development and enjoyment of social relations?**

A number of facilitators and barriers were identified from the participants' perspectives in the development and enjoyment of their social relations over the life course. The participants had strong bonds with their immediately family members while growing up, particularly those who were raised at home by their families. A number of participants mentioned they were members of community groups when they were children and young adults. Some participants stated their parents actively facilitated their participation in community activities and their relationships with their peers. It is unclear whether the parents of other participants living at home did so to the same extent.

The participants made few mentions of childhood friends and they identified bullying as an important impediment to their relationships with their peers in school and the community when growing up. Abuse by family members and romantic partners and conflicts with peers and direct support staff in residential settings were additional barriers to positive relationships for a number of the participants.

Most individuals move during their lives, and social convoys are impacted by these transitions (Antonucci & Knipscheer, 1990). However, these transitions are likely to impact individuals with intellectual disabilities to a greater extent than those in the general population as their convoys might be small to begin with. From young adulthood, most participants moved multiple times. They usually did not stay in contact with relationships made at previous residences.

Only a few participants indicated they independently initiate and sustain contact with their convoy members. Some mentioned instances of their convoy members facilitating

relationships with other convoy members. Most did not state that they needed additional social skills to successfully maintain their relationships. They stated that communication and transportation barriers hindered their ability to maintain their relationships. A unique study by Abbott and McConkey (2006) gained the perspectives of adults with intellectual disabilities on barriers to their social inclusion. One of the barriers their subjects identified concerned a lack of available transportation to community facilities. The participants in the present study likewise identified a lack of transportation as a barrier to in-person contact with convoy members.

5. **How do older adults with intellectual disabilities experience their social relations as they age?**

As they aged, the participants experienced both feelings of belonging and of longing. In comparison to the general older population, the participants had few close social relations. Most of them had no surviving parents, were never married, had no children, and few close friends. Previous research has found the same patterns (Bigby, 2002, 2004, 2005; Lippold & Burns, 2009; Maaskant, 1999, 2007; Meeusen & Maaskant, 2004; Robertson et al., 2001; Seltzer, 1985).

Most participants were satisfied with their friendships and their social roles. The participants' positive past life experiences, particularly with parents and siblings in their early lives, remained a source of continuing happiness and belonging. The participants clearly articulated the significant roles their parents had in their lives. Similarly, in a study by Walmsley (1996), adults with intellectual disabilities stated their deceased relatives had been important to them and they dwelt on the supportive nature of their families. One of the research participants in a study by Barber and Hupp (1993) said the convoy member who passed away: 'lived in his heart.'

On the other hand, the loss of their parents also continued to foster feelings of longing as the participants aged. They often referred to the passing of their parents and other family members. This has been reported before in research in the field. Knox and Hickson (2001) found that their study's participants with intellectual disabilities enacted their relationships by remembering and reminiscing over past times and experiences, even when these relations had passed away. The experience of loss of relationships with aging was prominent in the participants' accounts. Feelings of loneliness were less prevalent. For most participants, one did not equate with the other.

B. Methodological Considerations

This study demonstrated that social network mapping and life story methods can be effectively applied in research with older adults with intellectual disabilities under a number of conditions. The researcher must be comfortable with the fact that research participants with intellectual disabilities have different needs that need to be accommodated for this population to meaningfully participate in research. The researcher needs to be flexible and creative in applying individual approaches that meet these distinctive needs. Some participants independently completed their social network maps and others needed support to do so. Some participants benefitted from greater involvement of the key support person than did others. In some cases information on the participants' life histories had to be gathered from an unforeseeable number of sources, such as the participants' files, a third informant or even the internet. The researcher must also take time to work with this population. Meeting multiple times and providing ample processing time in between and during interviews helps build rapport with this population.

Preparing lifelines built rapport and was an accessible way to engage the participants in the research process. The visual representation of the life course in the Lifeline Interview

Method (Schroots & Birren, 2001) made the abstract concept of life history more concrete to the participants. It may be ineffective to use research methodologies that emphasize people's limitations and make them feel inadequate (Booth & Booth, 1996; van den Brandt-van Heek, 2011). The life line process did not ask information of the research participants that they were unable to provide. Rather, the lifelines empowered the participants as the lifelines gave them a sense of history about their own lives and were a source of pride to them.

A qualitative description of the experience and impact of the lifeline process on older individuals with intellectual disabilities was beyond the scope of the present study. Future research should gain more insight into the ways this methodology can benefit life story research with this population.

Even though I included the individual perspectives and experiences of the research population, it was still me, the researcher, who defined the research questions, handled and controlled the interpretation of the data and made and communicated the conclusions. The field needs to continue to develop and experiment with ways of including this group, not only as primary informants and participants in research, but also as partners in setting and implementing future research agendas (Bigby & Balandin, 2004). To make future research more inclusive, people with intellectual disabilities could be trained to become lifeline facilitators and co-researchers.

C. **Practice and Policy Implications**

This study provides insights into how older adults with intellectual disabilities experience their social relations from a life course perspective. These insights can foster development of strategies to support the social relations of this population that align with their needs and preferences.

It has been suggested a combination between support-based and skill-based interventions might prove most beneficial in strengthening the social networks of this population (Carter & Hughes, 2005). Support-based interventions include person-centered future planning²⁵.

Planning has been identified as a central task for establishing transition success of individuals with intellectual disabilities (Heller & Kramer, 2009; Kim & Turnbull, 2004). The present study illustrates the importance of these initiatives, as the participants experienced a number of life transitions that challenged their well-beings, such as moving out of family homes and parental death. The field has started to develop person-centered future planning activities to support adults with disabilities at different moments in their lives such as their transitions from childhood into adulthood and from middle age into old age (Heller & Caldwell, 2006; Heller et al., 1996; Schippers & van Boheemen, 2009). Future planning tasks relate to current and future vocational choices, residential options, education and training, and leisure-time activities (Parker Harris, Heller, Schindler, et al., 2012). The future planning process provides an opportunity for people with intellectual disabilities to develop and assert their self-determination skills (Heller & Caldwell, 2006). A growing literature base suggests that the development of self-determination of adults with intellectual disabilities leads to an enhanced quality of life (Blacher, 2001; Wehmeyer & Schwartz, 1998) and promotes aging well of this population (Heller, 2004).

Two related interventions to supplement and be integrated into person-centered future planning activities have yet to receive adequate attention in practice: social network mapping and life history work. Both hold potential to make person-centered future planning more effective.

²⁵Person-centered planning aims to develop collaborative, goal-oriented supports focused on community participation and positive relationships (Claes, Van Hove, Vandeveld, van Loon, & Schalock, 2010). The terms ‘person-centered planning’ and ‘future planning’ are used interchangeably in the field. I use the term ‘person-centered future planning’ to indicate activities that involve people with intellectual disabilities in the planning of their own lives at various moments across their life courses.

The social network mapping process can not only chart individuals' social convoys, but importantly, also investigate individuals' needs and desires regarding social relations.

Discrepancies between current and the desired convoys can be addressed by setting goals as part of person centered planning processes. These goals can be related to expanding the social convoy with new contacts and/or to strengthening existing ties with convoy members, such as family members (Bigby, 2004; van Asselt-Goverts et al., 2014). Regular mapping of relationships with the person with an intellectual disability can address potential challenges with maintaining social relationships when circumstances change (Bigby, 2004). Based on the present study's results this is particularly useful during transitions that are likely to disrupt convoy membership.

In person-centered future planning processes, close convoy members are asked to take responsibility in helping the individual with an intellectual disability achieve goals. The lack of social relationships of those with intellectual disabilities has been identified as an impediment to person-centered planning (Claes et al., 2010). Action based on social network mapping can address this obstacle by helping expand the convoy of support so that person-centered planning can be more successful.

This study demonstrated that both negative and positive life experiences with convoy members had a lasting impact on the participants' well-being as they aged. Understanding past experiences of older adults with intellectual disabilities is helpful to understand their current needs. 'Life books' have been used in some European countries to record the life stories of people with intellectual disabilities (Meininger, 2005; Van Puyenbroeck & Maes, 2008). Life story work can assist direct support staff to get to know the needs of the person with an intellectual disability better (Meininger, 2003). In the present study direct support staff learned new information about the participants' life histories from assisting with preparation of social

network maps and lifelines. Life story work can improve understanding of the history and significance of relationships of individuals with intellectual disabilities which, in turn, can make social network mapping more effective (Bigby, 2004, 2005).

Skill-based interventions aimed at strengthening the social networks of this population include social skills trainings. Such training can assist people with resolving conflict and expressing feelings (Heller et al., 2010; McConkey, 2005). This study confirms the importance of developing such skills as many participants recalled instances of negative encounters with convoy members. Additionally, training that promotes the development of self-determination skills among individuals aging with intellectual disabilities is warranted. Such training can improve people's ability to better advocate for themselves and articulate their needs.

In order to better meet individuals with disabilities' needs for social relations, support providers need to better advocate for them as well. Most participants in this study lived in residential settings; hence the following recommendations apply to strategies to be employed in such settings. Direct support staff often focus on providing instrumental support and do not give the same priority to other facets of support, such as encouraging the growth of informal networks of support (Knox & Hickson, 2001; McConkey, 2005; Power, 2010). Bigby's (2004) suggestion of consciousness raising among support providers provides a starting point to improve this situation. Direct support staff should be informed about the positive impact of supportive relationships on the well-being of older adults with intellectual disabilities. Additionally, they should be made aware of the roles they can play in network building of this population and find ways to foster the development of informal sources of support to this population (Bigby, 2000a, 2005).

Some residential settings might benefit from the implementation of a skilled inclusion/relationship worker responsible for mapping residents' social networks, and who develops individual strategies to engage residents in informal relationships (Bigby, 2008). This worker could address obstacles that residents experience in maintaining their social relations. These might include communication and transportation barriers.

Because many adults with intellectual disabilities occupy only few social roles, this worker might encourage residents to act on desired social roles by enabling participation in meaningful activities. This might include participation in social and community activities and volunteer work. An intervention program developed by Stancliffe, Bigby, and colleagues (2014) to assist individuals with intellectual disabilities transition to retirement, proved effective in promoting social inclusion and promoting these individuals' participation in community groups with the support from trained mentors from these community groups.

The present study's findings indicate that supporting older adults with intellectual disabilities in coping with age-associated losses needs precedence in support practices. The need for bereavement counseling for individuals with intellectual disabilities has been recognized by many in the field (Sterns, Kennedy, Sed, & Heller, 2000). Coping with the loss of significant others is a universal experience of older adults (Ludlow, 1999). For this study's participants, losing convoy members had great adverse impact on well-being, as their convoys tended to be small and unstable across their life courses. The work of Irene Tuffrey-Wijne (2013) on breaking bad news to people with intellectual disabilities has potential to help these adults cope with age-associated losses.

D. **Limitations**

The study has several limitations. The first limitations relate to the sampling and recruitment. The study relied on a small purposive sample. It therefore was mostly exploratory in nature. The study included only people in the Chicago area. The majority of the participants lived in the Chicago suburbs. The sample did not capture the experiences of those who live in rural areas. Their experiences might be different from the participants in the study. For example, research has indicated that adults with disabilities in rural areas experience unique barriers in community participation. The combination of being unable to drive and being unable to access public transport have been found to affect people with intellectual disabilities who live in rural areas (F. Myers, Ager, Kerr, & Myles, 1998). On the other hand, Nicholson and Cooper (2013) have argued that people with intellectual disabilities may benefit from the greater social support and community spirit found in rural areas.

This study's sample of research participants included eight Caucasian older adults (66.7%) and four African-American older adults (33.3%). In 2013, the Illinois population consisted of 77.7% Whites and 14.7% African-Americans. Sixteen point seven percent of the Illinois population consisted of Hispanics and Latinos and 5.1% of Asian-Americans (U.S. Census Bureau, 2011). Individuals from these groups were not included in the study even though they might have different life experiences because of cultural or other differences.

The participants were recruited from Cook, Lake, DuPage, and McHenry counties in Illinois. These counties include the city of Chicago and the north and west Chicago suburbs. Even though the study did include two participants who live in the city of Chicago, they both lived on the north side of the city. The participants were recruited from more affluent areas in

Illinois (U.S. Census Bureau, 2011). This might have impacted the experiences represented in this study.

The study did not include any older adults with intellectual disabilities who do not receive support services. Older adults with intellectual disabilities are less likely to be known to services than their younger counterparts, particularly if they have mild disabilities (Bigby & Balandin, 2004). Bigby and Balandin (2004) have acknowledged that locating older people with intellectual disabilities who do not access services is a major challenge for researchers.

The majority of people with intellectual disabilities in the United States live at home with family caregivers (Braddock et al., 2011). Yet only one participant in this study lived at home with a family caregiver. The major findings of this study therefore do not include the experiences of those people with intellectual disabilities who live at home with a family caregiver. The sample included participants who, after they were institutionalized as children, stayed in contact with their families. This was unusual for this time period. Because participants had to be able to communicate verbally to participate in the study, the experiences of people with severe intellectual disabilities were not included in the study.

Gender of the participants was found to be a factor related to differences in social relations across the life course. Even though race was also a sampling criterion, no clear patterns of differences were found between the social relations of Caucasian and African-American participants. Similarly, the use of residential history as a sampling criterion assisted in creating a diverse research sample, but did not result in obvious differences in findings between individuals with different residential histories. It is possible the subgroups of the study's participants based on race and residential history were not large enough to capture possible differences. Inclusion of the participants' families' socio-economic status as a factor in analysis might have

resulted in additional insights in potential differences in the experiences of the participants.

However, gaining this information would have been challenging, considering most participants would not have been able to provide this information. For those without surviving relatives, it might have been impossible to reliably retrieve that information.

Though the study aimed to include age as a sampling criterion, the participants did not vary significantly in age. For example, no participants in their late seventies or eighties were participants in the study. It was therefore difficult to make meaningful comparisons between those in different age subgroupings.

The study reported on the current social convoys of a small number of participants. The trends included provide insight into potential areas of interest to be explored in future research. However, they must be interpreted with caution as observed differences were not tested for statistical significance.

This study also reported how social convoys were experienced retrospectively by older adults with intellectual disabilities. I discussed the connections between early and late life experiences with social relations based the participants' retrospective views. This is of value as older adults' well-being is influenced by their previous life experiences. This type of research also knew challenges. Some participants had problems recalling certain aspects of their past experiences. I minimized participants having to rely exclusively on facts, concepts of time and memory and instead, focused on retrieving their experiences. I supplemented the information they provided with information from residential files and key support persons. However, residential files were often poorly kept and not all participants had key support persons who knew them their whole biographies.

I met with the participants multiple times to solicit their experiences. Member checks were completed with participants regarding their own personal data. Due to the researcher's lack of resources, they were not asked to provide feedback on the results of the study's analyses. This would have made the study stronger and more inclusive.

The results of this study must be placed into a historical perspective sensitive to cohort specific influences on life trajectories. Historically, life quality in large institutions in the U.S. was poor. Improvement in intellectual disability services started after the election of President Kennedy in 1961. The 1970s saw considerable progress in public policy for people with disabilities in the U.S. (Braddock & Parish, 2001). Since the 1970s a decreasing number of people with intellectual disabilities in the U.S. have lived in public institutions, private institutions and nursing facilities. Additionally, an increasing number of people with intellectual disabilities receive supports in smaller residential settings. The federal government supported these trends with the passage of the Americans with Disabilities Act (ADA) in 1990²⁶. Unlike individuals with disabilities who are coming of age today, the participants in this study did not benefit throughout their lives from these disability policies designed to improve their opportunities for learning, working, and living in local communities (Leiter, 2012).

E. **Recommendations for Future Research**

A number of recommendations can be made for future research on social relations of older people with intellectual disabilities. Longitudinal designs can follow people into new situations and across their lives (Elder & Giele, 2009). Such designs can provide additional

²⁶ In *Olmstead et al. vs. L.C. et al.* (1999 (527 U.S. 581)), the US Supreme Court affirmed that the ADA requires states to provide services for disabled people in the 'most integrated setting appropriate' and that states are obligated to place people with disabilities in community settings when treatment professionals determine such settings are appropriate; the individuals themselves do not oppose such placement; and the state can reasonably accommodate community placement, given its resources (Lakin & Stancliffe, 2007).

insights into patterns of social relations of individuals with intellectual disabilities across their life courses. This knowledge is critical for providing the psychosocial supports needed for aging well (Heller & van Heumen, 2013).

More research is needed to better understand the underlying forces that cause the differences between the convoys of older men and women with intellectual disabilities. The findings of this study suggest that specific attention be given to ensure older men with intellectual disabilities receive sufficient social supports.

The study found the participants had few close bonds with men. Future research can investigate how this sex specific bonding differential might impact women and men with intellectual disabilities differently. The relationships of men with intellectual disabilities with other males might serve different functions than the relationships of women with intellectual disabilities with males²⁷.

Relationships among people with intellectual disabilities and relationships of people with disabilities and their support staff are understudied (Clarkson, Murphy, Coldwell, & Dawson, 2009; Knox & Hickson, 2001). The findings of this study indicate research into these relationships and development of strategies to improve these relationships is warranted.

Research on the effects of social network interventions is rare in the field of intellectual disability (van Asselt-Goverts et al., 2014). There is a need for evidence-based practice that promotes social networks. A standardized social network mapping tool needs to be developed that can be used and tested in practice for its effectiveness.

The field could also benefit from the development of a scale to be used in research that measures satisfaction with social relations among those with intellectual disabilities. Such a scale

²⁷ Zach mentioned that his bonds with other men hold a unique function: “*We joke around. When I am with them, if I swear a little bit, it is okay, because I am with the guys.*”

could also help identify barriers and facilitators to meaningful social relations among this population.

The research literature on person-centered approaches to life story work is underdeveloped and diffuse. Life story work tools should be created and tested that can be used with people with intellectual disabilities by family caregivers and direct support staff. These tools enable direct support staff to understand the needs of individuals with intellectual disabilities from a life course perspective.

Future research employing life history research methods with persons with intellectual disabilities should improve its effectiveness and accessibility in its application. Researchers working with aging and disability populations need to collaborate to further the development and applications of life story research. There is a particular need for methods that rely less on or do not require verbal communication and a clear understanding of time and memory. Such developments can also aid the participation of those with severe and profound intellectual disabilities in research.

Little is known about ways of supporting older people with intellectual disabilities in coping with the loss of close relationships in their lives (Knox & Hickson, 2001; Ludlow, 1999). Dealing with the loss of close relationships through death needs to be addressed in the intellectual disability field. This is of particular importance for those who have relatively narrow social networks (Knox & Hickson, 2001).

F. **Conclusion**

This study's findings on how older adults with intellectual disabilities experience their relationships as they age are informative as the field of intellectual disability research has yet to fully engage with older adults' perspectives on their social relations. Additionally, this study's

findings reveal insight into this population's convoys from a life course perspective, and demonstrate the positive and negative ways older adults with intellectual disabilities are impacted by experiences regarding their convoys earlier in life.

APPENDICES

APPENDIX A

SEEKING OLDER PERSONS WITH INTELLECTUAL DISABILITIES (50 YEARS OR OVER) AND THEIR SUPPORT PERSON TO PARTICIPATE IN A RESEARCH STUDY

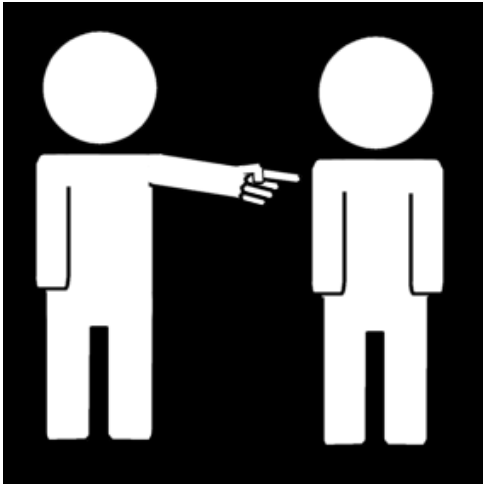


The study focuses on social relations of older persons with intellectual disabilities across the life course. As a participant with a disability in this study you will be asked to participate in interviews in which we look at your lifeline and talk about your life history and social relations. You might also be asked to participate in a DVD in which you talk about your life. You will be asked to meet with the researcher between 4 to 6 times. Participation will take 5 to 10 hours of your time. As a support person in this study you will be asked to participate in interviews about the life of the person with a disability. You might also be asked to support the person with a disability during his or her interviews. You will be asked to meet with the researcher between 4 to 6 times. Participation will take 3 to 8 hours of your time.

If you are interested please contact:

Lieke van Heumen, Rehabilitation Research and Training Center on
Developmental Disabilities and Health, University of Illinois at Chicago,
312.996.7988 or lvheumen@uic.edu

APPENDIX A (continued)



Are you a person with an intellectual disability?



Are you 50 years old or older?

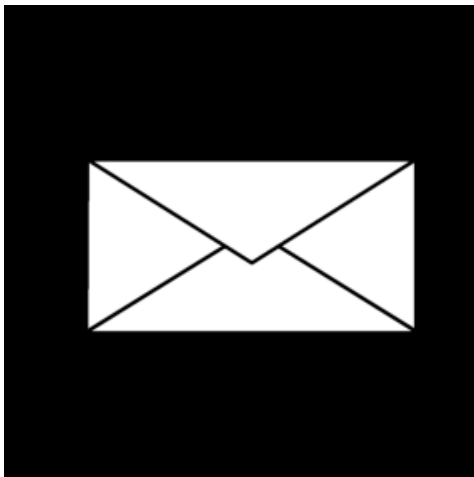


Would you like to take part in a research study?

APPENDIX A (continued)



Would you to like to talk
about your life and the
people important to you?



Write to Lieke van Heumen
at lvheumen@uic.edu

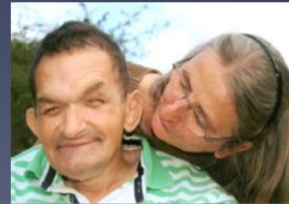


Or call her at 312.996.7988

APPENDIX A (continued)

Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective

Lieke van Heumen, MS
PhD candidate Disability
Studies
University of Illinois at
Chicago



Introduction

- * Increase in number of older people with disabilities
- * Older people with intellectual disabilities (ID) vulnerable group
- * Supportive networks evolve across the life course and are important for older people
- * Social support system of older people with ID rarely investigated
- * Supports and opportunities are needed to develop and maintain a supportive convoy to age with
- * A greater focus on this topic is needed in research and practice in aging and disability

APPENDIX A (continued)

Dissertation research

- * Main research question: 'From a life course perspective, what are the characteristics of the social relations of older adults with ID, how do they experience their social relations and how can these relations be supported in order to promote aging well?'

Aim of Study (I)

- * Contribute to knowledge on the status of the social networks of older people with ID
- * Investigate how these networks are shaped throughout the life course
- * Add to the limited understanding of the experiences of older adults with ID
- * Give insight into the validity of the social convoy model in this population

APPENDIX A (continued)

Aim of Study (II)

- * Add to the literature on life story research with older people with ID
- * Add to promoting and supporting social networks in this population
- * Add to the current status of theory on aging with a lifelong disability
- * Add to the integration of scholarship in disability studies and gerontology

Research participants

- * Persons with ID (N = 20)
 - * 50 years of age or older
 - * able to communicate verbally
- * Key support person
 - * Relative, staff (needs to know person for 2 years, be over age 18)
 - * Advocate
 - * Third informant

APPENDIX A (continued)

Data collection

- * Chicago land area
- * In-depth qualitative interviews with secondary informants including social network mapping
- * Creation of life lines
- * Recording of life histories with person with disability
- * In-depth qualitative interviews with person with disability
- * Additional DVD project

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APPENDIX A (continued)

SCRIPT FOR APPROACHING POTENTIAL PARTICIPANTS

Used by UIC staff when speaking to support persons:

“My name is Lieke van Heumen. I am a graduate student from the Department of Disability and Human Development at the University of Illinois at Chicago. I am doing a research study on the social relations of older adults with intellectual disabilities. I am looking for persons with intellectual disabilities to participate in the study with their key support person. The person with an intellectual disability needs to be 50 years of age or older and able to communicate verbally. As a support person you may participate in the study if you are 18 years of age or older and have supported the person with a disability for at least two years. In order for you to participate in the study, the person with a disability you support will be asked to participate in the study as well. The person with a disability and his or her guardian will need to agree to you being the support person for the study. As a support person in this study you will be asked to participate in interviews about the life of the person with a disability. You might also be asked to support the person with a disability during his or her interviews. If you would like to participate in this research study, you could call me or email me. You can find my contact information on this flyer. Do you have any questions now? If you have questions later, please contact me or you may contact my advisor, Dr. Tamar Heller, at (312) 413-1647.”

Used by UIC staff when speaking to persons with disabilities:

“I am Lieke van Heumen from the University of Illinois at Chicago. I am doing a study on the social relations of older adults with intellectual disabilities. I am looking for persons with intellectual disabilities to participate in the study with their key support person. If you have an intellectual disability you have to be over age 50 to participate. We will ask you to bring a support person to help with the study. This is someone who knows you well. If you participate in the study we will meet with you and your support person. We will talk about your life, your past and the people you know. We will also make a lifeline with pictures that helps us talk about your life. You might also be asked to participate in a DVD in which you talk about your life. If you would like to participate in this research study, you could call me or email me. You can also ask your guardian or support person to call me or email me. You can find my contact information on this flyer. Do you have any questions now? If you have questions later, please contact me or you may call my advisor, Dr. Tamar Heller, at (312) 413-1647.”

APPENDIX A (continued)

Used by community agency staff when speaking to support persons:

“My name is (name staff community agency). We at (name community organization) are helping Lieke van Heumen who is a graduate student from the Department of Disability and Human Development at the University of Illinois at Chicago. Lieke is doing a research study on the social relations of older adults with intellectual disabilities. Lieke is looking for persons with intellectual disabilities to participate in the study with their key support person. The person with an intellectual disability needs to be 50 years of age or older and able to communicate verbally. As a support person you may participate in the study if you are 18 years of age or older and have supported the person with a disability for at least two years. In order for you to participate in the study, the person with a disability you support will be asked to participate in the study as well. The person with a disability and his or her guardian will need to agree to you being the support person for the study. As a support person in this study you will be asked to participate in interviews about the life of the person with a disability. You might also be asked to support the person with a disability during his or her interviews. If you would like to participate in this research study, you could call or email Lieke. You can find her contact information on this flyer. Do you have any questions now? If you have questions later, please contact Lieke or you may contact her advisor, Dr. Tamar Heller, at (312) 413-1647.”

Used by community agency staff when speaking to persons with disabilities:

My name is (name staff community agency). We at (name community organization) are helping Lieke van Heumen from the University of Illinois at Chicago. Lieke is doing a study on the social relations of older adults with intellectual disabilities. Lieke is looking for persons with intellectual disabilities to participate in the study with their key support person. If you have an intellectual disability you have to be over age 50 to participate. Lieke will ask you to bring a support person to help with the study. This is someone who knows you well. If you participate in the study she will meet with you and your support person. You will talk about your life, your past and the people you know. Lieke will also make a lifeline with pictures that helps you talk about your life. You might also be asked to participate in a DVD in which you talk about your life. If you would like to participate in this research study, you could call Lieke or email her. You can also ask your guardian or support person to call or email her. You can find Lieke’s contact information on this flyer. Do you have any questions now? If you have questions later, please contact Lieke or you may call her advisor, Dr. Tamar Heller, at (312) 413-1647.”

APPENDIX A (continued)

RECRUITMENT SCRIPT

“Thank you for contacting me with your interest to participate in the study on the social relations of older adults with intellectual disabilities. My name is Lieke van Heumen, and I am the principal investigator in this study. I would like to ask you some questions about the person with a disability and his or her support person. This information is needed to determine if you can participate in the study. This information will be kept confidential.”

1) What is your name?	
2) Are you the person with a disability?	Yes/No If yes, is there a support person available to speak to?
3) Does the person with a disability have a guardian?	Yes/No
4) Are you the guardian of the person with a disability?	Yes/No If no, who is the guardian? Could you have <i>him/her</i> call me?
5) Does this person live at home with you?	Yes/No If no, where/with whom does the person with a disability live?
6) Where did the person with a disability live in the past and growing up?	
7) How long have you known the person with a disability?	
8) What is the age of the person with a disability?	
9) Is the person with a disability able to communicate verbally?	
10) What is the gender of the person with a disability?	
11) What is the race of the person with a disability?	

APPENDIX A (continued)

“For you to participate in the study, the person with a disability (name) needs to have an intellectual disability, be over age 50 and be able to communicate verbally. The support person needs to know the person with a disability for at least two years and needs to be eighteen years of age.”

“Unfortunately, you are not eligible to participate in the study. Thank you for your interest. I will immediately destroy your personal information.”

OR

“You are eligible to participate in the study. Would you and the person with a disability be able to meet next week to go over the research process? If so, when would be a good time? We can meet at a location of your choosing. I can come to your house, we can meet at a public place or you could come to my office. Where would you like to meet? It is important for you, the person with a disability and his/her guardian (if applicable) to be there. During this meeting we will discuss what the research project entails and ask you and the person with a disability to consent to participate. If you are interested to participate in the study, we can start with an interview on the social relations and the life history of the person with a disability. You may choose to bring any pictures, picture books or other artifacts belonging to the person with a disability.”

APPENDIX B

LIFE HISTORY INTERVIEW KEY SUPPORT PERSON

Names of persons present during interview: _____

Date: _____

Start time interview: _____

End time interview: _____

Location interview: _____

“Now that we talked about the social network of [*name of person with a disability*] as it is right now, I would like to talk about the life history of [*name of person with a disability*]. This will help us understand how the social network of [*name of person with a disability*] developed across *her/his* life and how *his/her* social network is different from the past. Did you bring any pictures or other artifacts?

Residential history

Could you tell me in which city and state [*name of person with a disability*] grew up?

Who was part of the household as [*name of person with a disability*] grew up?

How long, if at all, did [*name of person with a disability*] live in the family home for?

What was the neighborhood of the family home like?

How did [*name of person with a disability*] like growing up here?

What other places did [*name of person with a disability*] live after leaving the family home?

With whom has [*name of person with a disability*] lived after leaving the family home?

What was it like for [*name of person with a disability*] to leave the family home?(i.e did [*name of person with a disability*] know in advance he/she was moving, was he/she prepared, did he/she still visit) How old was he/she when he/she left the family home?

Where does [*name of person with a disability*] currently live?

With whom does [*name of person with a disability*] currently live?

If [*name of person with a disability*] ever got institutionalized, what was this like for him/her? How old was he/she when this happened?

APPENDIX B (continued)

History of social relationships

Could you tell me the name of the mother and the father of *[name of person with a disability]*?

What was the occupation of the parents of *[name of person with a disability]*?

What meaning, if at all, does this occupation have to *[name of person with a disability]*?

How did *his/her* parents call *[name of person with a disability]*?

How was the bond of *[name of person with a disability]* with *his/her* father growing up?

If *[name of person with a disability]*'s father is still alive, what does the bond of *[name of person with a disability]* with *his/her* dad look like today?

How was the bond of *[name of person with a disability]* with *his/her* mother growing up?

If *[name of person with a disability]*'s mother is still alive, what does the bond of *[name of person with a disability]* with *his/her* mom look like today?

If *[name of person with a disability]*'s parents passed away, when did they pass away and how old were they when they passed away? How old was *[name of person with a disability]*?

What was the death of *[name of person with a disability]*'s parents like for *him/her*?

What are the names of the brothers and sisters of *[name of person with a disability]*?

Are they younger or older than *[name of person with a disability]*?

Did any of *[name of person with a disability]*'s siblings pass away? How old were they? How old was *[name of person with a disability]*?

What was the bond of *[name of person with a disability]* with *his/her* siblings like growing up?

Did *[name of person with a disability]* share a room with any of *his/her* siblings growing up? What was this like for *him/her*?

What does the bond, if still existing, of *[name of person with a disability]* with *his/her* siblings look like now?

What was the bond of *[name of person with a disability]* with other relatives like growing up?

APPENDIX B (continued)

What does the bond, if still existing, of *[name of person with a disability]* with *his/her* other relatives look like now?

Where there any others *[name of person with a disability]* had a bond with growing up? (*i.e friends*)

If still existing, what does the bond of *[name of person with a disability]* with these persons look like now?

What pet, if any, did *[name of person with a disability]* grow up with? What was it like having a pet for *[name of person with a disability]* growing up? How did *he/she* call the pet?

Does *[name of person with a disability]* have any pets now? If so, how is it like for *him/her* to have this pet? If not, would *he/she* like to have a pet?

Did anyone important to *[name of person with a disability]* pass away *[other than [names of persons who passed]]*? How old was *[name of person with a disability]* when this happened?

Has *[name of person with a disability]* been part of any social groups in the community growing up? What was this like for *him/her*?

Is *[name of person with a disability]* part of any social groups in the community now? If so, what is this like for *him/her*? If not, what groups would *he/she* like to be a member of?

The disability

When was discovered that *[name of person with a disability]* has an intellectual disability?

How was the disability of *[name of person with a disability]* discovered? How old was *[name of person with a disability]*?

How, if at all, did the disability of *[name of person with a disability]* affect the family?

How did various family members respond to the disability of *[name of person with a disability]*?

What was it like for *[name of person with a disability]* having a disability growing up?

What supports did *[name of person with a disability]* need growing up because of *his/her* disability?

Who provided the most supports to *[name of person with a disability]* when *he/she* was growing up? What was this like for this person?

APPENDIX B (continued)

What supports does [*name of person with a disability*] need now because of *his/her* disability?

Who provides the most supports to [*name of person with a disability*] now? What is this like for this person?

Religion

What religion, if any, did [*name of person with a disability*] grow up with?

What did religion mean to [*name of person with a disability*] growing up?

What does religion mean to [*name of person with a disability*] now?

Sexuality

How, if at all, was sexuality a topic that could be discussed at home?

Does [*name of person with a disability*] have a romantic partner? What is this like for [*name of person with a disability*]? Did [*name of person with a disability*] have a romantic partner in the past? What was this like for [*name of person with a disability*]?

Educational history

What was [*name of person with a disability*]'s education like? Did [*name of person with a disability*] go to primary school? How did [*name of person with a disability*] like going to this school? How old was [*name of person with a disability*]? Was [*name of person with a disability*] integrated in a mainstream school?

Did [*name of person with a disability*] go to secondary school? How did [*name of person with a disability*] like going to this school? How old was [*name of person with a disability*]? Was [*name of person with a disability*] integrated in a mainstream school?

Has [*name of person with a disability*] been part of any other educational programs during *his/her* life?

Employment history

Was [*name of person with a disability*] employed during *his/her* life? What jobs did he/she held? How old was [*name of person with a disability*]? How did he/she like her jobs? Does [*name of person with a disability*] still work?

APPENDIX B (continued)

Life events

What, if any, negative or difficult events happened when [name of person with a disability] was growing up that had an impact on [name of person with a disability]? (i.e hospitalization, war, fire, theft, passing away of loved one, etc.) How old was [name of person with a disability]?

What, if any, are two positive events that happened when [name of person with a disability] was growing up that he/she remembers and talks about? How old was [name of person with a disability]?

What, if any, negative or difficult events happened when [name of person with a disability] was at middle age? (i.e hospitalization, war, fire, theft, passing away of loved one, etc.) How old was [name of person with a disability]?

What, if any, are two positive events that happened when [name of person with a disability] was at middle age that he/she remembers and talks about? How old was [name of person with a disability]?

What are the three most important life events for [name of person with a disability]? How old was [name of person with a disability]?

What are the three most important life transitions for [name of person with a disability]? How old was [name of person with a disability]?

What is growing older like for [name of person with a disability]?

Social network over time

Does the social network of [name of person with a disability] look similar as it looked in the past? What looks similar? What looks different?

How, if at all, were the relationships of [name of person with a disability] affected after moves to different homes across his/her life?

How, if at all, were the relationships of [name of person with a disability] affected at schools he/she visited across his/her life?

How, if at all, were the relationships of [name of person with a disability] affected by the different jobs he/she might have held across his/her life?

APPENDIX B (continued)

How, if at all, have [*name of person with a disability*]'s relationships supported him/her when moving to other homes?

How, if at all, have [*name of person with a disability*]'s relationships supported him/her at school?

How, if at all, have [*name of person with a disability*]'s relationships supported him/her at his/her different jobs?

Has [*name of person with a disability*] experienced any barriers during *his/her* life to build relationships with other? What has this been like for *him/her*?

Are there barriers to have relationships with others that [*name of person with a disability*] experiences today? What is this like for *him/her*?

What has helped [*name of person with a disability*] have relationships with other across *his/her* life?

What can help [*name of person with a disability*] today to have relationships with others?

Can you think of anything that can help build the social relations of [*name of person with a disability*] and what would that be?

How has [*name of person with a disability*] valued *his/her* relationships across *his/her* life?

Are there any differences in the number of social relationships of [*name of person with a disability*] now that *he/she* is growing older?

Are there any differences in how important the number of social relationships [*name of person with a disability*] has is to *him/her* now that *he/she* is growing older?

What, if any, are some of the differences in amount of contact [*name of person with a disability*] has with *his/her* social relationships now that *he/she* is growing older?

What, if any, are some of the differences in how important the amount of contact [*name of person with a disability*] has with *his/her* social relationships is to *him/her* now that *he/she* is growing older?

What, if any, are some of the differences in the amount of support [*name of person with a disability*] receives from *his/her* social relationships now that *he/she* is growing older?

APPENDIX B (continued)

What, if any, are some of the differences in how important the amount of support [*name of person with a disability*] receives from *his/her* social relationships is to *him/her* now that *he/she* is growing older?

What, if any, are some of the differences in the amount of support [*name of person with a disability*] provides to *his/her* social relationships now that *he/she* is growing older? How is this for *name of person with a disability*]?

Which of [*name of person with a disability*]'s relationships have lasted *his/her* lifetime? What do these relationships mean to [*name of person with a disability*]?

Which persons are no longer part of [*name of person with a disability*]'s social network that were so before? What are reasons these persons are no longer part of [*name of person with a disability*]'s life?

Who are the most important persons that became part of the social network of [*name of person with a disability*] after *he/she* became an adult? When did these persons become a part of the network? What is this like for [*name of person with a disability*]?

Has the number of intimate relationships of [*name of person with a disability*] changed across *his/her* life? If so, how? (*first circle of convoy*)

Has the number of people [*name of person with a disability*] does not quite feel as close to but who are still important to *him/her* changed across *his/her* life? If so, how? (*second circle convoy*)

Has the number of other persons who are close and important enough to [*name of person with a disability*] to be mentioned changed across *his/her* life? If so, how? (*third circle convoy*)

Conclusion

Is there anything I should know about [*name of person with a disability*] as I work with *him/her*? Can you think of any questions I should ask *him/her*?

Is there anything else you would like to tell me or talk about?"

Observations and comments of researcher

APPENDIX B (continued)

INTERVIEW PERSON WITH DISABILITY

Names of persons present during interview week 1: _____

Date interview week 1: _____

Start time interview week 1: _____

End time interview week 1: _____

Location interview week 1: _____

Description of pictures and artifacts used during interview week 1: _____

Name key support person: _____

Names of and relationships with intimate contacts: _____

Other names of and relationships with contacts among five discussed in social network map: _____

Current social network

***[Name key support person]* told me about the persons that are most important to you in your life. These are the persons you cannot imagine being without.**

I would like to talk about *[name intimate contact]*. Can you tell me about what *he/she* means to you?

How long have you known *him/her* for? Can you show me on your lifeline?

How do you like spending time with *him/her*? What is that like for you? How important is that to you?

How often do you see *him/her*? What is that like for you?

How often do you talk to *him/her* over the phone or by email or text message?

What are some of the activities you do with *him/her*? How do you like that?

APPENDIX B (continued)

What are some of the things *he/she* helps you with? How do you like that? How important is that to you?

What does *he/she* do when you are upset? Can you tell me some more about that? What is that like for you? How important is that to you?

What does *he/she* do when you do something well? Can you tell me some more about that? What is that like for you? How important is that to you?

What does *he/she* do when you do something that is not allowed or not good for you or not safe? Can you tell me some more about that? What is that like for you? How important is that to you?

Can you tell me if you ever have arguments with *him/her*? Can you tell me some more about that? What is that like for you?

Is there anything you help *him/her* with? Can you tell me some more about that? How do you like that? How important is that to you?

(repeat for all other intimate relationships)

***[Name key support person]* also told me about *[name contact]* (name other contacts up to five discussed in social network map).**

I would like to talk about *[name intimate contact]*. Can you tell me about what *he/she* means to you?

What is good about knowing *him/her*?

What is not so good about knowing *him/her*?

How long have you known *him/her* for?

How do you like spending time with *him/her*? What is that like for you? How important is that to you?

How often do you see *him/her*? What is that like for you?

APPENDIX B (continued)

What are some of the activities you do with *him/her*? How do you like that?

What are some of the things *he/she* helps you with? How do you like that? How important is that to you?

What does *he/she* do when you are upset? Can you tell me some more about that? What is that like for you? How important is that to you?

What does *he/she* do when you do something well? Can you tell me some more about that? What is that like for you? How important is that to you?

What does *he/she* do when you do something that is not allowed? Can you tell me some more about that? What is that like for you? How important is that to you?

Can you tell me if you ever have arguments with *him/her*? Can you tell me some more about that? What is that like for you?

Is there anything you help *him/her* with? Can you tell me some more about that? How do you like that? How important is that to you?

General questions

Is there anyone else that is very important to you who we did not talk about yet?

Can you tell me if you would you like to have more friends?

Can you tell me about anyone who was important to you and passed away? (probe with names if necessary as discussed with key support person)

Do you ever feel lonely? This means you feel like you are alone and do not have anyone to talk to. What is that like for you?

Religion

Do you believe in God? What does that mean to you?

Do you pray? What does that mean to you?

Do you go to the church or the mosque or the synagogue? How do you like going there?

APPENDIX B (continued)Sexuality

Do you have a girlfriend/boyfriend?

If yes:

How do you like being with [name romantic partner]. What does *he/she* mean to you?

If no:

Did you have a boyfriend/girlfriend before? What was that like for you?

Would you like to have a boyfriend/girlfriend? Can you tell me something about that?

The disability

Can you tell me something about your disability?

If yes:

What is your disability?

What was it like to grow up with your disability?

What did your family say about your disability?

How did your family help you because of your disability when you were growing up?

How did [name of person who gave most support] help you growing up?

What did people other than your family say about your disability?

How did others help you because of your disability when you were growing up?

Who helps you the most now because of your disability?

Observations and comments of researcher

APPENDIX B (continued)

Names of persons present during interview week 2: _____

Date interview week 2: _____

Start time interview week 2: _____

End time interview week 2: _____

Location interview week 2: _____

Description of pictures and artifacts used during interview week 2: _____

Residential history

Let us talk a look at your lifeline. You grew up [location]. How did you like to grow up here?

You grew up [family home/other place of residence]. What was it like to grow up here?

You grew up with [names persons in household growing up]. What was it like to grow up with them?

What was it like for you to leave your family home? Can you tell me something about that?

You also lived [description other places of residence]. What was it like to live there?

You have lived here with [description/names of others]. How did you like to live with them?
(answer for each person)

You now live [description place of residence] How do you like living here?

You live with [description/names of others]. How do you like to live with them? (answer for each person)

History of social relationships

Can you tell me about your mom and dad? (if applicable)

How did you get along with your mom when you were growing up? What was that like for you?

How did you get along with your dad when you were growing up? What was that like for you?

APPENDIX B (continued)

What kind of work did they do? What was that like for you?

If mother and or father passed away:

What was it like for you when your mom passed away?

What was it like for you when your dad passed away?

If mother and or father are still alive:

How do you get along with your mom now?

How do you get along with your dad now?

Can you tell me about [names brothers/sisters]?

How did you get along with [names brothers/sisters] when you were growing up? (if applicable, answer for each sibling)

How do you get along with [names brothers/sisters] now? (answer for each sibling)

How did you get along with [name other relatives] growing up? (answer for each relative)

How do you get along with [name other relatives] now? (answer for each relative)

How did you get along with [name others] growing up? (answer for each person)

How do you get along with [name others] now? (answer for each person)

Were there any other people important to you growing up? Who were they?

Do you still see [names other people]? What is that like for you? (answer for each person)

If person with disability grew up with a pet:

What was it like to grow up with your pet [name pet]?

If person currently has a pet:

How do you like having your pet [name pet]?

What was it like for you when [names deceased persons other than parents if applicable] passed away? Can you tell me something more about that? (answer for each person)

How did you like being part of [name or description of social group in community person with disability belonged to in the past]? (answer for each group)

APPENDIX B (continued)

How do you like being part of [name or description of current social group in community person with disability belongs to]? (answer for each group)

Educational history

How did you like going to [name or description of primary school]? What did you like about it? What did you not like about it?

How did you like going to [name or description of secondary school]? What did you like about it? What did you not like about it?

How did you like going to [name or description of other educational programs]? What did you like about it? What did you not like about it? (answer for each program)

Employment history

How did you like [name or description of previous day activities employment]? What did you like about it? What did you not like about it? (answer for each employment)

If currently employed:

How do you like [name or description of day activities or employment]? What do you like about it? What do you not like about it? (answer for each employment)

Would you like to retire? What would you like to do when you retire? Can you tell me something more about that?

Life events

What was it like for you when [description of negative/difficult events] when you were growing up? Can you tell me about that? Was there someone who helped you then? (answer for each event)

What was it like for you when [description of positive events] when you were growing up? Who was with you when this happened? (answer for each event)

What was it like for you when [description of negative/difficult events midlife]? Can you tell me about that? Was there someone who helped you then? (answer for each event)

What was it like for you when [description of positive events midlife]? Who was with you when this happened? (answer for each event)

What was it like for you when [description of three most important life events]? (answer for each event)

APPENDIX B (continued)

**What was it like for you when [description of three most important life transitions]?
(answer for each event)**

Social network over time

**How important are [name of lifelong contacts] to you? Can you tell me about them?
(answer for each person)**

What is it like for you not to see [names of persons no longer part of social network other than deceased] anymore? (answer for each person)

What is it like for you to make friends? What is easy about making friend? What is hard about making friends?

What helps you when you want to make a friend?

How do you feel about growing older? What is it like to grow older?

What do you like about growing older? What do you not like about growing older?

What is the nicest thing about growing older? What is the most difficult about growing older?

Do you have less, the same or more friends now than before? What is that like for you?

Do you get less, the same or more help from other people now than before? What is that like for you?

What are your wishes for the future?

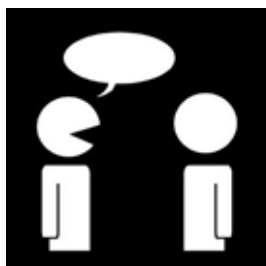
I am much younger than you. What advice would you give me?

Is there anything else you would like to tell me or talk about?

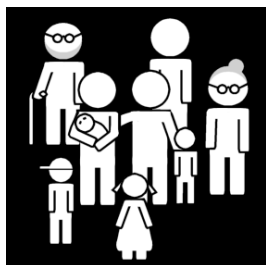
Observations and comments of researcher

APPENDIX B (continued)

ACCESSIBLE INTERVIEW PERSON WITH DISABILITY



We will ask you questions about



The people you know



What is good about the people you know



What is not so good about the people you know



Who helps you

APPENDIX B (continued)

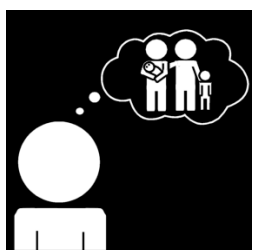
If you feel alone



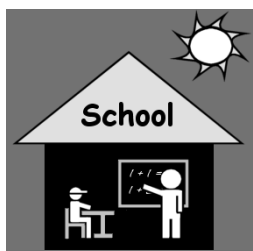
If you have a boyfriend or girlfriend



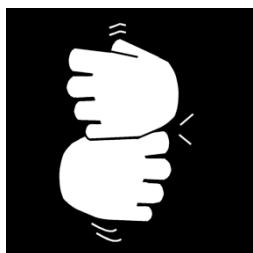
Your disability



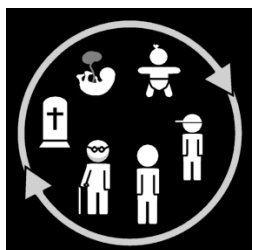
Your family when you grew up



Your school

APPENDIX B (continued)

Your work



Your life



About growing older

APPENDIX C

SOCIAL NETWORK MAP

Name of person with disability:_____

Name of key support person:_____

Relationship key support person to person with disability:_____

How long has key support person known person with disability:_____

Age key support person:_____ Gender key support person:_____ Race key support person:_____

Names of persons present during interview:_____

Date:_____

Start time interview:_____

End time interview:_____

Location interview:_____

“I would like to start with three questions about the disability of [*name of person with a disability*]. If [*name of person with a disability*] has a diagnosis of intellectual disability (or mental retardation), what level was specified?

- | | |
|---|----------------------------|
| 1. NA, does not have an intellectual disabilities | 4. severe |
| 2. mild | 5. profound, don't know or |
| 3. moderate | level not specified |

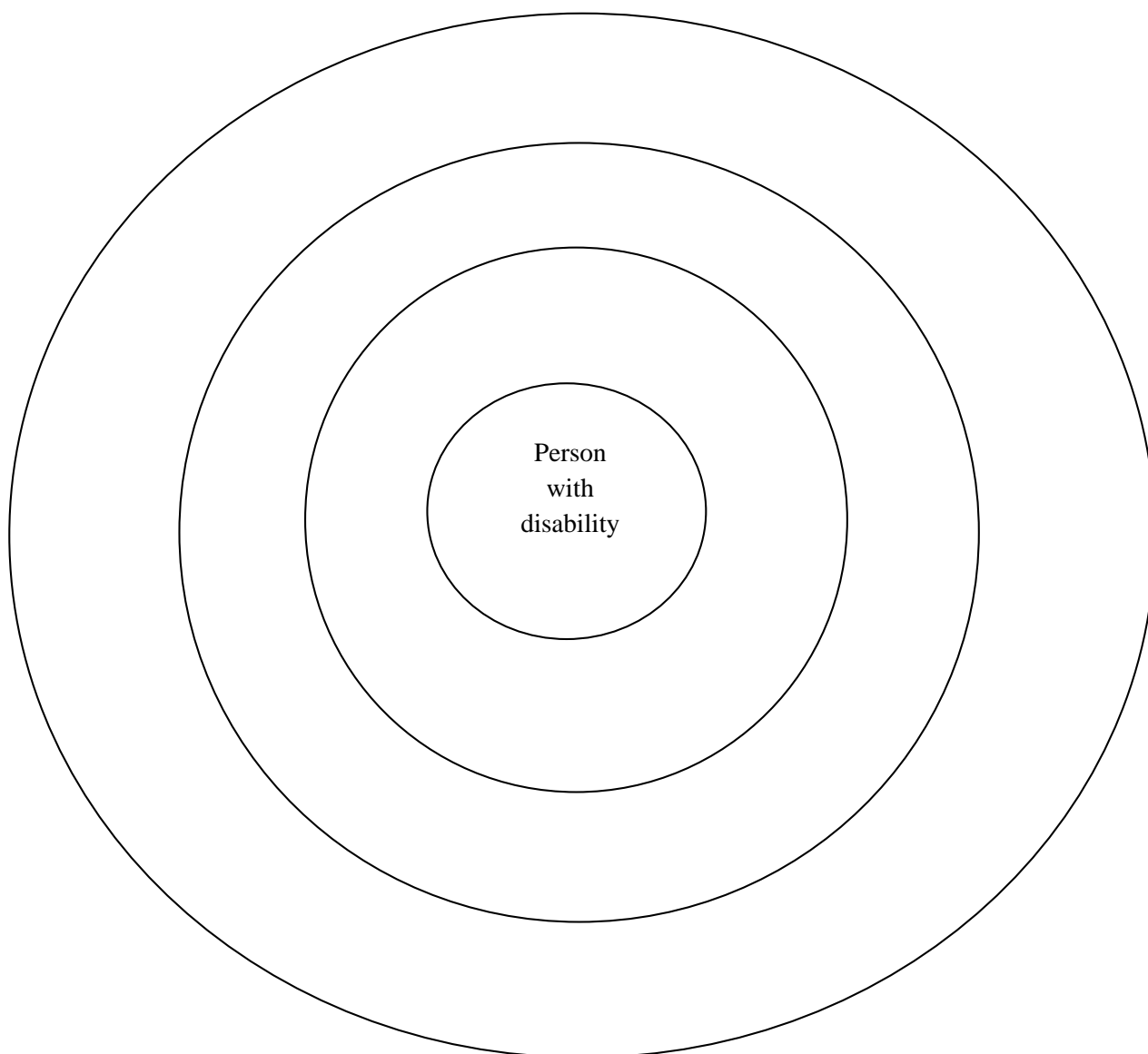
What is the cause of the intellectual disability or specific diagnosis? (*unknown, Down, Fragile X, Prader-Willi, Williams, Rett syndrome, PKU, other*)

Does [*name of the person with a disability*] have any additional disabilities?

- | | | |
|--|---------------------------|-----------------------------------|
| 1. mental illness | 6. chemical dependency | 11. other disabilities not listed |
| 2. autism | 7. vision or hearing | 12. no other disabilities |
| 3. cerebral palsy | impairments | 13. don't know |
| 4. brain injury | 8. physical disabilities | |
| 5. seizure disorder/
neurological problem | 9. communication disorder | |
| | 10. Alzheimer's disease | |

APPENDIX C (continued)

“These circles represent all the persons important in the life of *[name of person with a disability]* right now. First I would like to ask you who the people are that *[name of person with a disability]* feels so close to, it is hard to imagine life without them. What are the names of these persons? Secondly, who are the people who *[name of person with a disability]* does not feel quite as close to but who are still very important to *him/her*? Thirdly, who are the people you have not already mentioned but who are close enough and important enough in the life of *[name of person with a disability]* that they should be placed in *his/her* social network? Lastly, does the person with a disability have any pets?”



(Names or initials of individual persons are written in the different circles in the social convoy. When multiple person responses are offered such as ‘the people in my building’, ‘my colleagues’, ‘my nieces and nephews’, the researcher will probe twice for individual names. If not provided with individual names, the non-individual response will be used as a valid response with an approximate number of people in this group).

APPENDIX C (continued)

“Now, I will ask some questions about the persons in the social network one-by-one.”

(answer question 1 through 6 for all persons in the social network)

1. How is [*name of person with a disability*] related to this person?

1. Relative
2. Friend
3. Romantic partner
4. Colleague
5. Peer with disability
6. Staff
7. Other (please describe)

2. Is this person part of the formal or the informal network?

1. Formal
2. Informal
3. Other (please describe)

3. How frequently does [*name of person with a disability*] see this person?

1. Less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

4. How frequently does [*name of person with a disability*] speak to this person? (*by phone, email, text message, Skype, Facebook, other social media*)

1. Less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

5. How long has [*name of person with a disability*] known this person?

1. Less than 1 year
2. 1-5 years
3. Longer than 5 years

6. What is the proximity of this person to [*name of person with a disability*]?

1. Within a 30 minute drive
2. Within a 1 hour drive
3. Within a 3 hour drive
4. Further than a 3 hour drive

APPENDIX C (continued)

[illegible]

APPENDIX C (continued)

[illegible]

APPENDIX C (continued)

“Now I will ask you some questions about the persons in the inner two circles of the social network to a maximum of five persons.”

7. How often does the person provide instrumental support to [*name of person with a disability*]?

(provides direct personal assistance or supervision with tasks of daily living such as housekeeping and food preparation),

1. Never of less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

8. Can you give an example of the instrumental support provided by this person? (open answer)

9. How much instrumental support is provided by this person to [*name of person with a disability*]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

10. How often does the person provide material support to [*name of person with a disability*]?

(provides supplies or facilities or assists financially)

1. Never of less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

11. Can you give an example of the material support provided by this person? (open answer)

APPENDIX C (continued)

12. How much material support is provided by this person to [name of person with a disability]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

13. How often does the person provide informational support to [name of person with a disability]?

(for example provides advice, guidance, suggestions, or useful information)

1. Never of less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

14. Can you give an example of the informational support provided by this person? (open answer)

15. How much informational support is provided by this person to [name of person with a disability]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

16. How often does the person provide emotional support to [name of person with a disability]?

(provides affective support, for example comforts the person when upset, assists in stressful situations, is available to talk about emotions, provides love or concern, gives encouragement)

1. Never of less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

APPENDIX C (continued)

17. Can you give an example of the emotional support provided by this person? (open answer)

18. How much emotional support is provided by this person to [name of person with a disability]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

19. How often does the person provide appraisal to [name of person with a disability]?
(gives a compliment, shows appreciation or pride)

1. Never or less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

20. Can you give an example of the appraisal provided by this person? (open answer)

21. How much appraisal is provided by this person to [name of person with a disability]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

22. How often does the person provide normative support to [name of person with a disability]?

(corrects behavior, sets rules and restrictions)

1. Never or less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

23. Can you give an example of the normative support provided by this person? (open answer)

APPENDIX C (continued)

24. How much normative support is provided by this person to [name of person with a disability]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

25. How often are there negative interactions between this person and the person with a disability? (*for example differences of opinion, arguments, critique, negative behavior*)

1. Never or less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

26. Can you give an example of a negative interaction with this person? (open answer)

27. Do these negative interactions affect [name of person with a disability]?

1. Not at all
2. Very little
3. Somewhat
4. To a great extent

28. How often does the person provide companionship support to [name of person with a disability]? (*engages in shared activities, such as sports, outings, etc.*)

1. Never or less than yearly
2. Yearly
3. Monthly
4. Weekly
5. Daily

29. Can you give an example of the companionship support provided by this person? (open answer)

APPENDIX C (continued)

30. How much companionship support is provided by this person to [name of person with a disability]?

1. None
2. A little
3. A moderate amount
4. A lot
5. Very much

31. Does [name of person with a disability] provide support to this person? If yes, what type of support? (Is there reciprocity in the provision of support?)

1. Yes (please describe what kind of support)
2. No

32. How would you describe the relationship [name of person with a disability] has with this person? (open answer)

APPENDIX C (continued)

Question	Person_____	Person_____	Person_____
7			
8			
9			
10			
11			
12			
13			
14			
15			
16			
17			
18			
19			

APPENDIX C (continued)

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30			
31			
32			

APPENDIX C (continued)

Question	Person_____	Person_____
7		
8		
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17		
18		
19		

APPENDIX C (continued)

20		
21		
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31		
32		

APPENDIX C (continued)

“Here is one final question, not related to one specific person in the social network:”

33. Does [name of person with a disability] receive sufficient support?

1. Not enough support
2. Enough support
3. Too much support

“Is there anything else you would like to share about the social network of [*name of person with a disability*]?

Observations and comments of researcher

APPENDIX D

University of Illinois at Chicago

CONSENT TO PARTICIPATE IN RESEARCH

Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective

1. My name is Lieke van Heumen. I am a researcher at the Department of Disability and Human Development.
2. We are asking you to take part in a research study because you are a person with an intellectual disability and you are 50 or older. We are trying to learn more about the social relations of older persons who have an intellectual disability.
3. If you agree to be in this study you can choose with your guardian who you would like to be your key support person. This could be your staff, a family member or a friend. You can tell us who you would like to help you.

We will meet with you between 4 and 6 times in total. Firstly we will talk to your key support person about your social network and your life history. We will meet one time or two times to do this. You can be present too if you like.

The next two times we will meet with you to talk about your life, about your past and about the people you know. If you would like you can have your key support person or an advocate present to help you. We will ask you questions and make a lifeline. The lifeline will be a piece of paper with events in your life and pictures. We will decorate the lifeline and use it to help talk about your life. We will meet one last time with your key support person there too. We will then make sure that we understood everything you told us. Participation in the study will take between 5 and 10 hours.

APPENDIX D (continued)

4. We would like to ask you and your support person to bring any pictures of you and your friends or family. They can be pictures from long ago if you would like. You can also bring other things that tell us something about you and your life. They will help us talk about your life.

We will not take the pictures and the other things. They are yours. We will not show them to anyone. The lifeline we will make is also yours. You can take it home with you when we are done. We will make a copy of the lifeline. After one year we will no longer keep it.

5. Everything you say will be private. That means we won't tell anyone about just you. We want to audiotape the interviews with you. We will also write down everything you say. We will not use your real name when we talk about you. After one year we will erase the tapes and cut all the notes.

Only when you tell us you are being harmed we need to talk to others about what you said. In that case we might need to report what happened to you to the DHS Office of the Inspector General. Because we talk about your life during the study it might happen in a rare occasion that someone recognizes you even we do not use your name.

6. We might ask you if you would like to participate in a DVD. You can tell about your life in the movie. This way you can advocate for yourself. It will help others understand what supports persons with disabilities need.

If you are in the movie, others can see who you are. That means your story will not remain private. Before we finish the movie you can see it. We can change the movie if you do not like it. You do not have to be in the movie if you don't want to. Being in the movie is up to you and no one will be upset if you don't want to participate or even if you change your mind later and want to stop. You do not have to explain why you do not want to be in the movie. You can still be part of the study if you don't want to be in the movie.

APPENDIX D (continued)

7. It is not difficult or dangerous to be part of the study or the movie. If you do not want to answer a question you can just say so and we will talk about something else.
8. We hope that this study will be a fun experience for you. We hope it will help you share your life experiences with others. This might help us to understand how we can support people with disabilities so they can live happy lives.
9. If you participate, you will receive a \$15 gift card. We will give it to you when we meet for the last time. If you decide before then to stop with the study or the movie you will still get the giftcard. In that case we will be send it by mail.
10. Please talk this over with your guardian if you have one before you decide whether or not to participate. We will also ask your guardian to give their permission for you to take part in this study and the movie. Even if your gaurdian says “yes” you can still decide not to do this.
11. Remember, being in this study is up to you and no one will be upset if you don’t want to participate or even if you change your mind later and want to stop. If you don’t want to be in this study, you don’t have to participate. You do not have to explain why you do not want to participate.
12. You can ask any questions that you have about the study. If you have a question later that you didn’t think of now, you can call me at **(312) 996-7988** or email me at **lvheumen@uic.edu**. You can also ask me next time. You can also contact my advisor Dr. Tamar Heller at **(312) 413-1647** or **theller@uic.edu** if you have questions.

For any questions about your rights as a research subject, you may call the University of Illinois at Chicago Office for Protection of Research Subjects at **1-866-789-6215** (toll free) or email OPRS at **uicirb@uic.edu**.

APPENDIX D (continued)

13. Signing your name at the bottom means that you agree to be in this study. You and your guardian will be given a copy of this form after you have signed it.

Signature

Date

Printed Name

Phone

Email

Address

(City)

(Zipcode)

Name of nominated key support person

Name of nominated third informant (if applicable)

Name of nominated advocate other than guardian, key support person or third informant (if applicable)

My decision whether to be in the movie is:

☐ yes

☐ no

☐ does not apply

APPENDIX D (continued)

Signature of Guardian (if applicable)

Date

Printed Name

Phone

Email

Address

(City)

(Zipcode)

Investigator signature

Date

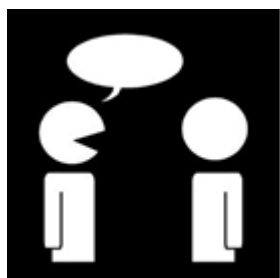
Printed Name of Investigator

APPENDIX D (continued)**University of Illinois at Chicago****ACCESSIBLE INFORMATION ABOUT THE RESEARCH PROJECT**

Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective



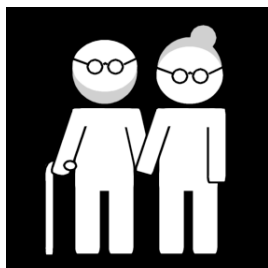
I am Lieke van Heumen from the University of Illinois at Chicago



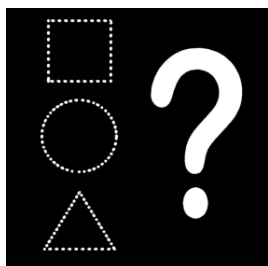
We would like to talk with you



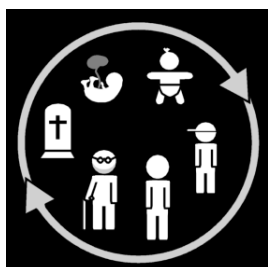
If you have an intellectual disability

APPENDIX D (continued)

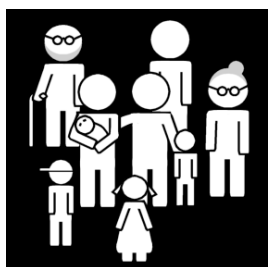
If you are 50 years or older



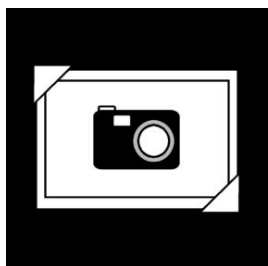
We would like to ask you questions



Questions about your life



Questions about the people you know



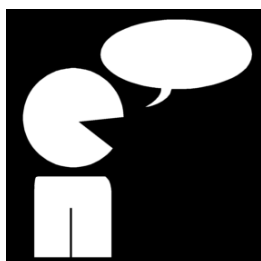
You can show us pictures

APPENDIX D (continued)

We will write down what you say but not tell anyone about just you



We will ask if you want to be in a movie



If you don't want to participate you can tell us



You can stop anytime



We want this to be fun for you

APPENDIX D (continued)

If you have questions you can call (312) 996-7988 or email at lvheumen@uic.edu

APPENDIX D (continued)

University of Illinois at Chicago

Research Information and Consent for Participation in Social Behavioral Research Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective

You are being asked to participate in a research study. Researchers are required to provide a consent form such as this one to tell you about the research, to explain that taking part is voluntary, to describe the risks and benefits of participation, and to help you to make an informed decision. You should feel free to ask the researchers any questions you may have.

Principal Investigator Name and Title:	Lieke van Heumen, MS
Department and Institution:	Department of Disability and Human Development
Address and Contact Information:	1640 West Roosevelt Road, 538B, Chicago, IL, 60608; lvheumen@uic.edu; (312) 996-7988

Why am I being asked?

You are being asked to be a subject in a research study about the social relations of older adults who have intellectual disabilities. You have been asked to participate in the research because you are the key support person of a person with intellectual disability who is 50 years of age or older. You might also be the guardian of the person with a disability or an informant or advocate for the person with a disability.

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future dealings with the University of Illinois at Chicago. **If you decide to participate, you are free to withdraw at any time without affecting that relationship.**

Approximately 50 subjects may be involved in this research at UIC.

APPENDIX D (continued)

What is the purpose of this research?

This research will help to better understand what the social networks of older people with an intellectual disability look like. We will also be able to have a better idea of how social networks of older people with an intellectual disability develop during their lives and how we can best support them.

What procedures are involved?

We are asking you to participate in an interview about the social network and the life history of the person with an intellectual disability. We will talk in detail about the relationships the person with an intellectual disability has and how these relationships developed during his or her life. The person with an intellectual disability can be present at this interview if he or she and the guardian desire so.

We will then meet three to four times with the person with an intellectual disability for work on an individual lifeline and two interviews. We will talk with the person with an intellectual disability about his or her social network and life history. We will make a lifeline with the person with an intellectual disability. This is a piece of paper that represents the events in the life history of the person with an intellectual disability. The lifeline will be decorated and pictures will be used as part of the lifeline. The lifeline will assist with the interviews. You might be asked to be present at these meetings.

You might also be asked to be present at a meeting with the person with an intellectual disability in which we go over all the information that was collected during the interviews to make sure we interpreted your opinions accurately. Each of these meetings will take place at a location of your choice and will last approximately one to two hours. You will be asked to meet with the researcher between 4 to 6 times in total. Participation will take 3 to 8 hours of your time.

APPENDIX D (continued)

What are the potential risks and/or benefits to participating?

The risks are minimal. The things you will be doing have no more risk of harm than you would experience in everyday life. If you feel uncomfortable answering any questions you may choose not to answer. You may also stop your participation in the study at any time. Your participation will probably not directly benefit you. This study is designed to learn more about the social networks of persons with intellectual disabilities as they age. The study results may be used to help other people in the future.

What about privacy and confidentiality?

The people who will know that you are a research subject are members of the research team. The person with disability might use pictures of you as part of the lifeline. These pictures will only be seen by you, the researcher and the person with disability. No copies will be made of these pictures, they will not be distributed and they will remain in the possession of the person with disability. The person with disability will have ownership over the lifeline that is created. The person with disability can take it home after the interviews are completed. We will make a copy of the lifeline and will destroy it after completion of the study within 1 year.

All meetings will be audiotaped and transcribed. The recordings will only be accessible to you and the members of the research team. The recordings and transcripts will be destroyed after completion of the study within 1 year. Pseudonyms will be used in the transcripts and dissemination materials to protect your privacy. When the results of the research are published or discussed in conferences, no information will be included that would reveal your identity. Information about you will only be disclosed to others with your written permission, or if necessary to protect your rights or welfare or if required by law. In case it becomes clear you or the person with disability has been harmed we might need to speak to the DHS Office of the Inspector General. Study information which identifies you and the consent form signed by you will be looked at and/or copied for checking up on the research by UIC OPRS and State of Illinois Auditors.

APPENDIX D (continued)

What are the costs for participating and will I get paid for my participation?

There are no costs to you for participating in this research, except for your time. You will not get paid for your participation. The person with disability will receive a \$15 gift card.

Can I withdraw or be removed from the study?

If you decide to participate, you are free to withdraw your consent and discontinue participation at any time.

Who should I contact if I have questions?

If you have any questions concerning this study or your participation, please feel free to contact Lieke van Heumen at the University of Illinois at Chicago by telephone at (312) 996-7988 or email at lvheumen@uic.edu. You can also contact advisor Dr. Tamar Heller at (312) 413-1647 or theller@uic.edu if you have questions.

What are my rights as a research subject?

If you feel you have not been treated according to the descriptions in this form, or if you have any questions about your rights as a research subject, including questions, concerns, complaints, or to offer input, you may call the Office for the Protection of Research Subjects (OPRS) at 312-996-1711 or 1-866-789-6215 (toll-free) or e-mail OPRS at uicirb@uic.edu.

Remember

Your participation in this research is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University. If you decide to participate, you are free to withdraw at any time without affecting that relationship. If you are the guardian of the person with a disability, you have the obligation to protect the person with a disability. You

APPENDIX D (continued)

should also make decisions based on what the person with a disability would want and you should discuss the study with the person with a disability.

Signature of Subject

I have read (or someone has read to me) the above information. I have been given an opportunity to ask questions and my questions have been answered to my satisfaction. I agree to participate in this research. I will be given a copy of this signed and dated form. Please note that if you are the key support person but not the guardian of the person with a disability, the guardian needs to be informed and has to sign this form as well.

I am: (check all that are applicable):

- ☐ the guardian
- ☐ the key support person
- ☐ the third informant
- ☐ an advocate of the person with a disability

Signature

Date

Printed Name

Phone

Email

Address

(City)

(Zipcode)

APPENDIX D (continued)

_____ Signature of Guardian (if person with disability has a guardian)	_____ Date
--	---------------

Printed Name

_____ Phone	_____ Email
----------------	----------------

_____	_____	_____
Address	(City)	(Zipcode)

_____ Signature person with disability	_____ Date
---	---------------

Printed Name

_____ Investigator signature	_____ Date
---------------------------------	---------------

Printed Name of Investigator

APPENDIX E

UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice Initial Review (Response To Modifications)

April 11, 2014

Lieke Van Heumen, MSc
Disability and Human Development
DHD
1640 W Roosevelt RD, M/C 626
Chicago, IL 60607
Phone: (312) 996-7988

RE: Protocol # 2013-1225
“Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective”

Dear Ms. Van Heumen:

Your Initial Review (Response To Modifications) was reviewed and approved by the Expedited review process on April 11, 2014. You may now begin your research

Please note the following information about your approved research protocol:

Protocol Approval Period: April 11, 2014 - April 11, 2015
Approved Subject Enrollment #: 50
Additional Determinations for Research Involving Minors: These determinations have not been made for this study since it has not been approved for enrollment of minors.
Performance Sites: UIC, Anixter Center, Lambs Farm, Ray Graham Association, Envision Unlimited
Sponsor: None
Research Protocol(s):
a) Research Protocol; Version 2; 02/10/2014

Recruitment Material(s):

- a) Accessible Recruitment Flyer; Version 2; 02/03/2014
- b) Recruitment Flyer; Version 2; 02/10/2014

APPENDIX E (continued)

- c) Information Staff; Version 2; 02/10/2014
- d) Script for Approaching Potential Participants; Version 2; 03/25/2014
- e) Recruitment Script; Version 4; 04/10/2014
- f) Accessible Information about Research Project; Version 1; 12/05/2014

Informed Consent(s):

- a) Consent Form Key Support Person; Version 3; 03/25/2014
- b) A waiver of consent has been granted under 45 CFR 46.116(d) for recruitment (for obtaining information from the guardian about the person with disabilities) purposes only; minimal risk; written consent/assent will be obtained at enrollment.
- c) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d) for recruitment purposes only (eligibility screening); minimal risk; written consent/assent will be obtained at enrollment.
- d) A waiver of documentation of informed consent has been granted under 45 CFR 46.117 and an alteration of consent has been granted under 45 CFR 46.116(d) for subjects who cannot physically provide written consent; minimal risk; alternative means of consent/assent will be obtained.
- e) A waiver of consent has been granted under 45 CFR 46.116(d) for secondary subjects whose identifiable data and/or images may be disclosed by primary subjects; minimal risk; impracticable to obtain consent.

Assent(s):

- a) Consent Form Person with Disability; Version 3; 03/25/2014

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific category(ies):

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
12/09/2013	Initial Review	Expedited	12/10/2013	Modifications Required
02/17/2014	Response To Modifications	Expedited	02/19/2014	Modifications Required

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03/26/2014	Response To Modifications	Expedited	04/11/2014	Approved
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Please remember to:

→ Use your **research protocol number** (2013-1225) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
"UIC Investigator Responsibilities, Protection of Human Research Subjects"
[\(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>\)](http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 355-0816. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Alison Santiago, MSW, MJ
 IRB Coordinator, IRB # 2
 Office for the Protection of Research

Subjects

Enclosure(s):

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects**
 - 2. Informed Consent Document(s):**
 - a) Consent Form Key Support Person; Version 3; 03/25/2014
 - 3. Assent Document(s):**
 - a) Consent Form Person with Disability; Version 3; 03/25/2014
 - 4. Recruiting Material(s):**
 - a) Accessible Recruitment Flyer; Version 2; 02/03/2014
 - b) Recruitment Flyer; Version 2; 02/10/2014
 - c) Information Staff; Version 2; 02/10/2014
 - d) Script for Approaching Potential Participants; Version 2; 03/25/2014
 - e) Recruitment Script; Version 4; 04/10/2014
 - f) Accessible Information about Research Project; Version 1; 12/05/2014
- cc: Tamar Heller (Faculty Sponsor), Disability and Human Development, M/C 626

APPENDIX E (continued)
UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
 Office of the Vice Chancellor for Research (MC 672)
 203 Administrative Office Building
 1737 West Polk Street
 Chicago, Illinois 60612-7227

Approval Notice
Continuing Review

February 23, 2015

Lieke Van Heumen, MSc
 Disability and Human Development
 DHD
 1640 W Roosevelt RD, M/C 626
 Chicago, IL 60607
 Phone: (312) 996-7988

RE: **Protocol # 2013-1225**
“Social Relations of Older Adults with Intellectual Disabilities from a Life Course Perspective”

Dear Ms. Van Heumen:

Your Continuing Review was reviewed and approved by the Expedited review process on February 19, 2015. You may now continue your research.

Please note the following information about your approved research protocol:

<u>Protocol Approval Period:</u>	February 19, 2015 - February 19, 2016
<u>Approved Subject Enrollment #:</u>	50 (data analysis from 25 subjects)
<u>Additional Determinations for Research Involving Minors:</u>	These determinations have not been made for this study since it has not been approved for enrollment of minors.
<u>Performance Sites:</u>	UIC, Anixter Center, Lambs Farm, Ray Graham Association, Envision Unlimited
<u>Sponsor:</u>	None
<u>PAF#:</u>	Not applicable
<u>Grant/Contract No:</u>	Not applicable
<u>Grant/Contract Title:</u>	Not applicable
<u>Research Protocol:</u>	

a) Research Protocol; Version 2; 02/10/2014

APPENDIX E (continued)

Recruitment Material:

g) N/A – Limited to data analysis only

Informed Consent:

f) N/A – Limited to data analysis only

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories: **(6)** Collection of data from voice, video, digital, or image recordings made for research purposes., **(7)** Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
02/16/2015	Continuing Review	Expedited	02/19/2015	Approved

Please remember to:

→ Use your **research protocol number** (2013-1225) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the OPRS website under:

"UIC Investigator Responsibilities, Protection of Human Research Subjects"

(<http://tiger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf>)

Please note that the UIC IRB has the right to seek additional information, require further modifications, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-9299. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Anna Bernadska, M.A.
IRB Coordinator, IRB # 2
Office for the Protection of Research

Subjects

Enclosure: None

cc: Tamar Heller, Faculty Sponsor, Disability and Human Development, M/C 626

APPENDIX F

TABLE A
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' INNER SOCIAL CONVOY CIRCLES

PWD* Pseudonym	Henry	William	Lucy	Charlotte	Barbara	Philip
PWD 3 Closest Relations	Sister	Male housemate	Brother	Sister	Sister	Female staff
	Brother-in-law	Female peer with disability (housemate)	Sister-in-law	Nephew and wife	Sister	Female staff
	Niece	Female staff	-	Female staff	Female friend	Female friend
Total Number of Relations	4	0	9	8	3	3
Family	Number	4	0	9	6	2
	Percentage	100%	0%	100%	75%	66.7%
Most frequent in-person contact	monthly	-	yearly	monthly	>yearly	-
Most frequent phone contact	daily	-	weekly	weekly	weekly	-
Longest duration relation	>5 years	-	>5 years	>5 years	>5 years	-
Closest proximity relation**	<30 minutes	-	30-60 minutes	1-3 hours	>3 hours	-
Staff	Number	0	0	0	1	0
	Percentage	0%	0%	0%	12.5%	0%
Most frequent in-person contact	-	-	-	daily	-	daily
Most frequent phone contact	-	-	-	-	-	-
Longest duration relation	-	-	-	>5 years	-	>5 years
Closest proximity relation	-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Duration of auto drive.

APPENDIX F (continued)

TABLE A (continued)
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' INNER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Henry	William	Lucy	Charlotte	Barbara	Philip
Peers**	Number	0	0	0	1	0	0
	Percentage	0%	0%	0%	12.5%	0%	0%
	Most frequent in-person contact	-	-	-	daily	-	-
	Most frequent phone contact	-	-	-	-	-	-
	Longest duration relation	-	-	-	>5 years	-	-
	Closest proximity relation***	-	-	-	-	-	-
Friends	Number	0	0	0	0	1	1
	Percentage	0%	0%	0%	0%	33.3%	33.3%
	Most frequent in-person contact	-	-	-	-	> yearly	monthly
	Most frequent phone contact	-	-	-	-	monthly	monthly
	Longest duration relation	-	-	-	-	>5 years	>5 years
	Closest proximity relation	-	-	-	-	>3 hours	<30 minutes
Others	Number	0	0	0	0	0	0
	Percentage	0%	0%	0%	0%	0%	0%
	Most frequent in-person contact	-	-	-	-	-	-
	Most frequent phone contact	-	-	-	-	-	-
	Longest duration relation	-	-	-	-	-	-
	Closest proximity relation	-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Peers stands for 'peers with disabilities'.

*** Duration of auto drive.

APPENDIX F (continued)

TABLE A (continued)
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' INNER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Henry	William	Lucy	Charlotte	Barbara	Philip
Female relations	Number	3	0	4	5	3	3
	Percentage	75%	0%	44.4%	62.5%	100%	100%
Male relations	Number	1	0	5	3	0	0
	Percentage	25%	0%	55.6%	37.5%	0%	0%

* PWD stands for 'person with disability'.

APPENDIX F (continued)

TABLE A (continued)
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' INNER SOCIAL CONVOY CIRCLES

PWD* Pseudonym	Betty	Roger	Matthew	Mary	Linda	Zach
PWD 3 Closest Relations	Sister Nephew	Brother Brother	Staff Female friend	Father Sister	Sister Brother	Sister Brother-in-law Sister
	Female friend	Female peer with disability (housemate)	Female friend	Female staff	Female staff	
Total Number of Relations	2	5	7	6	5	7
Family	Number	2	2	2	5	7
	Percentage	100%	40%	28.6%	100%	100%
Most frequent in-person contact	daily	> yearly	> yearly	monthly	monthly	monthly
Most frequent phone contact	-	weekly	-	daily	monthly	daily
Longest duration relation	>5 years	>5 years	>5 years	>5 years	>5 years	>5 years
Closest proximity relation**	-	1-3 hours	>3 hours	30-60 minutes	30-60 minutes	30-60 minutes
Staff	Number	0	2	1	0	0
	Percentage	0%	40%	14.3%	0%	0%
Most frequent in-person contact	-	daily	daily	-	-	-
Most frequent phone contact	-	-	-	-	-	-
Longest duration relation	-	>5 years	1-5 years	-	-	-
Closest proximity relation	-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Duration of auto drive.

APPENDIX F (continued)

TABLE A (continued)
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' INNER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Betty	Roger	Matthew	Mary	Linda	Zach
Peers**	Number	0	1	2	0	0	0
	Percentage	0%	20%	28.6%	0%	0%	0%
	Most frequent in-person contact	-	daily	daily	-	-	-
	Most frequent phone contact	-	-	-	-	-	-
	Longest duration relation	-	>5 years	>5 years	-	-	-
	Closest proximity relation***	-	-	-	-	-	-
Friends	Number	0	0	2	0	0	0
	Percentage	0%	0%	28.6%	0%	0%	0%
	Most frequent in-person contact	-	-	yearly	-	-	-
	Most frequent phone contact	-	-	-	-	-	-
	Longest duration relation	-	-	>5 years	-	-	-
	Closest proximity relation	-	-	>3 hours	-	-	-
Others	Number	0	0	0	0	0	0
	Percentage	0%	0%	0%	0%	0%	0%
	Most frequent in-person contact	-	-	-	-	-	-
	Most frequent phone contact	-	-	-	-	-	-
	Longest duration relation	-	-	-	-	-	-
	Closest proximity relation	-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Peers stands for 'peers with disability'.

*** Duration of auto drive.

APPENDIX F (continued)

TABLE A (continued)
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' INNER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Betty	Roger	Matthew	Mary	Linda	Zach
Female Relations	Number	1	2	5	3	2	6
	Percentage	50%	40%	71.4%	50%	40%	85.7%
Male Relations	Number	1	3	2	3	3	1
	Percentage	50%	60%	28.6%	50%	60%	14.3%

* PWD stands for 'person with disability'.

APPENDIX F (continued)

TABLE B
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' MIDDLE SOCIAL CONVOY CIRCLES

PWD* Pseudonym	Henry	William	Lucy	Charlotte	Barbara	Philip
Total Number of Relations	9	10	21	5	11	4
Family						
Number	4	0	13	4	1	0
Percentage	44.4%	0%	61.9%	80%	9.1%	0%
Most frequent in-person contact	yearly	-	> yearly	yearly	> yearly	-
Most frequent phone contact	-	-	> yearly	Yearly	-	-
Longest duration relation	>5 years	-	>5 years	>5 years	>5 years	-
Closest proximity relation**	30-60 minutes	-	<30 minutes	1-3 hours	>3 hours	-
Staff						
Number	3	6	3	1	4	4
Percentage	33.3%	60%	14.3%	20%	36.4%	100%
Most frequent in-person contact	daily	daily	weekly	daily	daily	daily
Most frequent phone contact	-	-	weekly	-	-	-
Longest duration relation	>5 years	>5 years	>5 years	<1 year	>5 years	>5 years
Closest proximity relation	-	-	<30 minutes	-	-	-
Peers***						
Number	2	4	3	0	6	0
Percentage	22.2%	40%	14.3%	0%	55.5%	0%
Most frequent in-person contact	daily	daily	-	-	daily	-
Most frequent phone contact	-	-	-	-	-	-
Longest duration relation	>5 years	>5 years	-	-	>5 years	-
Closest proximity relation	-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Duration of auto drive.

*** Peers stands for 'peers with disabilities'.

APPENDIX F (continued)**TABLE B (continued)****STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' MIDDLE SOCIAL CONVOY CIRCLES**

PWD* Pseudonym		Henry	William	Lucy	Charlotte	Barbara	Philip
Friends	Number	0	0	0	0	0	0
	Percentage	0%	0%	0%	0%	0%	0%
Most frequent in-person contact		-	-	-	-	-	-
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	-	-	-	-	-
Closest proximity relation**		-	-	-	-	-	-
Others	Number	0	0	2	0	0	0
	Percentage	0%	0%	9.5%	0%	0%	0%
Most frequent in-person contact		-	-	daily	-	-	-
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	-	1-5 years	-	-	-
Closest proximity relation		-	-	-	-	-	-
Female Relations	Number	6	6	11	4	10	1
	Percentage	66.7%	60%	52.3%	80%	90.9%	25%
Male Relations	Number	3	4	10	1	1	3
	Percentage	33.3%	40%	47.6%	20%	9.1%	75%

* PWD stands for 'person with disability'.

** Duration of auto drive.

APPENDIX F (continued)

TABLE B (continued)

STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' MIDDLE SOCIAL CONVOY CIRCLES

PWD* Pseudonym	Betty	Roger	Matthew	Mary	Linda	Zach	
Total Number of Relations	26	6	14	8	6	12	
Family	Number	12	0	0	3	0	2
	Percentage	46.2%	0%	0%	37.5%	0%	16.7%
Most frequent in-person contact	> yearly	-	-	yearly	-	yearly	
Most frequent phone contact	yearly	-	-	yearly	-	-	
Longest duration relation	>5 years	-	-	>5 years	-	>5 years	
Closest proximity relation**	1-3 hours	-	-	30-60 minutes	-	30-60 minutes	
Staff	Number	3	3	6	1	3	3
	Percentage	11.5%	50%	42.9%	12.5%	50%	25%
Most frequent in-person contact	daily	daily	daily	daily	daily	daily	
Most frequent phone contact	-	-	-	-	-	-	
Longest duration relation	>5 years	>5 years	>5 years	>5 years	< 1 year	>5 years	
Closest proximity relation	-	-	-	-	-	-	
Peers***	Number	7	3	6	3	0	7
	Percentage	26.9%	50%	42.9%	37.5%	0%	58.3%
Most frequent in-person contact	daily	daily	daily	daily	-	daily	
Most frequent phone contact	yearly	-	-	-	-	-	
Longest duration relation	>5 years	>5 years	>5 years	>5 years	-	>5 years	
Closest proximity relation	<30 minutes	-	-	-	-	-	

* PWD stands for 'person with disability'.

** Duration of auto drive .

*** Peers stands for 'peers with disability'.

APPENDIX F (continued)

TABLE B (continued)

STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' MIDDLE SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Betty	Roger	Matthew	Mary	Linda	Zach
Friends	Number	4	0	2	0	0	0
	Percentage	15.4%	0%	14.3%	0%	0%	0%
Most frequent in-person contact		yearly	-	monthly	-	-	-
Most frequent phone contact		yearly	-	monthly	-	-	-
Longest duration relation		>5 years	-	1-5 years	-	-	-
Closest proximity relation**		<30 minutes	-	<30 minutes	-	-	-
Others	Number	0	0	0	1	3	0
	Percentage	0%	0%	0%	12.5%	50%	0%
Most frequent in-person contact		-	-	-	daily	weekly	-
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	-	-	1-5 years	1-5 years	-
Closest proximity relation		-	-	-	<30 minutes	-	-
Female Relations	Number	17	3	5	7	5	5
	Percentage	65.4%	50%	35.7%	87.5%	80%	41.7%
Male Relations	Number	9	3	9	1	1	7
	Percentage	34.6%	50%	64.3%	12.5%	20%	58.3%

* PWD stands for 'person with disability'.

** Duration of auto drive.

APPENDIX F (continued)

TABLE C
STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' OUTER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Henry	William	Lucy	Charlotte	Barbara	Philip
Total Number of Relations		9	4	1	4	5	8
Family	Number	2	0	0	1	3	0
	Percentage	22.2%	0%	0%	25%	60%	0%
Most frequent in-person contact		yearly	-	-	> yearly	monthly	-
Most frequent phone contact		-	-	-	-	monthly	-
Longest duration relation		>5 years	-	-	>5 years	>5 years	-
Closest proximity relation**		30-60 minutes	-	-	1-3 hours	30-60 minutes	-
Staff	Number	0	3	1	1	0	1
	Percentage	0%	75%	100%	25%	0%	12.5%
Most frequent in-person contact		-	Daily	> yearly	daily	-	daily
Most frequent phone contact		-	-	> yearly	-	-	-
Longest duration relation		-	>5 years	>5 years	>5 years	-	>1 year
Closest proximity relation		-	-	<30 minutes	-	-	-
Peers***	Number	7	1	0	2	2	7
	Percentage	77.8%	25%	0%	50%	40%	87.5%
Most frequent in-person contact		daily	daily	-	daily	daily	daily
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		>5 years	>5 years	-	>5 years	>5 years	>5 years
Closest proximity relation		-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Duration of auto drive.

*** Peers stands for 'peers with disabilities'.

APPENDIX F (continued)**TABLE C (continued)****STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' OUTER SOCIAL CONVOY CIRCLES**

PWD* Pseudonym		Henry	William	Lucy	Charlotte	Barbara	Philip
Friends	Number	0	0	0	0	0	0
	Percentage	0%	0%	0%	0%	0%	0%
Most frequent in-person contact		-	-	-	-	-	-
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	-	-	-	-	-
Closest proximity relation**		-	-	-	-	-	-
Others	Number	0	0	0	0	0	0
	Percentage	0%	0%	0%	0%	0%	0%
Most frequent in-person contact		-	-	-	-	-	-
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	-	-	-	-	-
Closest proximity relation		-	-	-	-	-	-
Female Relations	Number	4	2	1	3	4	4
	Percentage	44.4%	50%	100%	75%	80%	50%
Male Relations	Number	5	2	0	1	1	4
	Percentage	55.6%	50%	0%	25%	20%	50%

* PWD stands for 'person with disability'.

** Duration of auto drive.

APPENDIX F (continued)

TABLE C (continued)

STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' OUTER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Betty	Roger	Matthew	Mary	Linda	Zach
Total Number of Relations		3	5	6	1	6	44
Family	Percentage	0%	0%	0%	100%	0%	59%
	Number	0	0	0	1	0	26
Most frequent in-person contact		-	-	-	yearly	-	yearly
Most frequent phone contact		-	-	-	yearly	-	-
Longest duration relation		-	-	-	>5 years	-	>5 years
Closest proximity relation**		-	-	-	>3 hours	-	30-60 minutes
Staff	Number	1	1	0	0	0	0
	Percentage	33.3%	20%	0%	0%	0%	0%
Most frequent in-person contact		weekly	daily	-	-	-	-
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		>1 year	>5 years	-	-	-	-
Closest proximity relation		<30 minutes	-	-	-	-	-
Peers***	Number	0	4	0	0	6	11
	Percentage	0%	80%	0%	0%	100%	25%
Most frequent in-person contact		-	daily	-	-	daily	daily
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	>5 years	-	-	1-5 years	>5 years
Closest proximity relation		-	-	-	-	-	-

* PWD stands for 'person with disability'.

** Duration of auto drive.

*** Peers stands for 'peers with disabilities'.

APPENDIX F (continued)

TABLE C (continued)

STRUCTURAL CHARACTERISTICS OF PARTICIPANTS' OUTER SOCIAL CONVOY CIRCLES

PWD* Pseudonym		Betty	Roger	Matthew	Mary	Linda	Zach
Friends	Number	2	0	2	0	0	0
	Percentage	66.7%	0%	40%	0%	0%	0%
Most frequent in-person contact		yearly	-	yearly	-	-	-
Most frequent phone contact		yearly	-	-	-	-	-
Longest duration relation		>5 years	-	>5 years	-	-	-
Closest proximity relation**		<30 minutes	-	<30 minutes	-	-	-
Others	Number	0	0	4	0	0	7
	Percentage	0%	0%	60%	0%	0%	15.9%
Most frequent in-person contact		-	-	weekly	-	-	monthly
Most frequent phone contact		-	-	-	-	-	-
Longest duration relation		-	-	>5 years	-	-	>5 years
Closest proximity relation		-	-	<30 minutes	-	-	30-60 minutes
Female relations	Number	2	1	1	1	6	25
	Percentage	66.7%	20%	20%	100%	100%	56.9%
Male relations	Number	1	4	5	0	0	19
	Percentage	33.3%	80%	80%	0%	0%	43.1%

* PWD stands for 'person with disability'.

** Duration of auto drive.

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- structured interviewing. *Ethnographically informed community and cultural assessment research systems (EICCARS) working paper series*. College Park, MD: Cultural Ecology of Health and Change.
- Widmer, E. D., Kempf, N., Sapin, M., & Galli-Carminati, G. (2013). Family beyond parents? An exploration of family configurations and psychological adjustment in young adults with intellectual disabilities. *Research in Developmental Disabilities, 34*(1), 201-217. doi: 10.1016/j.ridd.2012.07.006
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- Zink, J. B. (1992). Adjusting to early- and late-onset disability: A personal perspective. In E. F. Ansello & N. N. Eustis (Eds.), *Aging and disabilities: Seeking common ground* (pp. 111-114). Amityville, NY: Baywood.

VITA

EDUCATION

- University of Illinois at Chicago, USA Expected 2015
PhD Disability Studies (GPA 4.0)
Advisor Tamar Heller, PhD
- Radboud University Nijmegen, the Netherlands 2008
MS Psychology cum laude (specialization gerontology)
Advisor Gerben Westerhof, PhD
- Radboud University Nijmegen, the Netherlands 2006
BS Psychology (specialization gerontology)
- ArtEZ School of Music, Zwolle, the Netherlands 2003
Preparatory training in classical music (flugelhorn)

PUBLICATIONS

Peer reviewed

- Schippers, A. & **van Heumen, L.** (2014). The inclusive city through the lens of quality of life. *International Public Health Journal*, 6(4), 311-322.
- Heller, T., Arnold, C.K., **van Heumen, L.**, McBride, E., & Factor, A. (2012). Consumer-Directed Support: Impact of Hiring Practices on Adults with Intellectual and Developmental Disabilities and Families. *American Journal on Intellectual and Developmental Disabilities*, 117(6), 464-477.

Book chapters

- Schippers, A. & **van Heumen, L.** (2014). The Inclusive City through the lens of Quality of Life. In R. I. Brown & R. Faragher (Eds.). *Challenges for Quality of Life: Applications in Education and other Social Contexts (169-184)*. Hauppauge NY: Nova Science Publishers
- Heller, T. & **van Heumen, L.** (2013). Aging with Disability. In M. Wehmeyer (Ed.) *Oxford handbook of positive psychology and disability (pp.409-423)*. Oxford, U.K.: Oxford University Press.
- Parker, S., Heller, T., Schindler, A., & **van Heumen, L.** (2012). Problems, Controversies and Solutions. In T. Heller & S. Parker (Eds.). *Disability through the Life Course (pp.39-102)*. Volume 1 for Sage Reference Series on Disability. Sage Publications
- van Heumen, L.** (2012). Challenging the way we think about dementia. In *Zie meer Kijk anders. Tien jonge wetenschappers over disability studies (See more by looking in a different way. Ten young scientists on disability studies) (pp. 101-114)*. Utrecht: ZonMw.

Selected non-peer reviewed publications

- van Heumen, L.,** Werkema, L., & van den Bosch, K. (2013). *Conference Report Disability Studies International Conference 'The Art of Belonging' October 31st - November 2nd 2013, Amsterdam, the Netherlands*. Amersfoort: Stichting Disability Studies in Nederland.
- van Heumen, L.** (2013). What Does Growing Older Mean? In T. Heller & A. Factor (Eds.) *Self-Determination in Aging. Research to Practice in Self-Determination Series*, 5, 8. Kansas City, MO: National Training Initiative on Self-Determination & Association of University Centers on Disabilities.

CONFERENCE PRESENTATIONS

Oral presentations

- van Heumen, L.** & Schippers, A. (2014). *Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families*. Paper presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Orlando, FL, USA.
- Heller, T., & Fisher, D. by **van Heumen, L.** (2013). *Family Support Interventions: Crossing Networks of Aging and Developmental Disabilities*. Paper presentation at the Gerontological Society of America annual scientific meeting, New Orleans, LA, USA.
- van Heumen, L.** & Schippers, A. (2013). *Quality of Life Effects of Individual Support for Families*. Paper presentation at Roundtable of the Quality of Life Special Research Interest Group (SIRG), International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Amsterdam, the Netherlands.
- van Heumen, L.,** Schippers, A., Kleine, J., Steinbach, Z. & Adel Nikkhooij, A. (2013). *Evaluation of Family Quality of Life after Family-Oriented Support with Young Adults with Intellectual Disabilities and Families*. Paper presentation at "The Art of Belonging", 2nd International Conference Disability Studies in the Netherlands, Amsterdam, the Netherlands.
- van Heumen, L.** (2011). *Disability studies and aging*. Paper presentation at 'Beyond Access: From Disability Rights to Disability Justice', Society for Disability Studies Conference, San Jose, California, USA.
- van Heumen, L.** (2010). *Disability studies and aging*. Paper presentation at 'Diversity in Quality of Life' International Conference of Disability Studies in the Netherlands and VU University around World Disability Day, Amsterdam, the Netherlands.
- Heller, T., **van Heumen, L.,** McBride, E., Keiling, C. & Factor, A. (2011). *Consumer-Direction: Impact of Hiring Practices on Adults with ID/DD*. Paper presentation at Festival of International Conferences on Caregiving, Disability, Aging and Technology, Growing Older With a Disability, Toronto, Canada.
- Heller, T., Arnold, C.K., **van Heumen, L.,** McBride, E. & Factor, A. (2011). *Consumer-directed support: impact of hiring practice on adults with I/DD and families*. Paper presentation at State of Science Conference on Lifespan Health and Function of Adults with

Intellectual and Developmental Disabilities: Translating Research into Practice, Bethesda, MD, USA.

Heller, T., **van Heumen, L.**, Caldwell, K., McBride, E., Arnold, C. K. & Factor, A. (2010). Consumer-directed support: impact of hiring practices on families of adults with I/DD. IASSIDD Europe Congress, Rome, Italy.

Poster presentations

van Heumen, L. (2014). Social Relationships of Older Adults with Intellectual Disabilities from a Life Course Perspective. Poster presentation at the Annual Scientific Meeting of the Gerontological Society of America, Washington DC, USA.

van Heumen, L. (2014). Social relations of older adults with intellectual disabilities from a life course perspective. Poster presentation at the Annual Meeting of the American Association on Intellectual and Developmental Disabilities, Orlando, FL, USA.

Burke, M. B., Arnold, K., Xiong, S., **van Heumen, L.**, McBride, E., & Heller, T. (2014). *Comparing Caregiver Experiences of Parents and Siblings of Individuals with Intellectual and Developmental Disabilities*. Poster presentation at the 47th Annual Gatlinburg Conference, Chicago, USA.

van Heumen, L., Heller, T., McBride, E. & Arnold, C.K. (2013). *Satisfaction with personal support workers and well-being of aging family caregivers of adults with I/DD*. Poster presentation at the Roundtable of the Aging Special Research Interest Group (SIRG), International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD), Boston, MA, USA.

Heller, T., McBride, E., **van Heumen, L.**, Arnold, C.K., Factor, A. (2012). Consumer-Direction: Impact of Hiring Practices on Adults with ID/DD. Poster presentation at the American Association of Intellectual and Developmental Disabilities, Charlotte, NC, USA.

van Heumen, L. (2010) '*Social Relations of Ageing People with Intellectual Disabilities*'. Poster presentation at the Joint Roundtable of the Aging and Health Issues SIRG's, IASSIDD, Prato, Italy.

SELECTED INVITED LECTURES

Aging with intellectual and developmental disabilities (I/DD) 2015
Easter Seals, two part national webinar, USA

Lived experience of people aging with intellectual and developmental disabilities (IDD): the use of inclusive research methods 2014
Symposium Disability Studies preceding inaugural lecture Prof. Dr. Geert van Hove
VU University Amsterdam, the Netherlands

Lived experience of people aging with intellectual and developmental disabilities (IDD): the use of inclusive research methods 2014
Pre-conference workshop 'New perspectives in Community Based Participatory

Research on Aging and Developmental Disabilities' with Tamar Heller, PhD,
Joseph Caldwell, PhD, Susan Fox, MA, MS, and Tia Nelis
Association of University Centers on Disabilities, Washington DC, USA

Aging with disability 2014

Foundations of Disability and Human Development (DHD401), Department of
Disability and Human Development, University of Illinois at Chicago, USA

*Social Relations of Older Adults with Intellectual Disabilities from a Life Course
Perspective* 2014

Concepts in Interdisciplinary Research on Disability (DHD 510), Department of
Disability and Human Development, University of Illinois at Chicago, USA

Critical gerontology and aging in Disability Studies 2013, 2014

Disability Studies I (DHD 501), Department of Disability and Human
Development, University of Illinois at Chicago, USA

Aging of persons with disabilities 2014

Disability, Health and Society (DHD 202), University of Illinois at Chicago, USA

Aging with an intellectual disability 2014

Anixter Center, Chicago, USA

Aging with an intellectual disability 2013

Lambs Farm, Libertyville, USA

Aging and intellectual disability in the US: Context, challenges, & opportunities 2013

with Brian Grossman, PhD, Sc.M.
Leadership Education in Neurodevelopmental and related Disabilities (LEND)
Interdisciplinary Training Program, Department of Disability and Human
Development, University of Illinois at Chicago, USA

Aging Well across the Lifespan of Adults with Intellectual Disabilities 2013

Illinois Association for Rehabilitation Facilities conference
Springfield, IL, USA

Aging Well across the Lifespan of Adults with Intellectual Disabilities 2013

Network Gedragkundigen Ouderen (Network for Psychologists working with
Aging people with intellectual disabilities), the Netherlands

*Social Relations of Older Adults with Intellectual Disabilities from a Life Course
Perspective* 2013

American Public Health Association, Disability Section Student
webinar, USA

Aging with an intellectual disability 2011

LEND Interdisciplinary Training Program, Department of Disability and Human

Development, University of Illinois at Chicago, USA

The aging person with an intellectual disability 2007-2009
Clinical Psychogerontology course, Centre for Psychogerontology, Radboud
University Nijmegen, the Netherlands

Social relations among adults aging with intellectual disabilities 2008
Netwerk Gedragskundigen Ouderen, the Netherlands

GRADUATE ACADEMIC AWARDS AND SCHOLARSHIPS

American Association on Intellectual and Developmental Disabilities 2015 Student Award 2015

Renewal Chancellor's Graduate Research Fellowship 2014
University of Illinois at Chicago (\$4000)

Rue Bucher memorial award for qualitative studies in social processes 2014
University of Illinois at Chicago (\$700)
(The Rue Bucher memorial award is an annual research award for a doctoral student in any department or college across the University of Illinois at Chicago using qualitative or field methods)

Paul D. Doolen Graduate Scholarship for the Study of Aging 2014
University of Illinois (\$3500)
(The Paul D. Doolen Graduate Scholarship for the Study of Aging is an annual university-wide award across the Chicago, Springfield and Urbana-Champaign campuses recognizing two outstanding graduate students who are interested in the study of aging (one award in biomedical and one award in social-behavioral aspects of aging))

Chancellor's Graduate Research Fellowship 2013
University of Illinois at Chicago (\$4000)
(The Chancellor's Graduate Fellowship Program supports increased multidisciplinary scholarship opportunities and exposure to varied research and creative fields for graduate and professional students. Successful applicants show exceptional promise for future multidisciplinary research and creative activity in their fields of interest)

Best essay 2012
Disability Studies in the Netherlands (€1.000)

10th Ann & Edward Page-El, M.D. Scholarship 2012
Department of Disability and Human Development, University of Illinois at Chicago (\$500)
(Annual departmental award that supports the educational opportunities of one graduate student interested in social or medical aspects of neurological disabilities)

Chicago Consular Corps Scholarship	2011
University of Illinois at Chicago	(\$1000)
(Annual scholarship that supports nine international students each year. The competition is open to all international students at the University of Illinois at Chicago)	

Cultuurfondsbeurs Prins Bernhard Cultuur Fonds/Carolus Magnus Fonds	2009
(prestigious and highly competitive Dutch scholarship for outstanding scientists and artists who want to continue their studies abroad)	(€15.000)

VSB beurs	2008
VSB fonds (scholarship for motivated students to study or do research abroad after graduation from a Dutch institution of higher education)	(€7.000)

Travel awards

Accelerating Translation of Knowledge to Community Practices for Older Adults workshop on Aging with Disabilities travel grant , Gerontological Society of America and the National Center on Gerontological Social Work Excellence	2014
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Scholarships to attend roundtables of Health and Aging Special Interest Research Groups, International Association of the Scientific Study of Intellectual and Developmental Disabilities	2009, 2010, 2013
Canada, Italy and USA	

DisABILITY MUNDUS	2012
Participant at the first European doctoral school in Disability Studies	

Health Professions Student Council Travel Award, University of Illinois at Chicago	2010, 2012, 2013, 2014
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Scholarship Society for Disability Studies	2011
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Graduate College Presenters Award, University of Illinois at Chicago	2010, 2014
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Student delegate at the Special Olympics Winter World Games	2009
Boise, Idaho, USA	

Additional funding sources

Netherland American Foundation, NY, USA	2012
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Vreedefonds, the Netherlands	2011
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RESEARCH EXPERIENCE

<p>Research assistant (supervisor Tamar Heller, PhD) Ligas Evaluation study, Institute for Disability and Human Development, University of Illinois at Chicago</p> <ul style="list-style-type: none"> Collect and analyze quantitative and qualitative data, contribute to research briefs and publications 	2014-present
<p>Research assistant (supervisor Brian Grossman, PhD) Institute for Disability and Human Development, University of Illinois at Chicago</p> <ul style="list-style-type: none"> Provide support with grant applications and applications for the university's Institutional Review Board 	2014-present
<p>Research project coordinator (supervisor Alice Schippers, PhD) Disability Studies in Nederland, (Disability Studies in the Netherlands, DSiN) The Netherlands</p> <ul style="list-style-type: none"> The aim of DSiN is to stimulate the establishment of a coherent body of knowledge as well as research and education in the field of the Disability Studies in the Netherlands. The study is part of the larger project 'The Inclusive City' (http://disabilitystudies.nl/inclusieve-stad) Evaluated the long term impact of a project in which families were individually supported in the realization of personal future plans in the city of Almere, the Netherlands (2004-2006) Used fourth generation evaluation principles and data collection consisted of semi-structured interviews, focus groups and photo voice. Developed research proposal and materials and methods, collected data, supervised students, analyzed qualitative data, wrote manuscripts and presented of project at international conferences 	2012-present
<p>Research assistant (supervisor Tamar Heller, PhD) Rehabilitation Research and Training Center on Aging with Developmental Disabilities (RRTC/ADD), University of Illinois at Chicago, USA</p> <ul style="list-style-type: none"> Project was titled: 'Consumer-Directed Support: Impact of Hiring Practices and Training in "Learning to Direct your own Supports" on Adults with I/DD and Families' Prepared data collection materials, collected and analyzed quantitative and qualitative data, contributed to research papers, developed presentations and worked as co-trainer during training intervention 	2008-2014
<p>Abstract reviewer 2014 IASSIDD Europe Regional Congress</p>	2014
<p>Interviewer Study to investigate sleep disturbances in children with rare genetic syndromes Cerebra Centre for Neurodevelopmental Disorders, University of Birmingham, United Kingdom. Foundation for Angelman Syndrome Therapeutics conference,</p>	2013

Chicago, USA

TEACHING EXPERIENCE

Teaching assistant (supervisor Brian Grossman, PhD)

2014-
present

Disability in U.S. society, DHD101 (130 students)

Department of Disability and Human Development, University of Illinois at Chicago, USA

- Assist in development of course materials (syllabus, readings, assignments, etc.)
- Provide individual support to 40 students
- Grade assignments
- Provide guest lectures

Thesis advisor/editor

2013-
present

Schrijvers Gezocht, the Netherlands

- mentor students working on their undergraduate, postgraduate and graduate theses:
 - Nick Kreulen (Extra begeleiding of juist niet? Behoeften van chronisch zieke en fysiek beperkte jongeren ten opzichte van jobcoaching/Extra support or not? Job coaching needs of young adults with chronic illness and physical disability), Fontys University of Applied Sciences, the Netherlands
 - Karen Raes (Dans als helende kracht voor het gewonde lichaam/Dance as the healing power for the wounded body) , KAHO Sint Lieven University, Belgium
 - Caren van Rietschoten (De therapeutische meerwaarde van dierondersteunende therapie met de hond in de behandeling van getraumatiseerde kinderen/The therapeutic value of animal assisted therapy with dogs in the treatment of traumatized children) – Opleiding tot Kinder- en Jeugd Therapeut/Child and Youth Therapy Program, BGL & Partners, the Netherlands
 - Cynthia Visser (De beste benadering door verpleegkundigen aan cliënten met een psychiatrische stoornis en een licht verstandelijke beperking/The best nursing practices for clients with a psychiatric illness and mild intellectual disability) – INHolland university of applied sciences/Dijk en Duin, the Netherlands

Practical supervisor

2012-
2013

Comakerships (internships) of three undergraduate students (Jolanda Kleine, Zia Steinbach & Anice Adel Nikkhooij).

Disability Studies in the Netherlands and Windesheim University of Applied Health Sciences, the Netherlands

- These projects aim to promote social interactions, a diverse culture and a sense of social safety. Furthermore, the co-makerships aim to

stimulate the development of local youth to become independent, self-directed and contributing citizens of the community

Co instructor (with Elizabeth McBride) 2012

Foundations of Disability and Human Development - DHD401

Master of Science Program in Disability and Human Development, Department of Disability and Human Development, University of Illinois at Chicago, USA

Research fellow 2010-2012

Envision Unlimited, Chicago, USA

- provided trainings on aging of people with intellectual disabilities to direct support staff

Tutor in statistics 2008

Radboud University Nijmegen, the Netherlands

Teaching assistant in undergraduate courses in developmental psychology, clinical psychology and gerontology 2007-2009

Radboud University Nijmegen, the Netherlands

- Taught weekly seminars to groups of ± 20 students

RELATED PROFESSIONAL EXPERIENCE

Attended the 2014 International Elder Law and Policy conference 2014

John Marshall Law School, Chicago, USA

- Contributed to the drafting of the Chicago Declaration on the Rights of Older Persons

Executive assistant to Vladimir Cuk, Social Development Human Rights 2011

Officer International Disability Alliance Secretariat, New York, USA

- Responsibilities included reviewing UN related policy briefs, concept and background notes, drafts of resolutions and declarations. Additional responses included assistance during UN related meetings, note taking, and other personal assistance

CLINICAL EXPERIENCE

Direct support professional 2002-

Cello (organization for persons with intellectual disabilities), The Netherlands 2009

Psychologist 2007-

Stichting Pergamijn (organization for persons with intellectual disabilities), The Netherlands 2008

- Was responsible for the well-being of ± 80 persons with intellectual disabilities living in five different residences. Clients were of all ages, had mild to profound intellectual, developmental, physical, behavioural and

psychiatric disabilities

- Was a member of multidisciplinary support teams of the residences along with the physicians, occupational and physical therapists and direct support staff monitoring the well-being and support to the clients
- Was responsible for psychodiagnostics and behaviour plans
- Supported direct support professionals and management

Basic registration in psychodiagnostics

2008

Nederlands Instituut voor Psychologen (Dutch Institute for Psychologists), The Netherlands

SKILLS

Language fluency: Dutch, English, German, basic French

Software: Microsoft Office, Atlas.ti, SPSS, Endnote, Scrivener, basic web design

MEMBERSHIPS

Gerontological Society of America

Co-convenor Lifelong Disabilities Special Interest Group

2014-present

International Association of the Scientific Study of Intellectual and Developmental Disabilities