

TRANSITION TO ADULTHOOD: THE EXPERIENCE OF YOUTH WITH  
PHYSICAL DISABILITIES LIVING WITH A SERVICE DOG

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## ABSTRACT

Susan Jane Modlin

### TRANSITION TO ADULTHOOD: THE EXPERIENCE OF YOUTH WITH PHYSICAL DISABILITIES LIVING WITH A SERVICE DOG

The focus of this qualitative descriptive study is the experience of physically disabled young people as they transition into adulthood while living with a service dog. The cornerstone of young adulthood is transition. For any young adult leaving home, the transition involves inter- and intra-personal changes that affect future well-being. Unfortunately, the majority of young adults with congenital disabilities are less likely to be fully employed and to live independently than their non-disabled peers. To date, very little research about living with a disability exists from the point of view of young adults. Even fewer qualitative research studies exist that focus on service dog teams. This research report will add to the body of nursing knowledge about people with disabilities and their experience of transition in the areas of health, work/school, relationships and identity. The findings result from descriptive analysis of interviews with four young adults and one parent. Using qualitative descriptive methods, the researcher identified three themes that defined the experience of transition. *It's different now* contained stories regarding life before and after obtaining the service dog. This theme included elements of personality development similar to any young adult in transition, such as identifying "who I am now." *Going places* was the most personal theme, describing the social implications of going or not going places and the environmental and personal barriers related to learning to drive. *Calling the shots* centered on the ability to make choices for themselves and the dog, as well as to participate in age appropriate milestones, such as attending college and living away

from home. The findings of this study will be useful to professionals who place service dogs with persons with disabilities, rehabilitation specialists who desire appropriate interventions to facilitate transitions, and nurse researchers and clinicians who desire to understand the bond between animals and human beings.

Melinda M. Swenson, Ph.D, Chair

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## CHAPTER ONE: INTRODUCTION

The cornerstone of young adulthood is transition. For any young adult leaving home the transition involves inter-and intra-personal changes that affect future well-being. Everyday 18-25 year olds participate in age appropriate milestones, such as attending college, beginning new relationships, finding jobs and living away from home.

Although transitions are momentous events for the family and the individual, oftentimes moving out is taken for granted. This particular transition, however, is rarely taken for granted by young adults with a disability (Betz, 1998; Hallum, 1995; Sawin, Cox, & Metzger, 2000). In addition to making decisions about employment, schooling, housing and peer relationships, young adults with a disability must also consider the effect their health or disability will have on those decisions.

Recent figures indicate that 90% of children born with a chronic condition or disability will survive into their twenties or beyond (Antle, 2004; King et al., 2003; Lotstein, McPherson, Strickland, & Newacheck, 2005; U.S. Census Bureau, 2003), and most are expected to live well into adulthood. This increased survival rate is primarily due to early intervention programs for infants and improved preventive care for adolescents. As children with disabilities move through adolescence there is concern regarding the paucity of programs (e.g., health care, vocational, recreational) for adolescents and young adults with disabilities (Betz, 1998; Betz & Redcay, 2002; Blomquist, 2006; Hallum, 1995). Initial research identified transition needs, yet few outcome studies document successful program implementation. The Americans with Disabilities Act (ADA) of 1990 afforded adults with disabilities a safeguard from discrimination in the workplace, but did not include mechanisms for young adults with

disabilities to make a smooth transition from school to work or from their parent's home to independent living. Consequently, the revised Individuals with Disabilities Education Act (IDEA) of 1997 and IDEA of 2004 included mandates that transition plans for students with disabilities become part of every individualized education plan (IEP) by age 16 (Luther, 2001; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006).

The intent of the revised IDEA (1997) was to fill the gap between the services mandated for infants and children with disabilities and the ADA's focus on workplace and public accommodations for adults with disabilities. One unexplored possibility is the use of service dogs as a rehabilitation aide under the assistive devices section of IDEA (2004). As adolescents with disabilities plan for their future, service dogs could become part of the individualized education plan (IEP)/individualized treatment plan (ITP). Before the use of service dogs can be considered a rehabilitation intervention for youth with disabilities, the nature of the relationship and its meaning to the recipient must be clearly described.

The purpose of my study was to describe the experience of transition for young adults who have a disability and live with a service dog. The framework for the study was qualitative description focusing on the participant's point of view (O'Day & Killeen, 2002; Rich & Ginsburg, 1999; Sandelowski, 2000, 2004). Although the experience of young adulthood is many faceted, my study addressed the issues of transition to young adulthood in general, as well as the specific problems or challenges that face young adults with disabilities (Betz & Redcay, 2005; Ginsburg, 1996; Hallum, 1995; *Healthy People 2010*, 2002; Piotrowski & Snell, 2007; Scal & Ireland, 2005).

In this chapter I will (a) cite relevant literature identifying the problem, (b) discuss the evolution of the research question, (c) elucidate the need for a qualitative descriptive study, and (d) present a self-reflexive statement about the philosophical beliefs I bring to the study.

## Background and Problem Statement

### *Americans with disabilities*

Today, approximately 49 million Americans have a disabling condition that limits one or more of their daily activities. Of this group, more than 15 million require some or significant assistance with activities of daily living. An additional 9.7 million are unable to carry on the major activities of someone their age. Approximately 40 percent have mobility limitations, and more than 2 million people with disabilities use wheelchairs for mobility. More than 200,000 individuals with spinal cord injury and resulting paralysis have major mobility limitations. Estimates of lifetime costs of spinal cord injury exceed \$1 million dollars per person. Orthopedic impairments and arthritis, the main causes of disability in the working age population, rank as the top two causes of activity limitation, affecting 9.2 million people. The annual cost to the nation of disability-related payments and health care for people with disabilities is in excess of \$170 billion (Cornell University, 2005; U.S. Census Bureau, 2003; U.S. Department of HHS, 2006).

The incidence and prevalence of people with disabilities continue to rise due to dramatic increases in health care's ability to prevent deaths due to injury, disease, and conditions associated with aging. Annually, one third of the National Institutes of Health (NIH) rehabilitation research focused on issues related to mobility and assistive

technology. Outside the NIH, the National Institute on Disability and Rehabilitation Research (NIDRR) supports a significant amount of research related to socio-behavioral issues; the Centers for Disease Control and Prevention (CDC) support work on demographics, prevention, and secondary complications; and the Veterans Administration supports research on issues of particular concern to the health care of veterans (U.S. Department of HHS, 2006, p. 3-5).

In 2005, the percentage of working adults with a disability (the prevalence rate) was 12.6 percent in the US. In other words approximately 21 million of the 169 million working-age Americans reported one or more disabilities. Numbers relative to the current study reveal 11 percent of working adults with disabilities were ages 21-29 and only 22% of working-age people with disabilities worked full-time/full-year compared to 56% of people without disabilities (Cornell University, 2005, p. 10-11)

The majority of young adults with disabilities were less likely to be fully employed and to live independently than their non-disabled peers (Blomquist, 2006; Hallum, 1995; Scal & Ireland, 2005; Wolman, Resnick, Harris, & Blum, 1994). According to the National Center for Medical Rehabilitation Research (NCMRR) at NIH, the current federal research priorities address reintegration strategies for young adults with disabilities to increase their independence and employment potential and decrease the co-morbidity associated with long-term disability (Betz & Redcay, 2005; *Healthy People 2010*, 2002; Krahn, Putnam, Drum, & Powers, 2006; U.S. Department of HHS, 2006). Unfortunately similar priorities existed a decade ago (Betz, 1999; Laplante, Carlson, Kaye, & Bradsher, 1996; Scal, Evans, Blozis, Okinow, & Blum, 1999), with only slightly improved outcomes for youth today (Blomquist, 2006;

Wagner, Newman, Cameto, Garza, & Levine, 2005). A third of the youth with disabilities in Betz and Redcay's (2005) study had not completed high school, a finding consistent with previously reported drop-out rates (Cornell University, 2005; U.S. Census Bureau, 2003). However, many of the youth had some unpaid employment experience such as being a volunteer or participating in school-based employment training (Betz & Redcay, p. 54; Ville & Winance, 2006).

Depression related to social isolation and loneliness was another concern for young adults with chronic illness or physical disability (Antle, 2004; Sawin, Cox, & Metzger, 2000). Adolescents and young adults with disabilities have fewer opportunities for social interaction with their peers, which also reduced their social skill level. Although most studies indicated young adults have close relationships with their parents and siblings, this dependence on the family may hinder future goals of independence (Lotstein et al., 2005; Luther, 2001; Patterson & Lanier, 1999; Stewart, Law, Rosenbaum, & Willms, 2001).

In the last decade, many researchers included the point of view of young adults living with a disability (Neri & Kroll, 2003; Sawin, Brei, Buran, & Fastenau, 2002; Stewart et al., 2001; Woodgate, 1998; Yoos & McMullen, 1996). Disability literature predominately focused on how a disability affected others such as, parents (Kearney & Griffin, 2001; Larson, 1998; Patterson & Lanier, 1999; Treloar, 1999), schools (Blomquist, 2006; Mulcahey, 1992), or health care providers (Callahan, Feinstein, Winitzer, & Keenan, 2001; Hellstedt, 2004; Scal & Ireland, 2005); so it is encouraging to see the recent trend focusing on the young adults' experience. In the past, people with disabilities, especially children or adolescents, had something done to or for them; the

fact that they could have an opinion or voice was not acknowledged (Betz & Redcay, 2002; Hallum, 1995; Rich & Ginsburg, 1999; Telford, Kralik, & Koch, 2006).

### *Service dogs*

Currently, there is a limited supply of service dogs available. Of the more than 40 million Americans who have a disability fewer than 20,000 have a service dog. Of that 20,000 the majority are adults. Clearly the demand is greater than the supply. Each year the Delta Society's National Service Dog Center, a clearinghouse for questions about obtaining or training service dogs, receives thousands of calls from people who desire but are not able to obtain a service dog (Duncan, 1995; Hines, 2003; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Zapf & Rough, 2002).

Many authors described independence and companionship as the primary reasons for seeking partnership with a service or guide dog (Collins, Fitzgerald, Sachs-Ericsson, Scherer, Cooper, & Boninger, 2006; Nicholson, Kemp-Wheeler, & Griffiths, 1995; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Valentine, Kiddoo, & Lafleur, 1993). Instrumental support or help with tasks, such as retrieval of dropped items, was another frequent and consistent benefit cited by service dog users (Collins et al., 2006; Fairman & Huebner, 2000; Rintala, Sachs-Ericsson, & Hart, 2002; Sachs-Ericsson et al., 2002; Valentine et al., 1993; Zapf & Rough, 2002). Therefore, it is not surprising that many current service dog studies originated from the occupational or physical therapy domains with an emphasis on adaptation, assistive technology and task facilitation (Camp, 2001; Fairman & Huebner, 2000; Hanebrink & Dillon, 2000). Potential service dog recipients, service dog trainers and health care professionals need accurate and up-to-date information about the role of service dogs beyond assistance

with tasks (Collins et al., 2006; Collis & McNicholas, 1998; Modlin, 2000; Zapf & Rough, 2002).

Although Valentine, Kiddoo, and LaFleur (1993) and others (Camp, 2001; Lane, McNicholas, & Collis, 1998) found enhanced social skills and greater risk-taking evident in the ongoing partnership with a service dog; recent research by Collins et al. (2006) did not find significant results related to service dog partnership and community integration despite using matched controls and standardized rehabilitation measures. Inconsistent findings made drawing conclusions especially difficult when the studies have small samples (Rintala, Sachs-Ericsson, & Hart, 2002) or researcher designed tools (Fairman & Huebner, 2000; Zapf & Rough, 2002).

Until recently, the research studies of service dogs consisted mainly of simply designed questionnaires measuring functional assessment (Fairman & Huebner, 2000; Lane et al., 1998), independence (Valentine, Kiddoo, & LaFleur, 1993; Zee, 1983), social integration (Allen & Blascovich, 1996; Fairman & Huebner, 2000; Hart, Hart, & Bergin, 1987; Lane et al., 1998) and observations of interactions with service dogs (Eddy, Hart, & Boltz, 1988; Mader, Hart, & Bergin, 1989). The majority of studies did not address differential benefits found in people partnered with a service dog. For a complete review of methodological concerns of service dog studies see Sachs-Ericsson et al. (2002).

### Research Question

As I began my dissertation research I was sure the study was about service dogs. However, after pilot work and conducting an initial review of the literature, my study became less about the dogs and more about the experience of transition to adulthood for

youth with disabilities *who also have service dogs*. Because of the novelty of service dogs and because only recently adolescents with disabilities are moving into young adulthood in large numbers, my study was best suited to a method that allowed for exploratory description. I chose qualitative description for this study because it allowed me to appreciate individual stories, and it allowed comparison and interpretation across and within individual stories to create a greater whole (Baker, Norton, Young, & Ward, 1998; Caelli, 2001; Kearney, 2001). Using qualitative description provided the young adults the opportunity to describe the experience in their own words (Rich & Ginsburg, 1999).

Qualitative description was appropriate for this study because: (a) the literature to date has few qualitative studies of young adults with disabilities, (b) service dog studies lacked clear definitions and descriptions of the service dog as a possible intervention, and (c) this methodology brought to light the similarities and differences in the experiences of these young adults. Nursing practice is uniquely situated to benefit from the current study findings. Nurses working with young adults will have richer descriptions of the benefits and drawbacks of living with a service dog, as well as understanding the challenges and opportunities of transitioning to adulthood with a disability.

## Philosophical Assumptions

### *Qualitative description*

Qualitative description produces new nursing knowledge by examining the experiential nature of living with a disability, living with a service dog and transitioning to adulthood from the individual's point of view (Benner, 1994; Sandelowski, 2000, p. 337). Additionally, qualitative description can be informed by traditional qualitative methods such as phenomenology (Kearney, 2001; Sandelowski, 2000).

### *Phenomenology*

The tradition of phenomenology allows questions to be asked and stories to be told that lead to a clear description of the experience, (e.g., what living independently with a disability looks like for young adults). van Manen (2006) described phenomenology as a reflective method that produces knowledge in the form of narratives that describe and evoke understanding (p. 715). It is also a collaborative effort between the researcher and the participant to create meaning (Benner, 1994; Gullickson, 1993).

The epistemological premise of phenomenology encourages the researcher to elicit stories from each participant to find common meaning and to write an interpretation that is meaningful to the reader (van Manen, 1997, p. 361). Qualitative description also demands interpretive writing, achieved by pulling together the stories of each participant and developing descriptive themes (Crist & Tanner, 2003; Kearney, 2001). Phenomenology informed the study, but qualitative description defined the study (Sandelowski, 1998, 2000; Sandelowski & Barroso, 2002).

### *Self-Reflexive statement*

My personal experience with raising puppies to become service dogs provided a constant reminder of the bond between humans and animals. Nursing, as a holistic clinical practice, takes into account physiological, psychosocial, cultural and environmental aspects of an individual or group. Those same phenomena are associated with the benefits of the human-animal bond generally, and the relationship between the individual with a disability and their service dog, specifically (Barker, Rogers, Turner, Karpf, & Suthers-McCabe, 2003; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Virues-Ortega & Buela-Casal, 2006; Wilson & Barker, 2003). My nursing background, my own physical limitations and my interaction with service dog teams influenced my understanding of the experience of disability. I also recognize that the body is not an object that something is done to, but the body is a way of experiencing or knowing a phenomenon or experience (Benner, 1994; van Manen, 1998; Zitzelberger, 2005).

My ontological stance is one of being in the world as a caring, divergent thinker with the ability to imagine endless possibilities. I am situated in a particular way with animals generally and service dogs specifically, based on my experience with family pets and raising puppies as service dogs (Modlin, 2001). I wonder why something that seems ordinary is not. And I recognize that things that are easy for one person may be a struggle for another (Caelli, 2001; Dowling, 2007). My epistemological stance is one of contextual and created meaning. Knowledge is not out there to be discovered but it is evident in the life we live and the stories we tell. Generating knowledge comes from our experience with others (Dowling, 2007; Sandelowski, 1995, 1998).

## CHAPTER TWO: PRELIMINARY LITERATURE REVIEW

The literature reviewed for this study falls into three major categories. First, I reviewed qualitative studies that addressed transition, disability and the human-animal bond. Next, I presented transition issues for young adults with and without disabilities. The areas of focus included: (a) independence, (b) family and friends, (c) career, work or school, and (d) health or self-care. Finally, I reviewed the human-animal bond literature as it relates to health benefits and service dogs.

### Qualitative Studies

Many of the authors in this section of the review chose a qualitative methodology because there was a lack of information on the topic, or because the emic point of view was missing. DeDanto-Madeya (2006) and Gullickson (1993) found that most empirical studies of chronic illness or disability were disease-specific and intervention-focused. A categorical empirical approach does not allow for the reality of the person experiencing the illness/disability to be integrated into the findings. A lack of information about living with a chronic disease prompted qualitative studies of adolescents and young adults with chronic illness, (Woodgate, 1998), asthma (Yoos & McMullen; 1996), and a grounded theory study of hopefulness in both ill and well adolescents (Hinds, 1988).

Discrepancies between what is known empirically and what is known experientially were mentioned repeatedly. In a focus group study, Patterson and Lanier (1999) cited the need for health care professionals to consider the perspective of the adolescent rather than the perspective of the parent and health care providers. When the emic point of view was examined, Patterson and Lanier, as well as Pierce (1998) and

Cooper (1994), found the experience of disability as one of resilience and empowerment rather than an experience of loss and suffering. Likewise, Zitzelberger's (2005) account of women's experience with physical disabilities; Padilla's (2003) case study of disability and Harrison and Stuijbergen's (2005) study of aging with a disability, all found the subjective experience of disability more ordinary than extraordinary. Their research as well as others revealed the hidden meaning of life going on *in spite of* the disability (King et al., 2003; Larson, 1998; Stewart et al., 2001; Thorne & Patterson, 1998).

Finding meaning and making sense of what happened were the themes of Mulcahey's (1992) study of young adults with a spinal cord injury and Kinavey's (2006) study of identity. Charmaz (1995) and DeDanto-Madeya (2006) also found identity tied to adaptation, as defined by the person experiencing the disability. Participants in these studies were aware of societal obsessions with appearance and had to redefine meaning in their lives.

#### Transition Issues for Young Adults

Adolescents and young adults move from a state of dependence or reliance on parents during early adolescence (12-15 years old) to a state of independence and reliance on peers and interests outside the family during later adolescence (16-18 years old) and dependence on self and/or romantic relationships in young adulthood (18-25 years old). For most families the parent-child relationship changes from one of unilateral parental authority to parent-child interaction that is more co-operative and reciprocal (Feldman & Elliot, 1990; Hallum, 1995). Typically parents relinquish control and then are able to move on with their own mid-life tasks. However, for the family

with a young adult with a disability, the focus may not shift from parenting back to their own needs, but rather the demands of parenting are extended (Sawin, Cox, & Metzger, 2000; Wolman, Resnick, Harris, & Blum, 1994).

### *Independence*

The transition to independence often starts with a physical separation from the parents, for example, the teenager asks permission to drive the car and/or to ride with a friend to an event rather than being taken somewhere or being in the physical presence of the parent. For many adolescents and young adults with a physical disability this aspect of transition is difficult and may lead to social isolation (Buran, McDaniel, & Brei, 2002). The adolescent with a disability may miss social events unless the parents are responsive or the peers are accommodating.

Lavigne and Faier-Routman (1993) found mobility issues central to adolescent achievement of independence. Their study focused on a peer group that discussed mobility issues. They found adolescents were reluctant to discuss their fears of independent travel and were willing to make serious errors rather than ask for assistance. Adolescents with disabilities, who are unable to arrange their own transportation and subsequently rely on their parents, are at a disadvantage in attaining independence. However, if young adults solve transportation and access issues, then dependence on the parents lessens (Blomquist, 2006; Wagner et al., 2005).

Although financial independence may be an acceptable goal for most adolescents, some young adults with severe disabilities may never be able to attain financial independence. However, they may be able to attain autonomy in making financial decisions, (i.e., how the Social Security Insurance [SSI], vocational

rehabilitation money is spent.) Therefore, independent decision-making stems from interdependence on parents that respects the individual (Hallum, 1995; Scal & Ireland, 2005; Stewart, Law, Rosenbaum, & Willms, 2001).

### *Family and friends*

Adolescence and young adulthood is a time to explore the company of others outside the family. It is a time to find caring friends and develop closeness with peers while at the same time trying to maintain family connections (Feldman & Elliot, 1990; Hostler, Gressard, Hassler, & Linden, 1989). Young adults begin to decide what is important to them by exploring options such as who to date, what to value, where to work and when to leave home. They make plans for the future that are congruent with an emerging sense of self. During early adolescence approval and acceptance by peers is a central theme. In late adolescence and young adulthood, concerns with having a group identity lessen and identifying future, individual goals become more important. (Betz & Redcay, 2005; Swanson, Cronin-Stubbs, & Sheldon, 1989).

Compas, Orosan and Grant (1993) found that stress during adolescence was a product of not only learning to cope with new interpersonal relationships, but also a result of biological and cognitive developmental factors. An adolescent's ability to perform cognitive appraisals is less well-developed than an adult's ability. Consequently, any youth, but especially at risk youth such as those with physical disabilities, may suffer stress related to faulty cognitive appraisals of interpersonal situations related to dating, peer friendships and family support. Young adults with disabilities may experience an altered social experience due to: (a) their exclusion from school/work activities, secondary to absences, (b) their inability to keep up physically

with their peers, as well as exclusion from peer activities because of feeling ill or different, and (c) their lack of normal informal interactions with peers in or out of school/work (Betz & Redcay, 2002; Blomquist, 2006; Buran, Sawin, Brei, & Fastenau, 2004).

#### *Vocational or educational*

Establishing a personal and vocational (career) identity is another hallmark of young adulthood (Crittenden, 1990; Hallum, 1995). Often the personal and vocational outcomes of young adults with disabilities are not equal to those achieved by their peers (Hostler et al., 1989; Turner & Szymanski, 1990). The results of one study indicated that even with work place accommodations, few people with disabilities felt they got help from their co-workers, and most felt uncomfortable asking for help to complete a task (Natterlund & Ahlstrom, 1999, p. 1335). A unique opportunity at one hospital provided youth with vocational readiness training and subsequent adult employment (White & Shear, 1992). Despite innovative programming, the number of young adults who failed to make a successful transition from school to career or vocation continues to remain unacceptably high (Blomquist, 2006; *Healthy People 2010*, 2002; Natterlund & Ahlstrom).

#### *Health care/self-care*

Young adulthood is generally a time of good health. Risky health behaviors, such as smoking, drinking or poor eating habits indulged during this time, will not have effects for many years. For the typical young adult health care visits are rare and episodic. For young adults with disabilities the trend was quite different. Chronic illness or physical disabilities in childhood may cause significant alterations in physical and

emotional growth and development in approximately 20-30% of young adults (Betz & Redcay, 2002; Hellstedt, 2004; Neri & Kroll, 2003; Peterson, Rauen, Brown, & Cole, 1994; Spencer, 1991). Transferring care from a pediatric specialty clinic to a primary care practitioner was a difficult transition. Pediatrics is focused on the family and developmental issues, whereas primary health care is focused on individual and episodic care (Callahan et al., 2001; Patterson & Lanier, 1999; Scal & Ireland, 2005; Wojciechowski, Hurtig, & Dorn, 2002; Woodgate, 1998).

The transition from pediatric to adult health care practitioners for youth with chronic and/or physical disabilities is a topic of great interest (Callahan, Feinstein Winitzer, & Keenan, 2001; Hellstedt, 2004; Scal & Ireland, 2005; Wojciechowski et al., 2002). While earlier research focused on identifying the health care needs of children and adolescents with chronic illness or disabilities, the current national research agenda focused on identifying/understanding their transition needs moving into adulthood (Hallum, 1995; Neri & Kroll, 2003; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). As this cohort of adolescents survived into young adulthood, it was estimated 450,000 youth with special health care needs (SHCN) turn 18 years old and prepare to enter adulthood every year. This large group includes all types of special health needs such as, diabetes, asthma, epilepsy, congenital disabilities, cognitive disabilities and developmental disabilities.

In a meta-analysis of 38 studies, Lavigne and Faier-Routman (1993) found disease and disability status were less predictive of psychological adjustment to a physical disorder in childhood than family or individual characteristics. Factors identified most strongly with high self-esteem and lower self-consciousness in

adolescents and young adults were (a) parental interactions/communications that were age-appropriate, and (b) parental permissiveness in social situations. Their findings were consistent with recent research suggesting that more attention should be placed on individual and family characteristics rather than the disability per se (Coakley, Holmbeck, & Bryant, 2006, p. 1096; Nelson, Haase, Kupst, Clarke-Steffen, & Brace-O'Neill, 2004; Scal & Ireland, 2005). According to Telford, Kralik, and Koch (2006), it was valuable for health care practitioners to recognize various expressions of illness or disability, "...one that prioritizes actual experience and recognizes the complexity and uniqueness of each person's journey" (p. 458).

For example, it is not uncommon for parents to have periods of depression while raising a child with physical disabilities (Treloar, 1999). The familial nature of depression has a serious impact on family functioning because depressed individuals have significant problems with communication, problem-solving and affective expression. The combination of a depressed child and a depressed family member could further limit social integration of youth with disabilities due to the withdrawal of not only one family member, but the entire family system (DeDanto-Madeya, 2006; Resnick & Hutton, 1987).

Several studies identified both the youth and their parents had difficulty communicating health care needs to providers (Buran et al., 2002; Patterson & Lanier, 1999). Even though youth wanted to be included in health care decision-making and transition planning, they lacked the skills to interact appropriately with health care providers. Parents had an especially difficult time communicating transition needs to multiple providers, e.g., teachers, school nurses, vocational rehabilitation specialists

(Blomquist, 2006). Interestingly, most of the youth in Betz and Redcay's (2005) study did not identify the school or clinic nurse as a participant in transition planning.

#### Human-animal Bond Studies

Companionship and safety are the most frequently cited considerations for obtaining either a pet or a service dog (Baun, Oetting, & Bergstrom, 1991; Duncan, 1995; Siegel, 1995; Valentine, Kiddoo, & LaFleur, 1993; Wilson & Barker, 2003). Studies of the benefits related to pet ownership proliferated after a 1987 National Institutes of Health (NIH) study on the health benefits of pets proposed "all future studies of human health should consider the presence or absence of a pet in the home and the nature of the human relationship with the pet as a potentially significant variable" (*The Health Benefits*, 1987, sect. 7, para. 5). Collis and McNicholas (1998) proposed three underlying mechanisms for a relationship between health benefits and companion animal (e.g., pet) ownership. First, pets may have a direct causal effect on health, second, pets have an indirect effect on health by increasing social contact, and third, there is a common factor that affects both health and pet ownership, but there is no causal relationship between health benefits and pet ownership (p. 106). Additionally, they differentiated pet companionship as providing intrinsic benefits such as shared pleasures (e.g., recreation), and pet social support as providing extrinsic benefits such as buffering stress (p. 115). This model was useful in understanding the potential benefits of both companion animals and service dogs.

#### *General health benefits of companion animals*

McNicholas and Collis (2000) found that individuals who had a significant relationship with their pet were more likely to talk to others and attribute positive, stable

characteristics to both the pet and the family. Others surmised pet owners felt more positively about themselves, less depressed and less isolated than non-owners because pet ownership may lead to activities that decreased social isolation and improved feelings of self-worth. (Beck & Katcher, 2003; Collis & McNicholas, 1998; Stevens, 1990).

A review conducted by Siegel (1993) identified psychological and physical health benefits of companion animal ownership. Siegel's review emphasized that early studies identified differences between owners and non-owners, but later studies focused on an attachment or bond as a characteristic of ownership that may explain differences. Moreover, the later studies did not assume all pet owners to be attached to their pets. Siegel proposed differentiating naturally occurring pet ownership from animals introduced as an intervention (e.g., service dogs or therapy animals) to better identify differences between the groups.

#### *Physiological health benefits of companion animals*

Following the publication of a seminal article by Friedman et al. (1980) on the increased survival of pet owners following myocardial infarction or angina, many studies emerged trying to identify the relationship between physiological variables and pet-ownership. Several studies have identified the effects of pets on physiological variables in both stressful and stress free situations. Allen, Blascovich, Tomaka, and Kelsey (1991) measured attachment between the owner and pet as well as physiologic parameters of stress. Allen et al. found little variability between the subjects on attachment measures; however, they observed differences in attachment, (e.g., amount of eye contact, closeness to dog, etc.) despite high attachment scores.

Furthermore, after measuring attachment, Allen et al. (1991) and Friedmann, Katcher, Thomas, Lynch, and Messent (1983) found that the participant's *highest blood pressure* (BP) was when a dog was absent and the subject's stress was evaluated by performing a verbal task (e.g., reading or counting), and the *lowest blood pressure* was when the subject was resting quietly with the dog present. On the other hand, Gaydos and Farnham (1988) found the lowest heart rate (HR) occurred when the subject was reading quietly with no dog present.

There are several studies that suggested the following hierarchy of cardiovascular stress responses: the lowest BP or HR occurred when a person was accompanied by his/her own dog and/or was resting or reading quietly. Blood pressure also remained low when petting a dog without talking to the dog. Talking to a person increased BP more than talking to a dog, and there was no difference between talking to your own dog versus an unknown dog. Results of cardiovascular responses in adolescent populations (Vormbrock & Grossberg, 1988) did not differ from those found in adults (Allen et al., 1991; Gaydos & Farnham, 1988).

People with disabilities are living longer and may experience age-related cardiovascular or stress-related events previously not seen in these populations. If similar cardiovascular responses could be replicated in service dog owners, it would be very enlightening for health care providers caring for people with disabilities.

Another noteworthy study was Siegel's 1990 research on physician service usage by the elderly. Siegel found elderly participants who were living with a pet demonstrated a decreased use of physician services during times of stress. Siegel's findings are especially interesting in light of Lane et al.'s study (1995) that found 47%

of service dog partners felt their health had improved despite having a chronic or progressive disability. Zee (1983) also had participants self-assess their physical health after receiving a guide dog and found a similar number of participants (slightly less than 50%) felt better subsequent to receiving the dog. However, it was unclear how much of the perceived health benefit was due to increased activity (because both studies also reported the new assistance dog teams were more physically active) and how much of the benefit was related to increased self-esteem or general well-being. The role of the service dog in health maintenance, such as decreasing health care visits and increasing well-being, needs further exploration.

#### Service Dog Studies

Clearly, young adults with disabilities who are at risk for depression and stress-related illnesses may receive the same stress-reducing, affiliative benefits from a service dog as adults without disabilities receive from animal companions. Yet, only recently have robust psychosocial variables been included in service dog studies (Collins et al., 2006; Fairman & Huebner, 2000). On the other hand, no studies have explored potential physiological benefits of having a service dog despite the reports of companion animals providing such benefits for adults without disabilities (Allen et al., 1991; Baun et al., 1991; Friedmann, Katcher, Lynch, & Thomas, 1980; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Virues-Ortega & Buela-Casal, 2006).

In 1987 the following statement came out of a National Institutes for Health (NIH) technology assessment workshop, “The value of companion animals for visually handicapped persons has long been known... New research is needed to extend these relationships to further identify the benefit of companion animals to other handicapped

persons such as paraplegics and quadriplegics” (*The Health Benefits*, Section 7, para. 4). Following the NIH workshop on the health benefits of pets, simply designed research studies became the norm for early service dog research studies.

### *Methodological issues*

Five descriptive studies were frequently cited. Of the five, three used control groups (Eddy, Hart, & Boltz, 1988; Hart, Hart, & Bergin, 1987; Mader, Hart, & Bergin, 1989) and all five implied or explicitly stated independent and dependent variables (Eddy et al., 1988; Hart et al., 1987; Mader et al., 1989; Lane, McNicholas, & Collis, 1998; Valentine, Kiddo, & Lafleur, 1993). Although Valentine et al. implied that the service dog was an intervention and measured changes in tasks people performed before and after the obtaining the dog, they did not have a control group, random assignment or a description of the service dog as an intervention. These methodological concerns exist in many service dog studies. For example in a large study of over 200 participants, Fairman and Huebner (2000) did not obtain or report demographic data on the participant’s disability or length of time with their service dog, despite reporting on psychosocial and functional variables that would be dependent on disability type or length of time with service dog (e.g., participation in mental or physical activities; developing a network of service dog owner friends; assistance with work related activities). They did, however, address this error in their conclusions.

Over the last five years, several studies with more rigorous designs emerged, such as a longitudinal design using standardized measures by Rintala et al. (2002), a large group-matched study by Collins et al. (2006) and an ethnographic qualitative study by Camp (2001). In their six month longitudinal study, Rintala et al. found self-

esteem increased and depression decreased over time in service dog users. Collins et al. also used similar standardized measures (e.g., Rosenberg Self-Esteem scale and CES-D) with their 76 participants with service dogs and the 76 matched controls. They found clinically depressed participants with a service dog had a more positive affect than those clinically depressed participants without a service dog, but overall, self esteem and depression did not differ between the two groups, those with service dogs and those without service dogs.

Allen and Blascovich (1996), who reported on the only randomized controlled study, were widely criticized for their suspiciously perfect correlations at each data collection period, their lack of information regarding access to participants and their lack of clarity in describing the experimental group intervention (Sachs-Ericsson et al., 2002). The intervention was described only as a trained service dog (i.e., the dog's breed, temperament, training, etc. was not described in detail). If service dogs are to be used as an intervention, the unique qualities that the dog brings to the research need to be systematically described so interventions can be replicated.

### *Psychosocial benefits*

Lane, McNicholas, and Collis (1998) applied a model previously developed to explain the relationship of psychosocial benefits between pet ownership and health in a non-disabled population to individuals partnered with a service dog. The questionnaire had four dimensions: (a) social facilitation, (b) affectionate companionship, (c) relationship offering emotional and esteem support, and (d) influence on self-perceived physical health. They reported that participants felt comforted by the service dog's presence (70%) and often confided in the dog (59%). Furthermore, 92% of individuals

reported people stopped to talk more often when they were accompanied by their service dog and 60% reported a greater sense of belonging. These results resembled the field studies of service dogs in the 1980's by Eddy, Hart, and Boltz (1988); Hart, Hart, and Bergin (1987); and Mader, Hart, and Bergin (1989). Those three studies compared wheelchair users with and without service dogs on measures of social acknowledgment. In a variety of settings social acknowledgments were consistently higher for individuals who used a wheelchair accompanied by their service dog.

In a more recent study, Fairman and Huebner (2000) found similar results related to social interaction with 100% of their participants acknowledging an increase in social interactions after receiving a service dog. However, this is in contrast to Lane et al.'s (1998) study that found only men reported a better social life after receiving a service dog ( $p < .05$ ); and Collins et al. (2006) who did not find service dog users scored higher on a community participation scale than those who used a wheelchair and did not have a service dog. However, most authors report peer relationships improved after acquiring a service dog; both the number of social contacts and the number of friends increased in the service dog groups (Collins et al., 2006; Collis & McNicholas, 1998; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Valentine, Kiddoo, & Lafleur, 1993). Because casual social interaction increased for service dog users, potentially service dogs could reduce depression and anxiety and improve social skills (Bergin, 1988); but the benefit of that interaction over time has not been adequately assessed.

#### *General benefits of service dogs*

One consistent finding was the use of service dogs for instrumental tasks such as picking up dropped items, turning lights on and off, assisting with dressing and

grooming (e.g, pulling socks off), and assisting with mobility (Lane, McNicholas, & Collis, 1998; Fairman & Huebner, 2000; Rintala et al., 2002; Valentine, Kiddo, & Lafleur, 1993). Hanebrink and Dillon (2000) suggested service dogs could be considered assistive technology due to their impact on the lives of individuals with disabilities. Specifically, they addressed evaluation and recommendation strategies for matching the person with a service dog that was similar to choosing any assistive device, i.e., does the dog improve independence for the person.

Another consistent finding in the service dog literature was feeling safer after obtaining a service dog (Camp, 2001; Collins et al., 2006; Sachs-Ericsson et al., 2002). Fairman and Huebner (2000) found the majority of their 200 respondents felt safer and went more places after receiving their service dog. Lane et al. (1998) reported 69% of their sample reported feeling more relaxed since obtaining a service dog and Zee (1983) also found 36% of her guide dog users felt less vulnerable after obtaining their guide dog.

Camp's qualitative study of service dog users revealed a theme called "closer than family" in which the respondents described events such as, "being there all the time" and "having somebody here" (p. 513). Lane et al. (1998) found 93% of participants thought of their service dogs as family members, which agrees with Zee's (1983) findings that 51% of guide dog users claimed their dog was a devoted friend. Nicholson, Kemp-Wheeler, and Griffiths (1995) reported several guide dog owners in their sample were so attached to their dogs that when the time came for the dog to retire, the individual choose to care for the ailing older dog and not obtain a new guide dog partner until the previous dog had died.

Nicholson et al. (1995) found 71% of the participants felt the end of the guide dog partnership was like the death of a friend or relative. Gosse and Barnes (1994) suggested that scores on the Grief Experience Inventory (GEI) for pet owners were similar to the scores found in individuals following the death of a person. The issue of grief and loss was frequently reported in the companion animal literature (Gerwolls & Labott, 1996; Gosse & Barnes, 1994; Hines, 2003; Virues-Ortega & Buena-Casal, 2006); however, there were few studies on grief, loss and retirement of service dogs in the current literature (Sachs-Ericsson et al., 2002; See also Michalko, 1999; Nicholson et al., 1995).

From these studies it is evident that service dogs have psychosocial benefits and potential physical health benefits. It is also significant that Camp (2001), Hanebrink and Dillon (2000), and Zapf and Rough (2002) found that if the decision to get a service dog was their own idea the recipient was more likely to experience positive effects. If the idea to obtain a service dog was not their own idea then recipients were less likely to experience any benefits. Further exploration of who decided to get the service dog, i.e., the parent or the young adult, is warranted, especially in light of training and maintenance issues identified by Camp (2001), Fairman and Huebner (2000), and Coppinger, Coppinger, and Skillings (1998).

### Summary

This review demonstrated that young adults with disabilities lead complicated and complex lives. Developing programs based on needs assessments was complicated by the variability in the transition studies. Many combined chronic illness and disability for adolescents and young adults regardless of onset timing, whereas others advocated

for a categorical approach, studying only one disability, (e.g., spina bifida) or one disability group (e.g. acquired onset such as traumatic head injury or congenital onset such as cerebral palsy). According to Halfon and Hochstein (2002) and Krahn, Putnam, Drum, and Powers (2006), the acquired versus congenital transition experience differed dramatically due to vocational and educational experiences and social network development, which would explain the difficulties in evaluating program outcomes. Many of the qualitative studies helped to identify specific issues, such as care coordination and parental involvement (Larson, 1998; Patterson & Lanier, 1999); and areas for future study, such as assessment of unique needs, and identifying ability not deficits (Kinavey, 2006; Padilla, 2003).

Furthermore, the transition issues for young adults with disabilities overlap considerably with potential benefits of service dogs in areas such as independence, mobility, and social skills. Notably lacking from the service dog literature were robust qualitative studies of this experience (Camp, 2001; Sachs-Ericsson, Hansen, & Fitzgerald, 2002).

## CHAPTER THREE: METHODOLOGY

Due to a time lag of five years between data collection and data analyses the choice of methodology outlined in my proposal changed. After re-examining the interview data and considering the unique research trajectory for this study, descriptive qualitative analysis promoted by Kearney (2001) and Sandelowski (2000) proved a better fit given (a) my current circumstance as a novice qualitative researcher, (b) the level of the data, and (c) the lack of opportunity to create an interpretive environment for phenomenological analysis. The current methodology reflects the analysis suggested by Sandelowski (1998, 2000) for qualitative description and the analysis suggested by van Manen (2006) for qualitative or phenomenological writing.

Although I followed many of the steps outlined by van Manen (1990) as originally intended, during the final year of data analyses (April 2006-April 2007) I integrated Sandelowski's (2000), Kearney's (2001) and van Manen's (2006) ideas for qualitative writing; as well as suggestion for qualitative analysis identified by other nursing researchers (Caelli, 2001; Crist & Tanner, 2003; DeSantis & Ugarriza, 2000; Lopez & Willis, 2004). Because of the gap in the time from the initial data collection to the final dissertation production, I essentially started the research project anew in April 2006. I began the data analysis by reading the original transcripts while listening to the taped interviews to verify the transcription. Then I reread each transcript individually while making preliminary handwritten notes in the margins of the printed transcripts.

In addition to reacquainting myself with the data, in the spring of 2006 I reread key research from the original literature review, and then I immersed myself in recently published qualitative research articles. This step was necessary because I found it

difficult to begin writing the results without returning to the proposal. This took several months of rereading and rewriting the first two chapters in preparation for data analysis.

During this time I also remained active in Canine Companions for Independence (CCI) activities (e.g., training classes, graduations). CCI graduates and puppy raisers frequently asked about progress on my dissertation and over time I felt as much pressure from this peer group to finish my doctorate as I did from my academic colleagues. I felt obligated to CCI and the young adults who told me their stories, as well as the research community at large to add to the body of knowledge related to service dogs and people with disabilities.

#### Overview of Methodology

I followed three basic steps for conducting qualitative research. I began by obtaining the interview narratives or the raw data on which to base the study. After obtaining the interview data, I analyzed the participant's stories that lead to the development of themes and finally I presented the interpretation of the themes as findings (Sandelowski, 1998, 2000; Sandelowski & Barroso, 2002, p. 217). Novice qualitative researchers often make the mistake of writing too much and saying too little. Instead, the researcher should purposefully enrich the description by choosing only those stories that best exemplify the themes (Sandelowski, 1998, p. 376).

In detailing the steps of qualitative methodology, both van Manen (1990) and Sandelowski (2000) suggested beginning with a description of the philosophical background of the method and how that perspective fits with the question being studied. I identified the philosophical premise of the study in the introduction. As part of the methodology, the philosophical background also included a description of the

qualifications of the author as the human instrument, i.e., qualifications for conducting the study and any foreknowledge of the topic, i.e., involvement with the participants or topic prior to the study.

The next step was presenting the details of data collection, describing the ethical safeguards and describing access to participants. After that I outlined the process for generating data such as inclusion criteria for participants, type and amount of data collected and a time frame for the study.

In addition, van Manen (1990) suggested the researcher become familiar with experiential descriptions of the phenomenon in fiction or non-fiction literature, as well as reading other phenomenological studies. Research identified at this stage included Padilla's (2003) research on the meaning of disability, Camp's (2001) qualitative analysis of service dogs as an adaptive tool, and Stewart, Law, Rosenbaum, and Willm's (2001) description of transition into adulthood with a disability. I also read fiction and non-fiction accounts of service dogs and guide dogs (Chevigny, 1946; Garfield, 1958; Michalko, 1999) and non-fiction disability accounts of deafness (Sacks, 1990; Spradley & Spradley, 1985) to provide context and depth to my understanding of the phenomenon.

The third step was one of phenomenological reflection or data analysis. In this phase I described the process of making sense of the data. Sandelowski (1998) described the data as "...[data] there to think with and think about" (p. 376). Understanding the data led to themes that were carefully constructed across and within stories from the interviews. Some researchers prefer the term narratives to stories when describing the data. I chose to use stories to define the data I worked with as I created

the themes. As I read and reread the interviews, I clearly saw stories within each interview that described an experience. In the qualitative inquiry tradition, there is a commitment to understanding the experience as it presents itself without applying theoretical tenets (Sandelowski, 2000, p. 337). I looked for stories as they appeared in the interview, not according to some a priori concept. The danger at this point in analysis, according to Sandelowski (2000) and Morse (1994), was premature adherence to an organizing framework, or naming technique. As described later, qualitative data analysis and reflection should be intuitive and creative.

The final step in a qualitative study according to van Manen (1990) was interpretation via phenomenological writing. van Manen (1997, 2006) contends interpretation becomes evident through the writing and re-writing of the emerging findings and themes. Sandelowski (2000) and others (Caelli, 2001; Kearney, 2001) also encouraged the use of interpretation in conjunction with qualitative description, i.e., description is necessary but not sufficient to impart meaning or understanding. Although the level of interpretation in qualitative description does not reach the level of interpretation of Hermeneutic studies, nevertheless, a qualitative study is incomplete without some attention to interpretation of the data (Baker et al., 1998; Dowling, 2007).

Lincoln and Guba (1985) and Sandelowski (2000) encourage the novice researcher to use a creative, thoughtful process that allows for multiple drafts until the writing is true to the phenomenon. Through writing the researcher is able to weave the multiple stories of the participants into a thematic comprehensible whole. Writing for van Manen (2006) was the method of interpretation, whereas for Sandelowski (1998, 2002) writing was not about method or methodology, but simply the vehicle for

presenting the description. Writing about the findings needs to be more than just a string of quotes or examples. In the end, writing was reflective, informed by the data and representative of the participant's point of view (Sandelowski & Barroso, 2002, p. 216). For me, even though writing did not take place for months at a time, ideas incubated as the project was frequently in my thoughts.

### Philosophical Background

The philosophical premise of phenomenology is that the end product is greater than the parts, yet each part (including the researcher's story) is essential to understand the whole (Caelli, 2000, p. 274; van Manen, 1990). For example, each word in this sentence has individual meaning, yet it is only in context with other words, in this sentence, that meaning is created. In the same way, I used the context of transition to interpret the participant's experiences of living with a disability and having a service dog.

Although the initial questions were the same for each young adult, each interview revealed the young adult's unique story. I acted as an ally and an accomplice, coaxing and revealing the tacit knowledge heretofore only known by the interviewee. I interpreted the experience by creating themes representative of being a young adult with a disability making the transition to adulthood while living with a service dog. The resulting data analysis described the stories of each participant as well as describing a common or collective theme linking the stories (Kearney, 2001; Sandelowski, 1995, 2000; van Manen, 1990).

As the human instrument, my qualifications for conducting interviews must be stated (Caelli, 2001; Dowling, 2007; Rew, Betchel, & Sapp, 1993). I interviewed over

50 children with epilepsy and their parents by phone in one study (McNelis, Musick, Austin, Dunn, & Creasy, 1998) and I interviewed 25 adolescents with spina bifida and their parents in another study (Buran et al., 2004). I became adept at maintaining rapport and soliciting information during the interviews. I transcribed tapes of the aforementioned interviews which allowed me to identify any problems and self-correct my interviewing technique.

My responsibility as an interviewer was to engage the participant in storytelling regarding areas of their life related to disability and transition. My genuine interest in their story kept the story flowing rather than allowing the story to become a report or list of events (Kearney, 2001; May, 1991; O'Day & Killeen, 2002). Because each participant knew me from our mutual association with Canine Companions for Independence (CCI), I refrained from asking questions about the service dog first, so that I was able to obtain the whole story of living with a disability. I wanted to focus on the person first and allow the young adult an opportunity to place the dog in the context they chose, not a context I predetermined.

In the current study, I asked participants to tell their story of being a young adult with a service dog and I allowed the story to develop without leading or controlling the participant. It was necessary for me to be aware of, and understand, the biases, perceptions and knowledge I brought to the interview and subsequently to the deliberation and the interpretation of the experience, based on my prior experiences (Baker et al., 1998; Caelli, 2001).

## Data Collection

### *Ethical considerations*

I obtained Institutional Review Board (IRB) for the protection of Human Subjects approval by submitting a proposal outlining the data collection procedures and the safeguards for maintaining confidentiality and minimizing any harm. Access to the participants and recruitment was also part of obtaining IRB approval. I obtained access to subjects via Canine Companions for Independence (CCI).

As reported to the IRB, the benefit of participation was a \$15 gift certificate and perhaps personal insight or awareness. The \$15 gift certificate was sufficient as an incentive but not coercive. The insight may foster a sense of pride in being able to contribute to the study findings. Additionally, it is often therapeutic for people to tell their story to another interested party. The risk from disclosing personal information in an interview is minimal and clearly explained beforehand.

### *Participants*

The inclusion criteria for participants required (a) age between 18 and 25 years, (b) a congenital disability that causes mobility impairment such as cerebral palsy, muscular dystrophy, osteogenesis imperfecta or spina bifida, and (c) currently or formerly living with a service dog. An additional participant was the parent of one of the participants. She had a daughter in the study who met the criteria outlined above.

Generally, recruitment of participants for a qualitative study is purposive. I maintained that tradition by recruiting participants I knew through my association with Canine Companions for Independence (CCI), a non-profit organization that trains service dogs. I sent a letter of invitation to eligible participants identified by CCI (see

Appendix A). A purposive sample is identified when recruiting only subjects who experience the phenomenon of interest, in this case having a disability and living with a service dog. Sandelowski (2000) reinforced the importance of purposive sampling to obtain cases that are “information rich” for the purpose of the study.

Young adults were the focus in this study because there is a large cohort of surviving adolescents now moving into young adulthood. Four young adults agreed to participate in the study and signed an appropriate consent form (see Appendix B). Because many of the young adults may live at home or have recently moved from home, it was prudent to consider a young adult living with a service dog may have an impact on the family. In the interest of obtaining a complete picture of the phenomenon of living with a service dog, I invited either a sibling over 18 years old and/or a parent to participate. I contacted the parents by separate letter to determine their interest in being interviewed. One parent agreed to participate in the study and signed an appropriate consent form (see Appendix C).

The experience of a disability acquired during adolescence or young adulthood and growing up with a congenital disability represent two very different experiences. Self concept, social experiences and peer interactions differ between youth with acquired versus congenital disabilities (Coakley, Holmbeck, & Bryant, 2006; *Healthy People 2010*, 2002; Woodgate, 1998). Consequently, I focused on the experience of transition and the experience of growing up with a disability, rather than a broader focus that included both congenital and acquired disabilities.

Service dog is defined by the Americans with Disabilities Act (ADA, 1996, para. 1) as any animal individually trained to do work or perform tasks for the benefit of

a person with a disability. This can include guiding a person with impaired vision, alerting a person with impaired hearing to the presence of people or sounds, pulling a wheelchair, retrieving dropped items, etc. Service dogs are trained by programs, independent trainers, or the person with the disability who owns the dog. (Duncan, 2000, p. 170)

### *Setting*

I interviewed the participants at a time and place comfortable and familiar to them. One interview took place at a Canine Companions for Independence (CCI) training center; however, the majority of the interviews took place in the participant's home.

### *Data sources*

Audio-taped interviews and the transcribed text were the primary data sources. I also collected field notes of the non-verbal communication between the participant and the dog and the participant and myself during the interview. Field notes reflected the emotional tone and the level of distraction of the setting. I used reflective notes or journal entries to consider changes in my thinking throughout the course of an interview and/or the course of the study.

### *Time frame*

I scheduled one or two interviews a month to allow sufficient time for transcribing, and reading to occur between interviews. Because the data analysis coincides with the data collection; the data collection phase often takes at least four months, followed by several months of descriptive writing. Unique circumstances altered the timeline for this study. I obtained institutional review board (IRB) approval,

and several interviews were completed in a six-month time period (August 2000-January 2001) then several months elapsed before I obtained the final interviews (April 2001). During that year of data collection minimal reading, transcription, rereading and analysis occurred. Subsequently, over a six-month period the next year (June-December 2001) I transcribed, verified, read and reread the original transcripts. However, due to a series of life events, no analysis or writing took place for several years (January 2002-September 2005). From IRB approval to completion of writing was seven years. During this time I updated the literature review, as well as the IRB each year on any progress (Modlin, 2000, 2001).

### *Interview process*

Seven young adults meeting the selected criteria received a letter of invitation to participate. Four young adults and one parent agreed to participate in the study. I contacted them by phone to determine a mutually agreeable time for the interview. Before the interview began participants had adequate time to read and ask questions about the informed consent. I discussed the option of returning for a second interview or making a follow-up phone call as needed. I allowed ample opportunity to take breaks or to stop at any time during the interview. The audio taped interviews lasted one to two hours.

I conducted one interview over the phone rather than in person due to geographical distance. I made initial contact with this participant after sending out the letter of invitation for participants to a CCI email list. The participant responded to the email and I sent him a consent form, which he returned. Then via email we established a mutually agreeable time for a phone interview.

At each interview session I had a primary tape recorder and a back-up tape recorder, with several tapes and batteries for each in case of defective tapes or recording. I maintained a record-keeping device to keep track of contact with potential participants and the results of that interaction (e.g., completed interview, need to return to complete interview, typed field notes). I stored the data on floppy disk, hard drive, and zip drive, as well as having text copies of the transcript and original audiotapes. The audiotapes were kept in a locked cabinet and identified only by number, not by name. Confidentiality was maintained and pseudonyms were used when discussing the study results. After publication of the results or successful defense of the dissertation, the audiotapes will be destroyed.

#### *Interview questions*

I began each interview with a general question to open the discussion. Because I had previous contact with all of the participants, the beginning of the interview involved some social banter to put the participant at ease. I observed interactions between the participant and the dog and made notes of the interactions simply to put the interview data in context and to add interest to descriptions of the participants.

The process of conducting the interview involved a series of minimally structured open-ended questions (May, 1991; Rich & Ginsburg, 1999; Sandelowski, 2000). I asked the participant to tell the story of living with a disability and making the transition to adulthood with a service dog. To keep the stories flowing or to check for understanding, I encouraged the participants with the following interview statements:

- 1) Tell me about having a disability at this time in your life.

2) Tell me about (moving out, going to college, living at home) over the last few years. What has been the hardest part? The easiest part? Is there anything you would do differently?

3) Tell me about your decision to (get a job, go to college, live at home, move out on your own, and begin a relationship).

4) Tell me about your family. How did they interact with you as you made this decision?

5) If they did not mention their service dog in any of the stories then I asked about living with a service dog. I anticipated that the dog will be part of their story, but there was the possibility they would talk about the disability instead, or assume I know about the impact the dog has had (because I am a volunteer for Canine Companions for Independence, the organization that gave them the dog).

6) If they did not mention transition to adult health care providers or access issues with their service dog, then I asked about those experiences related to transition and independent living.

When I completed the interview I gave the participant time to think of anything they wanted to add. I ended the interview on a positive note and allowed the participant to answer one of the following:

1) If you could tell your classmates/co-workers anything you wanted, what would you say?

2) If you could tell the hospital or clinic staff anything you wanted, what do they need to know?

Although there are no known risks in answering questions like the ones asked, the participants had the option to stop the interview at any time or if they felt uncomfortable or ill at ease about something they said or if they had anything to add, they were given information about how to contact me or my advisor. They were also reminded that although confidentiality is maintained, due to the detailed nature of qualitative writing it is possible that people who know them well may recognize their story.

### Data Analysis

In qualitative research, data collection and data analysis occur simultaneously; but for the sake of clarity they are described as separate and discrete steps. Data collection included conducting the interview, but then after *each* interview there was a period of data analysis. It was during this period of initial listening to the taped interview and reading and rereading the transcripts that the data analysis began (van Manen, 1990; Sandelowski, 1995, 2000). Both authors encourage the researcher to keep working with the data until there is a fundamental grasp of the stories underlying the data. Data collection triggers data analysis, so it is important to get a sense of the whole as well as to honor the individual stories (Sandelowski, 1995, p. 373).

First, I listened to an entire interview to get an overview. Then I transcribed the taped interview and the transcription was verified by comparing it to the taped interview. Then each interview transcript was read in its entirety. This initial reading of the verified transcript was when I began making notes. I was careful not to name stories at this point, but rather merely acknowledging the presence of a story within the transcript. As mentioned previously, this process occurred with all the interviews, and

then there was a time period where no further analysis occurred. When I returned to the research process I re-read each transcript and began the intuitive process of identifying (but not naming) stories. Initial data analysis should not prematurely put closure to categorizing or naming the data (Sandelowski, 1995, p. 375). After noting several stories within in a transcript, I reread the complete transcript to ascertain that the stories still reflected the whole. I repeated the process multiple times with each interview transcript and between interview transcripts to compare stories within one interview and across multiple interviews.

One of the questions I asked as I re-examined the data was, “do these stories reveal the experience I am describing”? It is not the intent of qualitative research to identify every story and nuance conveyed by each participant. According to Sandelowski, there are usually only a few key stories in each interview (1995, p. 373). I identified the key stories within and across interviews using the following criteria (a) importance to participant as evident by time, words, or emotion spent on the story, (b) story was common across interviews, and (c) intuitive “pull” into the story.

Each participant’s interview contained multiple stories, and the stories common across interviews became themes. The intuitive process of sorting stories and finding themes resulted from a dialectic with the data asking questions such as “is this like this?” or “how does *this* relate to *this*?” What I identified as themes were clearly those stories that drew me in, and stories that appeared in multiple interviews. Stories reflected the individual experience and themes reflected the collective experience.

The final step identified the themes by attaching labels or naming them using the participants own words (i.e., in vivo coding) rather than names based on professional

jargon. As I used the participant's words to describe themes, I used action verbs and gerunds. I chose to organize the themes around what was common. I created a thematic metaphor not as an interpretive strategy but to describe the phenomenon. The description did not rise to the level of an interpretation in the sense of creating new meaning, but rather it is "a re-presentation" of what they said that accounts for the main stories in each interview (Denzin, 1994; Kearney, 2001, p. 147; Sandelowski, 1995; 1998). In the end I identified three themes to represent the stories of the participants. After identifying the themes I went back to the original text and verified the context of the theme. This recursive process occurred with each transcript and between transcripts/stories to maintain authenticity of the data as originally presented to the author. This process took several readings/re-readings over several months.

Another key task at this point was to keep track of the steps conducted during the analysis to assure consistent application of the steps to each interview transcript. If I changed what I did with one interview, i.e., renaming a theme, I would go back to the transcripts and apply the new name to be confident it fit the data. For example, when I added Sandelowski's (1998, 2000) ideas on qualitative description to the research process I returned to the transcript, listening, reading, rereading and writing in such a way that each story was seen from this new perspective.

### Phenomenological Writing

The goal for presenting the results was to produce a descriptive summary of the phenomenon, organized in a way that revealed the data and was appropriate for the audience (Caelli, 2001, p. 277; Sandelowski, 2000, p. 339). I had several options for presenting the results and chose to begin with a profile of each participant including

contextual and environmental information such as where they live, whom they live with, and their typical daily activities. These profiles or vignettes are helpful to the reader when quotes from individual stories are used to discuss the findings. Next, I arranged the discussion according to themes starting with the stories that I returned to time and again (Crist & Tanner, 2003). Each discussion of a theme started with a broad overview, then provided specific stories explaining an event or experience from the perspective of different participants (e.g., driving).

In the end, I described the stories of young adults with disabilities becoming independent in a way that is deeper, clearer, and richer, than any individual story, yet respects and honors each storyteller. Consequently, with each descriptive theme I relayed a bit more of the experience of living with a disability. The themes and ideas that came from the participant's interview were put into a larger context, into the "big picture." Therefore the "big picture" answered the question: in what context does this interview, this story, this idea, have meaning for the participant, for the family, for other nurses or researchers (Kearney, 2001, p.148; Sandelowski & Barroso, 2002, p. 215).

The purpose of this study was to present a descriptive analysis of interviews with young adults making transitions with a service dog. Participants interviewed told their story of being in transition. The reader is now the judge of the success of that endeavor. Ultimately there was writing and rewriting and reading and rereading to present a coherent whole as the end product of this descriptive qualitative study.

## Evaluation

The standard for evaluating the completeness and methodological rigor of qualitative works is still debated. However, I will address the following in my attempt to provide the reader with information that I performed the study in a way that is true to the method and respectful of the participants. Swenson and Sims (2003; personal communication, September, 1998) have described the following four criteria as essential in evaluating qualitative work: (a) self-understanding, (b) congruence, (c) clarity, and (d) usefulness.

Self-understanding was reflected in the topical presence statement in the introduction and in the description of the human instrument statement in the methodology. Self-understanding provided the reader with the presuppositions of the researcher. For example, my interaction with the participants through CCI prior to recruiting them for the study is a good example. Congruence is assessed based on the question asked and the methodology chosen. I conducted a pilot study using phenomenology early in my graduate school career and ultimately chose qualitative description inspired by van Manen (1997, 2006) as the best fit for this study on youth with disabilities (O'Day & Killeen, 2002; Rich & Ginsburg, 1999). The philosophical statement in the introduction and the description of the methodology provided details of this choice. The reader will be the final judge of whether or not there is congruence between the methodology and the research question. Did qualitative description provide insight into living with a disability?

Clarity was assessed based on the detail given regarding the data collection procedures. The reader must be able to follow a trail that describes how information

was obtained and what decisions were made during analysis. During the data analysis I asked for feedback from graduate student peers and professional peers regarding the themes and stories. Their feedback allowed me to check for understanding regarding the direction I was taking. Finally, usefulness was assessed related to the specific discipline of the researcher. Usefulness is reflected in the significance to nursing presented in the conclusion, as well as the discussion of the findings. Kearney (2001), described several options for nurses to use qualitative data, such as gaining insight or empathy, and providing anticipatory guidance (p. 151). Insight or empathy could be used to understand the experience of the client from their point of view. After reading this study, a nurse could have insight regarding a future client that could benefit from a service dog or a nurse would have empathy for a client with a disability. Using anticipatory guidance, the nurse could share stories from the study with someone contemplating a service dog. Usefulness will be fully explored in the significance for nursing in the final chapter.

## CHAPTER FOUR: FINDINGS AND DISCUSSION

Transition is a classic experience for adolescents and young adults. (Betz & Redcay, 2002; Callahan, Winitzer, & Keenan, 2001; Mulcahey, 1992; Rich & Ginsburg, 1999; Sawin, Cox, & Metzger, 2000). Three themes, *It's different now*, *Going places*, and *Calling the shots* guide the discussion of the experience of transition for young adults with a physical disability and a service dog. Several stories from different participants provide the context for each theme. The young adults in this study not only experienced typical transition issues such as choosing to work or to attend college (*Calling the shots*), but also experienced additional transitions related to mobility (*Going places*), and their service dog (*It's different now*).

I conducted five interviews over a ten-month period. Four young adults 18-25 years old participated in the study as well as a mother of one of the young adults. Two of the participants had a service dog for greater than eight years, and two of the participants had recently received their service dog (i.e., less than two years.) A brief vignette describes key features of each interviewee to assist the reader in identifying the participants. Each participant is referred to throughout the remainder of the paper by a pseudonym to maintain anonymity.

### Participant Vignettes

#### *Betty and service dog Ariel*

Betty was a 20-year-old woman who has cerebral palsy and used a power wheelchair. Betty was a petite, energetic, and outgoing college freshman when we met for the interview at her dorm room on campus. Betty smiled and laughed as we conducted our initial introductions and was very engaging, and friendly throughout the

interview. Her service dog, Ariel, was a female black Labrador retriever about four years old. Betty got her service dog the summer before her junior year of high school, but only occasionally took the dog to high school with her. Instead, Betty used that initial time with Ariel to hone her service dog handling skills and to become familiar with how Ariel could help her when she went to college. Betty found that plan worked well for her, because it provided the opportunity to bond with Ariel, but she did not have to subject Ariel to the teasing and distractions of “immature kids” (emphasis hers).

Ariel accompanied Betty to all her classes, as well as trips off campus. Update: Betty graduated from college with a degree in education in 2006. Ariel died unexpectedly from complications due to cancer the semester prior to graduation.

#### *Jane and service dog Annie*

Jane was a 22-year-old woman who at the time of the interview lived in her own apartment. Jane was a small woman, about 4 feet 2, with short blonde hair. During the interview she sat barefoot in her power wheelchair. Jane has spina bifida with no outward sign of a disability other than her small stature and the use of a wheelchair for mobility. However, due to common problems associated with spina bifida she has had numerous hospitalizations related to kidney/bladder problems and surgeries related to her cerebrospinal shunt revisions necessary to prevent hydrocephalus.

Annie, Jane’s service dog, was a female black Labrador retriever, about 85 pounds of wiggling, tail-wagging happiness. During the interview she alternately carried a ball in her mouth or chased a tiny gray and white kitten across the living room. Jane received her first service dog when she was in junior high school and then got her second dog, Annie, when she was in high school. Jane attended college for two years,

but withdrew due to failing grades and personal stress. She returned home to live with her mother for a few months prior to finding fulltime employment and independent housing. Jane was working at her third job since leaving college. At the time of the interview Jane was preparing for Annie's retirement as a service dog due to age and health problems. She decided to get a successor service dog and my interview with Jane's mother, Kate, took place during the training for the third service dog. I first met Jane over ten years ago when I moved to the neighborhood where Jane attended college and discovered she had a service dog. Subsequently, we would get together for training sessions with her service dog and my service dog puppy in training. Update: Jane received a third service dog, a yellow Labrador retriever, and moved into a single family house built especially for her by Habitat for Humanity. Annie died in 2005.

#### *Kate*

Kate was Jane's mother. She was a middle-aged divorced woman, who worked full time and lived about 40 minutes from her daughter. Kate was outgoing and outspoken, especially about her daughter's needs. Mother and daughter spend a lot of time together. Although she is an advocate for her daughter's independence regarding many issues (e.g., access with a service dog), she did most of the chores at her daughter's house including bill paying, cleaning, and grocery shopping. Jane lived with her mother until she went to college and again lived at home for a brief time before getting her own apartment. Kate's interview took place at the hotel where they were staying while Jane was attending team training to receive her third service dog.

### *Mark and service dog Reba*

Mark was a 25-year-old man with spina bifida who lived with his mother. He suffered from chronic back pain after spinal surgery. Mark's service dog, Reba, was a 4-year-old female golden retriever. They had been together just a year. He was clearly excited about participating in the study and considered it an opportunity to share information about himself and his service dog. He attended college for two years but withdrew due to his medical problems and his mother's poor health. Since being partnered with Reba, Mark does plan to return to college. Mark voiced strong opinions about how people with disabilities are treated by society at large and health care practitioners, specifically. This interview took place via the phone after Mark responded to an email request asking for volunteers to participate in my study. Although we never met in person, it was obvious over the phone and via e-mail that Mark was articulate, opinionated and passionate about living with a service dog.

### *Rick and service dog Lacey*

I first met Rick when he was 11 years old. He had received his service dog about the same time I was training my first puppy for Canine Companions for Independence (CCI) and we attended many training and fund-raising events together. Rick was a 20-year-old college student who had muscular dystrophy. He was medium height, dark hair and very slender. His service dog, Lacey, was a 12-year old female black Labrador retriever who was retired from service dog duties. Lacey accompanied Rick from grade school through high school. However, when Rick attended college he elected not to take Lacey with him. She retired and lived with Rick's mother while he was at college. At the time of the interview Rick had withdrawn from the university and was living at

home, recovering from pneumonia. Because of Rick's muscular dystrophy he had recurrent bouts of pneumonia and other respiratory problems due to respiratory muscle weakness. During the interview he moved around the room in his multi-positional power wheelchair. Update: Lacey died in 2002. Rick died two years later from complications due to pneumonia. Rick never returned to college although that was his plan at the time of the interview.

## Theme One: It's Different Now

*It's different now* described the social implications of life before and after obtaining the service dog. This theme included elements of personality development similar to any young adult in transition, such as identifying “who I am now.” Although the participants provided limited personal insight and critical thinking about their circumstances, they were able to provide information helpful in understanding the experience of *It's different now* in the context of being with their service dog, being with friends, and being with or without family. Holmbeck, Greenley, Coakley, Greco, and Hagstrom (2006) identified the need for interventions aimed at increasing activities with peers to assure that youth with physical disabilities can successfully navigate the tasks of young adulthood. For example, youth with disabilities experience more social isolation than typically developing youth, which included lower rates of social participation with peers and less frequent dating (Antle, 2004). The following stories highlight relationships the youth in this study experienced.

### *Relationships with peers*

During young adulthood, relationships with peers take on greater importance. Peers, rather than parents, become the confidante and major source of social and psychological support for youth (Crittenden, 1990; Hallum, 1995; Kinavey, 2006). The normal developmental pattern of friendships moves from same sex friends, to same sex groups of friends, to heterosexual groups of friends, to intimate relationships and dating (Feldman & Elliot, 1990; Zaslow & Takanishi, 1993). In the following, Rick described a peer relationship pattern that was typical of many young adults:

I . . . came home 3-4 am sometimes. I work during the day, change clothes, eat and by the time they [parents] come home I'm ready to

leave. I don't go to sports stuff much anymore, my friends are music people. [I] went to a lot of concerts in the summer, but it gets expensive. [I'm] not really involved; I just bounce back and forth from different people or group dating but not girls and guys dating. [My friends have] known each other, then we met at college, then they left [college] and now we're all here and hanging out. I want what I can't have [in a girlfriend], but I discovered what I want . . . over the summer. . . I went out with her and she's still in high school and I'm there [working at the school] so now we have to get along but we fought a lot over the summer.

Kate acknowledged a lack of dating experience for her daughter Jane consistent with a lower level of peer interaction typical of young adults with disabilities:

Well she had some friends, like Becky and Frannie . . . some were older, she has had "boy friends" who took her up to Beef and Boards, but they all went as a group. Then there was Sam from high school. I think she would like him to think of her as more than a friend, but he's so sweet, talks to her at her level, he's sensitive to her needs but he's moving to California and she's heart broken. But really dating, no not really. She hasn't had that in her life yet. I think she really would like to.

The experiences of these young adults demonstrated a lack of sophistication with dating consistent with other research findings (Buran, Sawin, Brei, & Fastenau, 2004; King et al., 2003; Kinavey, 2006); however, their stories of peer relationships indicated some measure of success in maintaining peer relationships, at least while in college. Jane described a significant change in behavior from college to the present:

I was more social in college than I am now. I am a total homebody now. I'm not used to it. I can't stand it. I loved going out with my friends, I hate to say it, but the bars y'know. I don't necessarily want to go to bars, but I want to go to dinner or do this or that. My friends now are older, they have families and they don't have time. Here I am only 24 years old and I'm ready to go. All I have is two pets.

Typical of college freshman, Betty described her living arrangements with two roommates and the ability to expand her social network by interacting with their friends:

Well it is two singles and one double with the three of us. We have a big living room area we share and a bathroom we share. My roommates grew up together and were best friends. And I didn't know anyone and I said I didn't care so I got to room with them. They live in the same general area (of Indiana) I do, so I'm glad about that. I was really happy when I heard that we're all country girls and come from the same size towns. I don't feel different. We have a lot in common. Socially they have lots of friends and I got to know them, and then [you] feel like you're not so totally different. Feel like I've known them forever. The people who placed us together [as roommates] told them about Ariel to make sure they weren't allergic to dogs or afraid or anything like that. . . For Ariel [it has been] easy. For me . . . easy but stressful. I'm not too good at handling stress and at one point I thought it was too much. But I worked through that with my support system here.

Betty's experience mirrored Rick's experience of an expanding social network typical of young adults. Betty specifically stated that her peers were her "support system" and she was able to depend on them during a time of stress. Neither Rick nor Betty stated a restriction in or lack of peer contacts, which was contrary to findings in the literature (Buran et al., 2004; Blomquist, 2006). Individual differences may account for this phenomenon, however, the fact that both Betty and Rick found peers supportive cannot be ignored as insignificant. Rick described his friends this way:

The second year first semester I wasn't doing very well. Just burned out. My friends from first year had flunked out. They were all from Indianapolis too. They were friends that for the first time in my life were real friends. I've always had great friends, but these were the best I'd ever had, they were fun, they took good care of me. They cared about me and everything else. It's hard to find friends . . . and when they weren't there I just gave in to the stress more than anything else. People were there but not ones I could trust. I have always seen a difference between friends you can hang out with and have fun with and friends you can trust.

Living arrangements and accessibility to peers seem to be primary factors in peer support. Rick, even though he lived at home, was able to maintain contact with his college buddies. On the other hand, after Mark and Jane left college they had decreased interactions with peers. Jane moved into an apartment away from friends, and Mark moved home with his mother, also away from college friends.

Although research with young adults with disabilities indicated that they experience difficulties with relationships (Lotstein, McPherson, Strickland, & Newacheck, 2005; Luther, 2001), my participants maintained relationships via typical interpersonal interactions (e.g., “hanging out”), as well as using typical technologic means such as e-mail, much like their able bodied peers. Indeed, Betty found the Internet key to keeping in touch with her family while she was at college:

I miss having a confidante', my mom . . . I like to call and talk to them but it's not easy. I have phone cards and they only last so long. I love AOL messenger. You can talk as long as you want . . . my mom doesn't have messenger yet, but I'm going to teach her. My cousins and aunt and uncles have it and e-mail. They e-mail me all the time.

Blomquist (2006) reported 69% of her respondents used computers and 51% could navigate the internet. Even though e-mail communication was not specifically noted, Blomquist suggested nurses assist youth with disabilities to develop computer skills to be used not only for school or work, but also recreation (e.g., communication). Mark described potential interactions with peers via even more sophisticated computer skills in the following:

. . . for example I attended a computer conference in Las Vegas and everybody is there, Bill Gates, it's a place to be to learn about new technology. Because I build my own computers it's something I do to keep occupied. I can talk to anyone, anywhere in the world.

### *Relationships with family*

Betty described handling the stress of college by developing a peer support system, however when I asked: “What is the hardest part about living away from home?” Betty shared her struggle with moving from family support to peer support in the following:

I’m used to having family members right there at a drop of a hat. Not like the Waltons, but bigger than just main family . . . . Like my cousins are like brothers and sisters to me. And my aunts and uncles just kind of---we sort of overlap our roles. I don’t know if every family does that or that’s just something they do for me.

My aunts and uncles came over last weekend and they brought me food, brought me drinks, they made sure I was okay. Kind of like a mother or father figure . . . it’s always been like that. Before they were always a phone call and ten minutes away, now they are a phone call and three hours away. And even though I know if I really needed it any one of them would come at the drop of a hat, still I know they have their lives. They have their work and it’s hard to get used to.

Even though the participants described close peer relationships during college, further evidence revealed they spent more time or had closer relationships with family than friends. This is indicative of a different developmental trajectory than typical young adults, who have already moved from family support to peer support. In the following examples the young adults described living at home with a parent as their main social network. Although Mark described a limited social network, he clearly articulated his future dreams. This was similar to any young adult’s story of searching for an identity or searching for a way to define himself. Mark lived with his mom and described his situation as:

. . . at home, my mom and I get along okay. My brothers and sister are married with their own family off doing their own thing. So it is just her and I and Reba, now. My mom is a retired nurse so there is plenty of company at home. She has some osteoarthritis so can’t work really. We

get along really well, she understands my interests. It's different now at home, there's not something at home I'm passionate about [like at school]. It's a boring little town, basically agricultural and the sidewalks roll up at night. There is NOT a lot of intellectual stimulation. I am very cerebral and need people I can talk to. Where I belong is there, at UCLA or Berkeley, or Stanford, getting my degree and going on with what I want to do with my life.

In another example, Kate acknowledged the role Jane's disability played in their relationship. Their unique bond was a result of that shared disability experience.

Surprisingly, as she described being a proud mother she used another disability as a metaphor:

[we've] been so fortunate. She never back talked me she's been able to state her opinion, she may not get what she wants but she can state her opinion and I've never had that normal teenage stage of rebellion belligerent or calling me names. I'm sure she had those thoughts, but she never said 'em to me. She had enough respect not to tell me . . . it's [spina bifida] always been a blessing she and I wouldn't change a thing and I think if you asked her "Jane if you could change your life and make it so you could walk" and she'd say no, my life's fine. I've tried to build Jane's life for the fact that I'm not going to be here forever. I'm not always going to be around and it's inevitable, it's a fact of life. She has to be able to rely on herself. I feel that right now at this point in my life if I got in a wreck and was paralyzed from the neck down and all I could do was lay there . . . I could think my daughter could take care of herself, her dog and get to work.

Kate's remark about spina bifida being a blessing was supported by Kearney and Griffin (2001) who found parents called the disabled child a "giver of gifts" (p. 589).

The tendency of health care professionals in their study was to offer instrumental support rather than hope regarding disability outcomes for children. Clearly the parents in Kearney and Griffin's study, as well as Kate in this study, felt the child and the disability were more than something to be endured.

Jane reiterated her mother's thoughts about spina bifida and disability in her comments that she tried live a normal life. Yet she described the difficulty of living in

an apartment that was not handicapped accessible. She also recognized that adapting may mean acknowledging her disability:

I don't think I've led that much of a handicapped person's life. I've tried to live as normal a life as possible. All the things I go through aren't really handicapped related, but when I moved to the apartment it was like more, how am I going to adapt? The toilet isn't quite right, how can I do this without twisting my ankle or falling off? Or the space is not quite as convenient, it's not exactly the way I would have it.

The reality of living with a disability and understanding the meaning of that disability was explored further in the interview with Kate. She told about connecting with other families and the meaning that had for her:

Y'know whenever she was born they said she had spina bifida I had no idea what this life entailed. My parents couldn't come up to see her. She wasn't in good health . . . they wanted me to touch her, but I couldn't hold her. She's taught me a lot. I wouldn't trade her for the world. I offered to help to other spina bifida families but they never called. I have a friend who is trying to convince a young man [with spina bifida] to get a service dog. She's going to take Annie out there [so he can] get an idea what they [service dog] can do and the mom is resistant and looks at it [service dog] like a burden . . . but there's benefit all around really. So if I can help one person then I've done my duty.

For Kate, and probably for Jane as well, the service dog was another aspect of dealing with the spina bifida. As Kate stated, "she's [Jane] brave, she gets help she doesn't need sometimes but not very often. And sometimes a little help is appreciated." Leaving home and moving away from parental support was difficult for the youth in my study. However, the next stories highlight the role of the service dog in that transition.

#### *Life is different with a service dog*

The constant presence of a service dog provided a mechanism of social support cited by numerous authors (Collins, Fitzgerald, Sachs-Ericsson, Scherer, Cooper, & Boninger, 2006; Mader, Hart, & Bergin 1989; Modlin, 2000; Rintala, Sachs-Ericsson,

& Hart, 2002; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Valentine, Kiddoo, & LaFleur, 1993). In fact Collins et al. (2006) suggested that future research on service dogs should consider that the mere *presence* of the dog may be as beneficial as any training the dog received. That is, no study to date has compared psychosocial or physiologic variables for people in wheelchairs who use service dogs with people in wheelchairs who have pets. It is possible that the interaction in general led to benefits rather than any specific skill/training demonstrated by the service dog.

Nevertheless, there is a relationship that developed between the service dog and the human partner even though the nature of the relationship was variable (Fairman & Huebner, 2000; Sachs-Ericsson et al., 2002). For example, two of the youth in this study (Rick and Jane) received their first service dogs as preteens. At the time of the interview Rick chose not to get another service dog, whereas Jane was about to receive her third dog. As participant's stories unfolded it was apparent the experience of having a service dog helped shape friendships (Rick, Betty, Jane), self-image (Jane, Mark), confidence and independence (Betty, Jane), as well as providing companionship. The service dog affected personal identity and self-esteem in at least two ways. First, others viewed the participants differently when they were accompanied by the service dog, and secondly, the participants felt differently about themselves when accompanied by the service dog. In this example, Jane described her relationship with Annie and its effect on her feelings of independence:

I am much more independent with a dog and it helps my self-esteem. I don't know if without a dog I would be as independent as I am. I don't know without a dog if I'd do some of the things I'm doing---working, driving---it makes it easier somehow. Especially meeting new people, like at work. In a way I am a very social person, but I get the jitters and I wonder what people are thinking of me? "Oh poor her." Or with the dog

they're not thinking that, they see us as a team. When Annie got sick I said, "I'm independent enough, I don't want another dog" but I thought "no I have to have a dog." I haven't been without a dog since I was 12, and now I'm 24. I can't imagine going from having this to not having this [a service dog]. . . So I'd have to rely on people more for the little things she does and I hate that. I hate going, "hey, can you help me", "can you get that", "can you do this." I felt like an invalid the week she [Annie] was sick [recovering from surgery]. It was real obvious those little things she does . . . I needed to get another dog, but my immediate emotional reaction was NO, how can I get this attached again. How can I go through this again? I couldn't imagine going through that hurt I was going through again.

Betty identified the confidence Ariel provided in social situations. In fact, she demonstrated an understanding that college freshman in general have difficulty making friends and she recognized that Ariel made it easier for her. She attributed her ability to make close friends to Ariel's presence:

That helped to have her at college, that's the main reason I got her. I mean I want to keep her forever, but the main reason was college. So that she really drew me out of my shyness. But now I'm not [shy] really at all. And it's a good thing because around here [dorm] if you don't know anybody . . . you gotta get to know people and you can't be afraid because they might be afraid. I don't feel so alone, they [roommates] are starting to feel like family. Being here is starting to feel more like home. I couldn't have gotten this far without her pulling me out of my shell.

However, Rick had a somewhat different experience and was the only one of the youth that was not sure he would get another service dog. Rick described his early years with

Lacey:

When I was younger having a dog helped because I was reliant on adults. I need assistance but I'm a person first. Treat me like anyone else. When I was younger, I went into middle school with her [Lacey] because kids were uncomfortable around me [and the wheelchair], then she made it a good way to talk [to the kids]. But it can be unnecessary attention. I didn't like that it labeled me as more handicapped, less independent because I had a dog. I don't know if I'll get another one. I haven't really thought about it. She retired before I went to college. I have other ways to deal with it [limitations]. It's not that I don't want one---As good a thing as it is, there are negatives.

Zitzelberger's (2005) qualitative research identified the person with a disability as being visible (due to the disability), but accentuating feelings of being invisible due to lack of social contact. This coincides with what Rick was trying to express about the dog making the disability more visible. Extending Zitzelberger's premise begs the question: could the dog by doing the simple tasks and everyday things make the person more visible and the disability less visible? According to Rick, the dog's presence highlighted the disability making him feel more disabled.

Rick also pointed out additional service dog ownership challenges that may have influenced his decision to get another service dog. These challenges were similar to the training/behavior issues identified by Camp (2000), and cost, behavior problems and access issues identified by Sachs-Ericsson, Hansen, and Fitzgerald (2002) and Fairman and Huebner (2000). Negative aspects of dog placement in Rintala, Sachs-Ericsson, and Hart's (2002) study included additional work in caring for the dog, inconvenience, expenses and other peoples' negative reactions to the dog. Examples of negative reactions from other people included avoidance of the dog due to allergies, shedding, or fear and challenging the person's right to have a dog in a place of business. In one example Jane had to choose between spending time with a friend and being away from Annie because her friend did not like having Annie present. Although at times she could justify being apart from Annie, in the end, Jane chose being with her dog over being with her friend:

Well I wanted to go out and one of my really good friends didn't want her (Annie) in her room, so if I wanted to hang out with this person I had to leave Annie in my room . . . and we went out a lot so she'd [Annie] spend quite a bit of time, I mean I spent a lot of time with her, but there were times that she didn't have anybody for her [Annie]. I'd like her with me all the time. One night this friend wanted me to spend the night

with her. I am so used to having Annie with me at night I couldn't sleep without her and I had to go back to my room. I said, "I can't do this."

The constant companionship provided familiarity and comfort for Jane when she was with Annie, and discomfort and guilt when she was apart from Annie.

Kate explained the positives and negatives of living with a service dog using Zitzelberger's (2005) metaphor of being seen. Kate can not "see" her daughter without the dog. In other words she saw them as a team, one with the other. Any potential disadvantages to having a service dog are nothing in comparison to "seeing" her daughter with the dog.

My daughter got this wonderful dog and that's a great benefit, but at the time I had a stepson who was asthmatic and I vacuumed everyday because I didn't want the dog to become an issue with his asthma. So I got home from work and first thing I did everyday was vacuum. So there was increased work there and then there's bathing, clipping the nails. I had to bathe the dog because Jane couldn't get to the tub. So that was my responsibility always. I wouldn't call it a burden, but an extra thing I had to do and that was no big deal, I just made it was my time with Annie, and it gave me a chance to bond with her without interfering with Jane's bond between her and the dog. . . . Oh there's not enough negative to even tip the scale. She was part of our lives, she had such a powerful influence over Jane. There's no way I can even see Jane without a dog.

*Making friends and acquaintances.* All of the participants mentioned that having the dog changed their interactions with others. Rintala, Sachs-Ericsson, and Hart (2002) found that service dogs met the expectations of their participants regarding feeling safe in public places and being more confident in social situations. Social activities and interactions are often limited for youth with disabilities and those limitations lead to feelings of incapability according to Coakley et al. (2006). The service dog's presence increased interactions and increased social interactions may increase feelings of self-worth (*The Health Benefits*, 1987; Siegel, 1993,1995; Valentine et al., 1993).

Betty described an experience typical of service dog users (Eddy, Hart, & Boltz, 1988; Hart, Hart, & Bergin, 1987; Modlin, 2000) when she described people approaching her more often when Ariel was with her. For some service dog users that increased social contact was an advantage and an opportunity, however for others it was also time consuming and frustrating (Camp, 2001; Duncan, 1998).

She [Ariel] makes it so much easier to meet people, I couldn't believe it. When I first brought her home I went to a record store and there was this really cute guy. I was a little shy and didn't say much but he was "Hey, your dog is cool, what's her name?" And I thought this is GOOD!!, this has potential. So she picks up guys for me.

In conjunction with Zitzelberger's (2005) findings, the importance of being seen and interacting with others is highlighted in Mark's story of interactions facilitated by his service dog at a computer conference:

. . . People notice me . . . I can talk to them about the dog and about myself. Reba helps out . . . she's there and she wants to work, she was instrumental in people giving me software or products because she warms them up and she is outgoing and once they talk to me we have a lot in common [with computer geeks]. I've heard numerous stories about their dogs. It engages them that way and it's a more personal conversation and it leads to something. I can spend a couple of hours talking to someone.

The IBM rep donated a laptop and that's partly because of Reba, she [the rep] came over to me because of the dog. The dog is cute, well Reba is adorable, really more so than most, she's gorgeous. . . . she got to know me and went back her company and got IBM to donate it. They see me as more than someone with a disability and they've already seen the wheelchair, but some of them see past it and think you could use this or I was thinking of you and you could use this as well, we'll send it to you. They remember me because of Reba.

Being seen as a person first and then being seen as someone in a wheelchair allowed the individual to make an impression based on their character, not on their disability. The service dog facilitated that process by drawing people to the individual.

In some way the service dog normalized the situation for others and allowed them access to the real person. Many people have dogs as pets, whereas far fewer know someone with a disability in a wheelchair. The dog allows the person with a disability in a wheelchair to be more familiar and less intimidating (Duncan, 1995; Eddy, Hart & Boltz, 1988; Lane et al., 1998). Others are able to “see” the person because as Mark put it “the wheelchair disappears.” Betty expressed similar sentiments in her description of meeting a new friend:

Absolutely, people are naturally drawn to her. Most people, unless they are afraid of dogs, are drawn to them, which cause them to ask questions about her and that causes them to talk to me. As a matter of fact, Thursday I got a girl’s phone number after she saw me and Ariel and she’s studying psychology and interested in service dogs. We are going out this weekend.

These youth took advantage of the opportunity provided when people approached and at first wanted to talk about the dog, and then wanted to get to know the person with the dog. The constant presence of the dog provided psychosocial benefits for these participants similar to what other researchers found with service dogs and family pets (Fairman & Huebner, 2000; Sachs-Ericsson et al., 2002; Siegel, 1993). Whereas most people with pets spend some time during the day with them (e.g., after work), the participants in my study spent most of the day with their service dog (Michalko, 1999). My participants offered stories of friendship, familiarity and ultimately comfort in their relationships with the service dog. Betty told a story of confidence and risk-taking only possible due to Ariel’s presence:

Even though people are dog lovers, people will stop and they wait to approach me and will not approach us until they realize she’s okay. And some people I don’t want to approach me so it’s just fine with me if they stay away because of her . . . and I don’t know why, but one time I was in the science building and saw this guy . . . she got nervous. Her tail

stood straight up she started to bark a little --- still her reaction. I don't know if it was the guy really or if there was something wrong with him or what, but she kind of keeps me aware of my surroundings . . . and I kind of know to watch out, because [usually] she's such a friendly dog and she doesn't do it [act protective] very often at all, but when she does I know something's wrong and think "why is she doing that?" And she made it easier on my parents, too. They were hoping she would make it easier on me emotionally. Not necessarily that she'd hurt people, but that they'd [strangers] be less apt to come right up to me.

*Being a family member.* The service dog partner was not the only one to benefit from the dog's presence. The feeling of relief was extended to the parents sending their young adults off to college with a service dog as evidenced by Betty's story, as well as Kate's comment in the following: "...and with Jane going off, I knew Jane wasn't alone that eased me some. I'm not going to say I didn't cry for several weeks---the worry..."

Camp's (2000) respondents called the safety provided by the service dog "someone to watch over me" (p. 515) and Rintala, Sachs-Ericsson, and Hart (2002) supported Betty's and Kate's stories in their findings that families have more peace of mind when the service dog was present. In fact several of the participants described the role of the service dog within the family, for example Betty described her mother's attachment to Ariel:

Well---I--- not that I can think of at the moment. Well, one major thing was my mom got majorly attached to Ariel and so when I left [for college] she had to deal with losing Ariel, too. That's a big thing, we're a whole family. When someone adopts a canine companion it's not just that person, it's the whole family that the dog is a part of the family. And what's really weird is my mom did not want a dog because it was going to be in the house and she likes her house to be so-so. And [she] didn't want the dog hair, but now she's like, "oh well", she could care less.

The parent's interactions with the dog, and their observation of the protective benefits the dog provided, allowed them to let go of having the sole responsibility for protecting their child. Just as parental control typically changes during transition to

adulthood; the service dog fostered separation and allowed the youth in this study to rely more on peers and self and less on their parents. Kate concluded, “I don’t know if Jane would’ve ever moved out on her own if she’d not had Annie. I don’t think she would’ve went off to college without Annie, I think Annie was that confidence.”

Having a service dog was part of Betty’s plan to make a successful transition to college. She acknowledged the important role Ariel had in helping her adapt to college:

Like I said I always knew I was going to college but it did put a safety coat on it, I guess you’d call it. I didn’t feel like I was going with nothing. I like to be alone, but when I am out, and when I am here alone, I’m glad she’s with me. It’s such a big difference. At home I lived in the country and maybe 10 cars would go by a night. Here it’s constant. There’s so much, the trains, people, new noises, new everything. I love having her sleep in my bed at night, I don’t know---I am---I feel comforted---sort of, I guess. I [went] off campus a little while and I was glad she was there.

Beyond the safety provided, participants revealed stories of being comforted by having the companionship of the dog. In fact, the participants described the dog as family members. Mark stated, “...she’s MY baby now.” Jane’s story described both emotional support and a deep connection with her dog. In fact Jane’s connection with Annie was lifesaving:

As you know I went through a very depressed time and I think if it wasn’t for her I probably wouldn’t be alive. I really believe that. I kept myself alive for her. I was that depressed. She was someone that I felt responsible for, a family member.

Jane acknowledged that her concern for Annie was one way she dealt with depression and suicidal thoughts. Being Annie’s caretaker gave Jane hope and a purpose for living. Clearly there was reciprocity in the relationship and the young adult’s expressed pleasure in caring for the dog as well as expressing gratitude for the dog’s assistance. Given the limited opportunities for social reciprocity, being a

caretaker was an important developmental step provided by the interaction with the service dog (Betz & Redcay, 2005; Camp, 2001; Fairman & Hubner, 2000). Betty eloquently expressed similar sentiments regarding Ariel:

I say the command with confidence, she picks [what I dropped] up and hands it to me and I go off, no big deal and people stare. “Oh my gosh, I can’t believe that dog just did that” It’s so great; it gives me a natural high! . . . Like you have no idea how smart she is. You’re proud. She’s like my kid, WOW I taught her French. So she’s a bilingual dog, it’s a good feeling when you teach them something. . . . to know she’s actually learning things from me. That I taught her rather than the trainer, that is a good feeling---awesome.

Rintala, Sachs-Ericsson & Hart (2002) found self-esteem, as measured by the Rosenberg Self-esteem Scale, improved significantly after placement of a service dog. Betty described feeling good about herself and her ability as a caretaker and a teacher for Ariel, similar to how a parent would feel about a child. Furthermore, Betty provided another example of the reciprocal caring in the relationship “...she’s like an extension of me, she picks up on stuff and she has helped me in very very stressful situations. She’ll come over to me and put her head on my lap and that comfort, that feeling of ‘I’m right here for you’, is good. It’s great.”

*Breaking down barriers.* A number of authors (Kirschner, Breslin, & Iezzoni, 2007; Pierce, 1998; Neri & Kroll, 2003) proposed that living in a wheelchair decreases the ability to make casual acquaintances, which provides a challenge for youth with disabilities to expand their social network. DeSanto-Madeya (2006) also found that wheelchairs cause barriers to a variety of interactions, yet early studies of service dogs found that wheelchair users with service dogs had increased social interactions compared to wheelchair users without a service dog (Eddy, Hart, & Boltz, 1988; Mader,

Hart, & Bergin, 1989). These early studies focused not only on the tasks provided by the dog but also on the dog's ability to decrease the stigma of the wheelchair.

The specific rationale of why people approach someone in a wheelchair with a service dog more than they approach someone in a wheelchair without a service dog is uncertain. One theory is normalization, for example seeing the dog is familiar and makes it safe to approach the person in the wheelchair (McNicholas & Collis, 2000; Valentine et al., 1993). Another consideration is the novelty/curiosity factor. Even though there are more service dogs working now than 10 years ago, service dog teams are still rare (Collins et al., 2006; Sachs-Ericsson et al., 2002). Regardless of the mechanism at work, the end result was increased interaction for someone in a wheelchair with a service dog:

. . . And y'know in the beginning Jane and I would be out in public pushing her chair and people shy away from you. They're like no you're in a wheelchair you probably can't talk. I don't know why people assume that, because anytime anybody would say anything they'd only talk to me and not to Jane. Well when we got the dog, first time we went to the mall, [it] took us three hours and we didn't do much shopping, we were just trying to get through the mall because people were stopping and they were talking to Jane. This dog was just unbelievable, it brought people to her.

Mark described others becoming desensitized to the wheelchair and in the process physical and social barriers were removed. They saw Mark differently when he was accompanied by Reba and she improved access to people:

. . . A lot of people and professors have told me this. The wheelchair literally disappears and then it doesn't matter. The only thing that remains is a subconscious, "oh there's a ramp" or Mark could come here. It's not about them not needing to help me its like . . . they like Reba there but then it doesn't matter whether Reba is there or not they are relaxed with it [the wheelchair], it's just different now. People who don't even like animals or are afraid of dogs get used to her or friends who don't like animals in their home . . . Reba is the only one allowed.

Many studies found that others assume the person in the wheelchair had a mental defect as well as a physical disability or that strangers saw the wheelchair and ignored the person in the wheelchair (DeDanto-Madeya, 2006, p. 273; Pierce, 1998; Treloar, 1999). My participants also told about challenges, such as being labeled stupid, because of using a wheelchair. When I asked for clarification, both Mark and Jane described the experience of people approaching them but talking to their mother instead of talking to them. Mark made the comment; “I’m not stupid, [I have] physical limitations not cognitive.” Jane expressed amazement at people’s insensitivity:

...at least they know I can talk because I’m working with the dog. I used to get that [unable to speak], not so much now. When I’m with someone they’ll ask my Mom or that person about me or about the dog and I just interrupt. She’s my dog and I can talk for myself, then they’ll talk to me.

Jane confidently and assertively explained why she had a service dog when someone asked. Without the dog she may not have had the opportunity to develop those specific communication skills.

*Making it easier.* The instrumental tasks accomplished by the service dog was the hallmark of service dog studies, especially the more recent studies that focused on occupational therapy (Camp, 2001; Fairman & Huebner, 2000; Hanebrink & Dillon, 2000). It is clear from the previous stories that the dog provided more than merely the animal version of an assistive device.

I would like to end the discussion of *It’s different now* with the many stories describing how the service dog assisted the participants with physical tasks. Jane described the difference Annie made when she used a manual wheelchair:

I’m fairly independent as it is, so Annie doesn’t do a whole lot for me. Like other people have said I’m sure, it’s the little things. When I was in

high school and college I had a manual chair. . . she pulled the chair so you did see her working and she made it so I wasn't physically exhausted . . . otherwise I was physically exhausted if I had to wheel all the way across campus.

Each of the participants stated that relying on the dog was not the same as relying on a person to complete a task. There is a reciprocal relationship that develops between the dog and the individual that is easy and natural and often automatic, for example, Betty described an example where the dog anticipated the task request before she gave the command:

She helps me, I rely on her for things you do yourself and she just does major picking things up. This wheelchair is high and to bend down and pick things up doesn't look very lady like. Today I bet I dropped 20 separate sheets of paper and she was so good she picked them all up and put them in my lap. It is the coolest thing I just love it . . . but it's not "oh look at me I am in a wheelchair I need your help" feeling. Some people think that's dumb, well if that's the only reason you have her people will pick things up for you. And it's not that they wouldn't, but I don't have to ask them, I show others I can do it differently, that means a lot. I don't have to ask for help all the time and she just does it [picks things up]. She did it without me saying "hey can you help me." And it gets you out of some embarrassing moments, if they don't notice and she picks it up and they don't know then we are on our way.

The big thing in class is dropping my ink pen. If someone is busy taking notes it's hard to get them to help me without bothering the whole class and making a federal case out of a dropped ink pen, you know. One time, first time [Ariel picked up a pen] the teacher stopped her lecture, they aren't supposed to do that, and [he] stared at Ariel and everyone stopped to watch. Another time, she carried my clothes for me, and we had company and she was carrying my bra from the shower to the room and she wanted to go greet them and I said "oh please no" and she didn't and I was so thankful [laughing].

Kate offered her perception of the benefits Annie provided to Jane as the little things.

There was also unspoken relief in her words. Now that the dog was there to help with the little things she (Kate) could focus on the big things:

. . . it's the simple stuff; it's nothing monumental to go shout off the tops of the mountains, these dogs do the simplest things we all take for granted everyday. And y'know I praise the program as high as I can praise it . . . it makes a difference...there's that one more dependency thing. She doesn't have to depend on me y'know? I heard "mom-mom" it was simple things---she dropped her comb. Even with the phone, she can send the dog back and forth with the phone . . . "take it to mom."

For some tasks not even the service dog can help, and Betty chose to rely on a friend. Even though being in a wheelchair made the task of doing laundry more difficult, asking a friend to join her was not that dissimilar from any college student's tale of doing laundry.

Only thing I can't do really well by myself is laundry because it is hard to carry the big basket, detergent, those little softener things, quarters and everything. Ariel would... I'm sure she could carry something, the detergent, the quarters, but she can't carry the big basket. But it is no big deal. I have a friend here who is a resident assistant and she is good about calling every weekend. "hey when do you want to get together to do laundry?" So I learned how to do the basics before I left home, I just need somebody there so I can get everything . . . get in the door . . . .

Mark described the assistance Reba provided as saving energy and decreasing frustration. Interactions with people were tiring and trying, but interactions with the dog were energizing and fun:

I can't pick something up if it drops and I have to wait for someone to come and pick it up and ah y'know person is bitching about it and sometimes I choose to wait quite a long time. At CCI they said a common thing is that when you get home at the beginning you may drop fewer things because you're not worried about dropping them and I've noticed that. Since I've had her she's on the spot and ready to get it for me that's Reba.

In summarizing the theme, *It's different now*, I use Betty's words as she described working with Ariel . . .

the best part of living with a service dog . . . [she] never gives up, [she] keeps trying, [laughs & looks at dog], and she makes me laugh. [The] hilarious thing is she will get it [the thing I want] but she'll pick up the

wrong one three different times, goes in a circle, forgets which one I said no to!! Its really fun living with her [smiling, petting the dog]. And also, I didn't expect her to be so---I don't know--- devoted. Like I said I don't have to say anything to her and she's just right there.

The participant's lives are different now because of the service dog. They are able to speak more freely with others, they are able to navigate their environment safely and they are comforted by the dog's presence. The dog's presence also allows others to "see" them differently. Repeatedly in the interviews the words "seen" or "visible" were used to describe interactions in the dog's presence. On the one hand the visibility improves access to new acquaintances; on the other hand it draws attention to the disability, i.e., the need for the dog in the first place. Another contradiction was that while the disability may be more obvious, the wheelchair, another symbol of the disability, seemed to disappear for the observer. These stories have provided richer descriptions of the relationship between an individual and their service dog than are currently expressed through various survey tools (Collins et al., 2006; Fairman & Huebner, 2000; Hanebrink & Dillon, 2000; Sachs-Ericsson, Hansen, & Fitzgerald, 2002).

## Theme Two: Going Places

*Going places* described the social implications of going or not going places and the environmental and personal barriers related to learning to drive. *Going places* came from stories such as getting around campus, going places with their service dog, taking road trips, and the illustrative story of driving. Each participant had a compelling story about driving that tied to their disability and their transition to adulthood and ultimately to their service dog. Whether or not they chose to learn to drive, the decision-making process around driving affected how they thought about going places, including how they were limited in going places. The stories here depicted the actual preparation for and coordination of activities related to mobility via a wheelchair, such as the practical reality of being in a wheelchair and navigating an environment that is not always accessible or disability friendly (Blomquist, 2006; Ripat & Booth, 2005; Ville & Winance, 2006).

### *Going to school*

All of the participants described situations related to school access, elementary school, high school or college. Kate, Jane's mother, had the most to say about access issues. Parents are the champions for their child's right to participate in as many regular activities as possible (Buran et al., 2004; Law, King, King, Kertoy, Hurley, Rosenbaum et al., 2006); therefore, Kate experienced behind the scene knowledge of the problems; whereas, the participants as adolescents and young adults only experienced the outcomes of the parental interventions. Kate described the relentless discussions necessary to achieve the outcomes she wanted for Jane:

I did a lot of fighting over the years with the school system for access. I did a lot of things. The year before she started school I went and told them they would have a child in a wheel chair and I fought them till she graduated for things like access to the lunchrooms. And she couldn't get to the library because it's in the basement. Finally in her last year there [6th grade] they got an elevator, before that she had to go outside school on a sidewalk from the top level to the bottom, that's if weather permitted . . . [but unless] it rains or snows [the] school didn't offer her help [she had to go alone outside]. [I] had the school and me and a mediator meet because this was before ADA. Finally, thru different programs money became available and it took time and it took nagging. My name is still known around the school.

The majority of studies with adolescents and young adults with disabilities found participation in activities an important variable when measuring successful transitions. (Luther, 2001; Stewart et al., 2001; Swanson, Cronin-Stubbs, & Sheldon, 1989). For example, one review found a lack of social participation to be a concern for 25% of youth 18-29 years old who were not working or in school (Blomquist, 2006, p. 168). Other authors found lack of participation in school events, especially after school or weekend events, was higher for those with disabilities than those without disabilities. Restricting access to peers was one consequence of not being included in school events, but a more serious consequence was being denied the opportunity to learn communication skills associated with those activities (Antle, 2004; Betz & Redcay, 2005; Hallum, 1995). On a more positive note, Kate described fewer battles for access when Jane went to college:

And so then we checked out Butler and even though they didn't have a lot of access [at first] they [it] did for Jane. They put a ramp to the library and chair openers on those big elegant wooden doors. They made sure there was a place for Annie to play on the fenced in tennis courts . . . One time when a paving company was there they paved a strip to the tennis courts and then Jane could take Annie there and have a good time. So Butler did everything, a lot on their own, for Jane to come there, they helped with the transition immensely. I didn't have to beg or plead. They said you tell us what she needs and they got back to me and said this is

what we'll do. It was above and beyond what I said she needed. I was always so impressed . . . they had the compassion to see beyond. They did it for Jane and others too, after her.

Access to peers was easier in a disability-friendly environment such as the one Kate described. Jane could go places with her peers without worrying about stairs or heavy doors to open. Jane's account of being at Butler was similar to her mother's:

"They made it that way. We went over when I got accepted to Butler. They went and took that room [dorm room] and specialized it for me with the "door opener thingy", lowered counters in the bathroom and [put in] a tub and toilet for me."

Rick was less expansive in describing his access issues; however, the message was still about the importance of being able to go places:

High school wasn't at all [accessible]. Well it was, but the elevator lets you out in the middle of a classroom . . . there I am with my hat, talking on cell phone, sunglasses and here are all these kids. I'm a pretty easy going guy so I don't put up a fuss. But that is weird. [at college] the dorm for wheel chair users is in the middle of campus, so it was central to get to all the buildings. [I'm] a pretty good driver and get places quickly.

Being at school was a transition for each of the young adults, and much like their non-disabled peers they needed to make adjustments to the new environment. Of the four young adults, Betty's description of her adaptation to life on campus demonstrated great self-awareness:

Well it's just like it has everything you need, a medical center, tons of food, bookstores; [I] don't have to leave campus for anything and now I feel comfortable. It's like a little town everything is here and I don't need to get out much . . . I miss the wide open spaces and more trees--well less trees, actually some people it might not seem like too big a deal, but that was my outlet. If I got too stressed I went outside and listened to the birds, you know? You go outside here and hear factory whistles and trains. It's not the same . . . There is a fountain in the middle near the union center that's pretty. I like to go to it. If I'm feeling really good [I] get up early before my first period class and go there, down by the

fountain and sit there. It's kind of peaceful, not many people out. Also peaceful here at night. . . . there is a field of grass and nothing but grass. Not big like living in the country, but resembles it a little bit.

It was insightful on Betty's part to recognize her stress and to identify a strategy to reduce the stress. Her experience is contrary to Crittenden's (1990) report of the difficulty many youth with disabilities have in developing appropriate coping strategies, especially strategies related to having a supportive network of friends. Buran, Sawin, Brei, and Fastenau (2004) also found youth with spina bifida in their study to have immature decision-making and infrequent peer interactions. On the other hand, Van Naarden Braun, Yeargin-Allsopp, and Lollar (2006) found that youth making a successful transition to adult life had successful post-secondary experiences, similar to Betty's experience. Hughes, Robinson-Whelen, Taylor, and Hall (2006) developed a stress management intervention for women with physical disabilities. They found that women, similar to Betty, who managed their stress proactively, had enhanced self-efficacy and social connectedness which promoted positive well-being. Many young adults do make successful transitions and it is important to understand their perspective as well as those that are less successful (Hallum, 1995).

Typically the young adults in this study described moving around campus in a power wheelchair, except Jane, who only had her manual chair and "Annie power" when she was in college. For people with disabilities who have adequate arm strength, moving about in a manual chair is preferred because of the cardiovascular as well as general health benefits. Frequently, as in Jane's situation, the service dog assisted the person in a manual wheelchair by pulling the chair. Kate, Jane's mother, explained the benefit Annie provided to Jane in this regard:

The transition to [college] went fairly well. Annie was with her the whole time [at college]. She could get Jane to class lickety split time by pulling her. She had a manual chair then. I don't think Jane could have had the stamina to go to college without Annie. . . . wouldn't have had energy to study and pay attention in class. Having Annie as a "motor" for her wheelchair made an ungodly difference.

*Going places with or without the service dog*

One challenge identified by many service dog users was obtaining access to public places (Camp, 2001; Fairman & Huebner, 2000). The Americans with Disabilities Act (ADA) of 1990 protects the rights of the service dog team to ensure that they have access to public places with their service dog (ADA, 1996; Duncan, 2000; Modlin, 2000). Reasonable accommodation for a person with a disability under ADA (1996) may mean a service dog accompanies the person to public places such as theaters, schools, shopping malls, and health care facilities. However, it is the person's choice, not the facility owner's choice, whether or not the service dog accompanies the person due to the nature of the event. Rick demonstrated protectiveness toward his service dog stating ". . . but I don't think a service dog should go to concerts, her [Lacey] being black she'd get trampled and it's not safe." Likewise, Jane did not always take Annie with her when she went to a movie or shopping because she usually went with her mother and they did not want to distract others (at the movie) or be distracted by others (while shopping). Leaving Annie behind was not easy, "Annie's got personality plus as evidenced by getting her pack and throwing it at us . . . [we] just feel so bad [for leaving her behind] she was a character."

Generally, common sense prevails when making the decision whether or not to take the service dog into a public place. For example, if either the person or the dog is ill then it may make more sense for the dog to stay home than for the dog to accompany

the person. Betty described an incident when Ariel was ill and she made the decision to leave her at home. Similar to Kate's story of leaving Annie behind, the owner and the dog struggle with "being left":

. . . well I left her and I went to class, it was the day she was going to the vet, she was sick. I didn't know what was going on so I left her . . . she was mad at me, [Ariel's thinking] 'but wait a minute I ALWAYS go there with you'. She has an internal clock. She knows what time we leave every day, knows which direction we go, where we're going, where else we're going, how long we'll be there, she know exactly what time I'm supposed to feed her. Like I'll be working on a paper and its time to feed her and she'll just sit there and look at me. I'll look at the clock and go "oh, okay, yeah."

In another example Kate explained a time when Annie did not accompany Jane to the hospital "She [Jane] was really sick one time, her bladder perforated and she was in the hospital for three weeks and we had people at home to take care of Annie . . . brought her up on Sundays to see Jane." If the service dog did accompany the person to the health care facility it would not be the health care provider's responsibility to care for the dog. If the service dog accompanied someone for an in-patient hospital stay, then prior arrangements should assure family or friends take care of the dog's needs (ADA, 1996; Duncan, 2000; Modlin, 2001). The crux of the matter is simply, does the dog need to be present, and if so, is there adequate support for both the dog and the individual?

Houghtalen and Doody (1995) described complaints regarding a hearing dog's barking when accompanying a deaf person on a psychiatric unit. Even under the reasonable accommodations of ADA (1996), the dog (not the person) can be asked to be removed if posing a direct threat or causing a fundamental alteration to the nature of the business. When a dog barks repeatedly during a movie, for example, or in a hospital, the

animal can be asked to leave. However, it is important to balance the needs of the deaf person to be alerted to sounds against the disruptions caused; and at the very least be prepared for the eventuality of the service dog and the person being separated (Duncan, 2000; Modlin, 2000).

According to the ADA (1990, 1996) a person's right to have a service dog is protected and it is illegal to confront someone with a service dog and ask about the disability. The dog, according to ADA, does not need any identifying paperwork or harness or cape to prove it is a service dog. The only requirement was the dog needs to be assisting someone with a disability (ADA, 1990; Duncan, 2000, p. 172).

Mark showed insight and awareness of his rights regarding access and found he had few problems gaining access, even if he was initially denied:

. . . No problem at the hospital or clinic. I wouldn't say its major but a guy wasn't going to let me in the grocery store because he thought she was a pet. When I said 'she is a service dog as you can see' then he was like oh, sorry. Every once in awhile you have some people who will be vague and say 'just a moment', 'I don't want to let you in,' 'it's not you it's the dog' . . . then it comes down to you can't do that. I can strong arm people, I can be pretty blunt if I need to be and say she is a service dog and you know she is allowed in here she's a service dog. She's federally protected and it's against the law in California to not allow her in---you can be arrested for it. And I tell them that if I need to, and that usually moves things along. But y'know some places people have hang ups about it and they just have to get over it.

Unfortunately, some people have tried to take dogs into public places under the guise of the pet being a service dog. That behavior by pet owners then precipitates people with (legitimate) disabilities with a service dog being questioned and even harassed for impersonating someone with a disability.

*Going places taken for granted*

Some travel problems that may be merely annoying for someone who is able-bodied, (e.g., long airport delays, mis-communicated hotel reservations), can become burdensome for people with disabilities. For example, not having a handicapped accessible room as requested presents quite a different problem than not having a king bed as requested. In the following, Mark showed his determination not to allow his disability to impair his traveling ability and demonstrated quite a flair for “making arrangements”:

When mom and I travel we just go. I don't need extra attendant care, I make all the arrangements . . . we don't fly we drive. She gets us there and I've made all the arrangements at the hotel so whatever we need is there. It's about forethought. You get good at it. And with Reba there are a few more things to pack, she has her own suitcase believe it or not, with food, bowls etc.

Using a wheelchair for mobility limits opportunities to go places unless the person with a disability had a handicapped accessible van, or used a manual, lightweight wheelchair that fit in the trunk/backseat of a car. Both Betty and Jane described situations related to their wheelchair that restricted trips off campus. In one example, Betty matter-of-factly chose not to go off campus and relied on friends or family to bring her things. “Well my friend, the one I told you about, he goes to Wal-Mart once a week and I go with him sometimes, but I haven't needed to because my family has been coming up and bringing me stuff I need like dog food and clothes.”

In a second example, Betty described being able to access a variety of venues on campus:

I can get most places, like that big theater place, and basketball. I haven't been to a game yet but I talked to one of the basketball players the other day and he said there are seats available with handicapped seating. I

went to the big theater once, there was a big assembly when school first began and it's accessible. It took me awhile to find an elevator, these buildings are so big, [elevators] never really easy to find.

Jane indicated that in college she went out with others because she had a lighter, manual chair rather than the power chair she currently used. "I always went with somebody cuz I didn't have my license until I got out of college---about 2 years ago, but just got a car a year ago. So I went with somebody and I had my manual chair then, it doesn't weigh a 100,000 pounds y'know, and was easier. We could go and that was a big issue . . . it was easier." Now, even with an accessible van she can drive, Jane rarely went out with friends:

I can meet someone somewhere but I work 7:30-4:30 and I am tired when I come home. But at college things were spread out more and had time to go out in the evening. I'm more apt to just want to stay home and if someone wants to do something [I ask] can you come here. I can come and go as I please. I'm not stuck in this stupid apartment y'know. I can go shopping, but I can honestly say I don't go out anymore than I did---I'm not the type---I don't like going to the mall by myself. I feel like a "freaking idiot".

This story poignantly shows that being able to drive actually disconnected Jane from friends she used to rely on for transportation. Ideally, Jane would invite others to accompany her when she drives, but she chose not to do so. She continued to rely on her mother as her primary source of companionship. Clearly, Jane sees herself as "a freak" when she is in public alone, even when accompanied by Annie. That is an interesting contradiction to research findings that suggest the service dog role was one of being an "ice breaker" in public (Mader et al., 1989; Sachs-Ericsson et al., 2002). Perhaps, as Kinavey (2006) suggested, young adults with spina bifida who internalize negative cultural images of their disability may struggle with identity development. Many young adults struggle with being alone versus being a couple as they move into

adulthood. Despite all the other positive benefits Annie brings, the presence of the service dog did not overcome social stigma (i.e. the dog does not make her feel less alone or less “a freak” in public).

Betty related an incident that took her off campus to meet a friend for dinner. There was a sense of pride in telling the story and pride in her ability to go outside the safe confines of campus accompanied by Ariel.

Well as a matter of fact a couple of blocks off campus is a restaurant called Saratoga and my friend lives above it in an apartment and he said, I'll meet you downstairs and if you aren't there in a few minutes I'll come looking for you. So I went on the sidewalk and got there. I took Ariel with me and she did fine. She was so happy she gets all excited going new places, y'know smelling other dogs, she's like wow. It's called major confidence. I have horrible, horrible sense of direction and I chose not to drive. When you are going just with someone and not driving you look around but you kind of pay attention, but don't go turn here turn there, because you don't have to get yourself there cuz you know you don't drive. So I was shocked I could get there without getting lost. I feel safer with her; I would never have gone off campus without her.

Mark in his typical way explained how much he enjoyed Reba's company when traveling. Much like Betty's story, Mark seemed to gain energy and confidence in the dog's presence. “She goes with me to a Las Vegas convention and loves it. The Las Vegas nightlife just me and her . . . that is enormous. She struts her stuff, came home, ate, took a nap but when I clicked (turned power on) the chair to go get dinner . . . or do something, she is up and ready.”

### *Going places and driving*

Driving is a rite of passage for most young adults. It signals movement away from the family and toward peer-centered activities and independence. Blomquist (2006), in a large multicenter study of Kentucky youth with disabilities, reported 65%

of the youth were driving, and they identified transportation (50%), education (49%) and employment (32%) as the three most common issues (p. 175). Buran, McDaniel and Brei (2002) found younger youth more concerned than older youth with transportation issues. The explanation for their finding was that young adolescents were just beginning to experience access and transportation issues as they began the journey to independence, whereas the older youth were more likely to have developed strategies and plans for access to friends, etc. over time. (p. 261).

Each of the youth in my study had a compelling story about driving that was unsolicited. In fact, it was not a question that I asked until it came up in the first two interviews. Jane was the only one with a van adapted with controls so that she could drive. Rick had his own wheelchair accessible van that others could drive, and Betty and Mark both relied on wheelchair accessible family vehicles.

Jane told the story of driving to and from work, but never driving at night until one night when Annie was sick . . . “I wouldn’t have driven at night if it was for me, but I did for her. We’re inseparable.” Taking care of Annie allowed Jane to overcome her fear of driving at night. She would not drive at night if it was to meet her need, (e.g., a fast food run), but she would drive at night to meet Annie’s needs. Jane was aware of the significance of this event and described it further:

When Annie got sick and everything . . . I did it [drove] one night because I was concerned about her and it was an issue “I have to do it”, so I did . . . [but] my vision . . . I don’t think I see as well [at night], but the doctor said I am okay, but I feel blinded by the bright lights.

Jane’s story of driving presents a certain hopefulness juxtaposed with inertia. She says she wants to “go places now”, but in reality, as depicted in her earlier story, Jane rarely drove anywhere except back and forth to work. However, she overcame her inertia in

order to care for Annie and take her to the veterinarian, even at night. Another issue Jane had with driving was following directions. This was due not only to lack of driving experience, but also memory or spatial orientation deficits as a result of spina bifida (Buran, Sawin, Brei, & Fastenau, 2004; Coakley, Holmbeck, & Bryant, 2006):

As long as I know where I'm going that's really a big thing with me. They will say "go here" or "go there" and I don't know where that is at. . . . and "its this street and this street" and I'm like you have to come here and guide me there. I'm one of those you can't just tell me the streets and go. If it's someplace I've been before I'm okay, but if it's not I get nervous. I don't drive at night very often but I can, but it's very very rare.

Being able to drive did not increase Jane's ability to go places. She primarily used her van to go to and from work and rarely used it go places with friends. Merely providing adaptive equipment does not ensure the desired outcome, (e.g., improved access to social network). Several authors expressed concern regarding the coordination of services for young adults in transition). For example, it was unclear whose responsibility it was to ensure adequate knowledge or appropriate expectations (e.g., driving) were in place initially and whose responsibility it was to provide training and subsequent evaluation and assessment of the adapted equipment (Buran, Sawin, Brei, & Fastenau, 2004; Stewart et al., 2001). Nurses working in acute care and outpatient clinics often have some responsibility for coordinating transition services between and among rehabilitation services.

Rick's story of a road trip with friends demonstrated a sense of urgency. Rick had been hospitalized several times and nearly died of pneumonia in the spring before our interview. He expressed a need to take the trip soon before it was too late. In fact it was Rick's one and only road trip:

I was on this trip when you were trying to get a hold of me. It was planned on the fly. Two weeks before we were to leave I got into a big [fight with mother] . . . she didn't want me to go. We didn't talk for a week and half. I wanted to go. I needed to go. I've never been away. I wrote her a really long letter. She was telling everyone else why she didn't want me to go . . . overprotective, but we worked it out. I took the van and four friends . . . If I was healthy 20 year-old it would be my decision to go . . . in one of their cars. But it was hers [mother's decision, too]. I've never gone with only kids my age. That was the point. Just to go. So we did spend three days in San Diego. Driving was the best part --- the freedom, the conversations--- just being able to do it. First time I was with people my own age and no adults. The experience I needed. I was apprehensive about who will take care of me. . . . people around me can I rely on people my own age . . . Even if she [Lacey] wasn't retired probably not [taken Lacey on the trip] because it was crowded. Not a lot of room. She wouldn't be very happy in the car and the hotel.

This short story was one of the most memorable I heard in all the interviews. He went away from home, overnight, long distance, with only his friends to rely on. It seemed a simple task, a normal event for most young adults, yet it clearly was a battle of wills between Rick and his mother to accomplish this feat. I can imagine her concern, not only for his health and safety (e.g., others driving her van), but also her concern for the responsibility his friends assumed. Giving up that responsibility, after a lifetime of caring for her son must have been difficult, yet she did give in. I could hear the pride and relief in his voice as he described the effort it took on his part to accomplish it. He did not take it lightly, but in the end Rick, his mother, and his friends negotiated the steps necessary to make the trip happen.

As Rick's story pointed out, driving was more than physically getting from one place to another. His story contained the elements of any young adult's story of a road trip because driving was also about risk, adventure and being with others. Driving for Mark was about desire. He desperately wanted to be able to drive or at least to have an accessible van that others can drive. There is a sense of determination in his story as he

explained why he wanted to drive. Mark found it difficult to consider dating without having his own means of transportation. Many studies have found that transportation needs are essential to developing social interactions, but none of them linked driving and dating per se (Hallum, 1995; Van Naarden Braun et al., 2006; Ville & Winance, 2006).

I can't afford an accessible van I can drive . . . I mean I could drive, the doctor approved it, but it's just the being able to afford it. I won't date until I can drive, who wants their mom hanging around like a third wheel. I don't date right now. Where I live it's not really easy to do. And I have friends. I don't want mom going out on a date . . . she'd have to drive me to a date. I have to separate me from her[mother]. [Girlfriend to] see me as a 25 year old adult capable of thoughts and feelings and not just part of family with mom tagging along.

I don't want to go out with somebody and have her listen to my mom talk about one of my physical problems. How do I say "mom, shut up." She's just being likable mother and I can't assert my identity if there is a third wheel. Lots of people go out on double dates but have you ever heard of going out on a date with the third wheel being your mom? So I go out with friends, they come here; I go to friend's house sometimes or out for coffee.

Perhaps dating was related more to driving than to the opportunity to meet the opposite sex, (i.e., access to meeting people and the opportunities to go places and do things alone was due to the lack of appropriate transportation not the number of people available per se). The message here was not just about driving but about what driving represented. For both young men driving represented getting away, being away from his mother, and being with friends.

There was a sense of resignation in Betty's decision not to drive which demonstrated clear, logical decision-making based on information available to her at the time:

I'll start by telling you I took driver's ed. [They] said you aren't getting hand controls you need both hands for steering because my judgment was horrible. At home, it's weird, in the parking lot I do fine, I could park, I could steer, drive whatever, but you get me out on the road it's like I turn my brain off. I have no idea---I am scared to death. I'm driving 15 mph and think I am going 55. I would think I would run off the road . . . I did great on reasoning and logic and math and reading I can do, but spatial skills are horrid . . . I don't see it [the missing piece and how they fit together]. I can't do it. Like those 3 D pic's, the magic eye [shakes her head] I could stare at it for a week and it wouldn't come. But I can do any algebra problem.

She [driver's education instructor] said I could [learn to steer], with extra practice but I chose not to because I have a problem I call road phobia. Whenever I get on the road I'm scared to death and if I was out just practicing and I hurt someone I'd never forgive myself. I just can't do it. I choose not to. They [my family] don't mean to put me down but they are always "you should reconsider driving; it is a good skill to have." They think it's new driver's syndrome. But unless you have CP [cerebral palsy] and you have the same fears I have, same kind of and [bad] coordination . . . know I'm not as fast as everyone else out there. I know my legs aren't as fast. I'd feel more confident not having to use my legs. I don't trust them as much as my upper body. I [could learn to] steer with one hand, and use [brake] control with the other, but I have to steer with both hands because my judgment is so bad on the road. So it scares me. Where's the middle road? My thought is I've got four and a half years of college . . . I've got everything I need [here] and driving isn't a priority skill right now. I'll worry about that later. I've got a degree to get now.

Driving is a landmark milestone in the transition to adulthood. Driving is associated with notable events such as buying the first car, getting a job and driving to and from work. Many young adults may choose not to drive due to location, (e.g., living in an urban area or using public transportation), but that choice is not the same as being unable to drive due to a disability. In the latter case, the physical condition limits the ability to drive but not the desire to drive.

Fortunately, many young adults with disabilities are driving adapted vehicles, albeit acquiring the skill somewhat later than their peers. Blomquist (2006) described

inviting a conversion van company representative to retreats and meetings to show families vehicle adaptation options, as well as other accessible transportation options. Jane made the transition to driving to work, yet she was more socially isolated than ever before. Jane was doing all the things youth are supposed to do, getting a job, learning to drive, living in a house that is handicap accessible, yet she was isolated and lonely despite having those advantages and having a service dog. As an outsider looking in, perhaps the service dog provided a measure of companionship that ameliorated some of the loneliness. Of greater concern is recognizing that providing the young adult with adaptive tools was not sufficient (Betz & Redcay, 2002). Successful transition and adaptation to adult norms will be measured individually not collectively. Just being able to drive does not necessarily equate with a wider social network or social sphere, as Jane demonstrated.

### Theme Three: Calling the Shots

*Calling the shots* centered on the ability to make choices for themselves and the dog, as well as to participate in age appropriate milestones, such as attending college and living away from home. *Calling the shots* presented four types of stories involving decision-making, (a) making the decision to get a service dog, (b) making the decision to attend college or obtain a job, (c) everyday decisions related to activities of daily living (ADLs), and (d) making health care/self care decisions. In these stories the participants emphatically demonstrated their decision-making capabilities and how those decisions affected their life. Mark expressed concern that his disability kept others from seeing his potential and his decision-making ability:

People have to realize we aren't all retarded [laughs] you can have a physical problem with your body but your mind is completely there . . . and they don't realize all of us with normal intelligence have a lot going for them.

Similar to Mark's story, Kate compares Jane to another young adult with a disability, who is not as fortunate as Jane. Kate then identified making the choice for Jane to go college because she did not want Jane to "be a burden to society. . ."

She's [Jane] been responsible for herself, a girl like Jane sits at home, won't go out, it's so sad. Jane has a full life the way I feel . . . I always wanted Jane to be a contributing member of society. College . . . and I'll be honest here, was more for me than her. I just felt Jane wasn't going to be able to get a decent job unless she had a degree.

Making vocational or educational choices during transition affects not only future employability, but also impacts self-perception and others' perception of the person with a disability. As described previously, having a service dog also affected other's perception of the young adult. Although they may not have been aware of it at the time, all the young adults had stories about deciding to get a service dog.

*Making the decision to get a service dog*

Of the five participants, only Rick did not have a story about getting a service dog. Rick's service dog, Lacey, was retired and he had no immediate plans to get another dog. He had moved onto another phase of his life without a service dog. He remarked:

When I was younger [the] dog helped because I was reliant on adults. Now I can rely on peers. It took me a year and a half to let a friend help me to the bathroom and [I] never would have done that before. I retired Lacey when I was a senior in high school so she wasn't at college. It [dorm room] was a small room and she was ten years old. I didn't even think about it [taking her with me]. Being there I didn't need [her help]. [Being there] would be hard for her. As long as she's still around I don't want another dog, she's very loyal and I think it would upset her if I had another dog. One day I put her pack on [another dog] and she got excited at first, then [she] got upset that the other dog had her pack on.

In Rick's story of making the decision of who will assist him, he identified Lacey's presence as helping with the transition from relying on adults to relying on peers. Even though the task he mentioned was not one Lacey assisted with, he still articulated that she made it possible to have friends, rather than adults, assist him. Working with a service dog presents opportunities for decision-making and for problem solving. Those skills transferred from communicating with the dog, or about the dog, to allowing Rick to make other choices for himself, (e.g., asking a friend for help). Working with a service dog provided Rick with the communication skills and possibly the negotiation skills needed to move from relying on adults to relying on peers.

It is interesting that he did not see the benefit of taking Lacey with him to college; whereas, the other three participants all suggested that going to college was a reason to get a dog in the first place. Rick's disability was progressively worsening, whereas the other three participants had more stable congenital disabilities. Rick stated

he did not want to take Lacey with him because of her age and space constrictions; however, Rick also wanted a more “normal” college experience and perhaps not drawing further attention to his disability and to differences was more of a priority than the benefits that Lacey provided. In addition, Rick had more demanding self-care needs and perhaps the combination of caring for the dog and caring for himself was more responsibility than he wanted during the transition to college. One of the drawbacks to having a service dog is the care they require. However, the other participants told stories of the benefits outweighing any drawbacks to having a service dog.

Jane had Annie since the 8<sup>th</sup> grade and described her relationship with Annie over time. Both Mark and Jane demonstrated immature knowledge of canine cognitive abilities and both had the tendency to anthropomorphize the relationship. Mark mentioned the dog being lazy and intentionally not wanting to carry out commands. Jane mentioned something similar when she talked about Annie’s “attitude:”

. . . she wants to stay with me. We are joined at the hip. I’ve had her since 8<sup>th</sup> grade. I had her four years of high school, then at college, now here . . . now thinking about her retirement. Healthwise she’s had problems and an attitude. She does things when she wants to . . . she has this attitude of “I’m retired. I love you but I don’t want to do this anymore.”

CCI and other service dog trainers stress the importance of knowing how a dog thinks and understanding what motivates the dog. Dogs do not refuse commands out of “spite” or “laziness”; but they do need to be motivated to do the task. It is the individual’s responsibility to motivate the dog (Coppinger, Coppinger, & Skillings, 1998).

Making the decision to retire a service dog is difficult. Rick made the choice based on Lacey's age and his needs; Jane's decision was an emotional one, as she described:

It's been an emotional decision. I had been thinking about it long before she got sick and I just kept putting it off. Then when she got sick it became more apparent that I needed to . . . and I sent the paperwork into CCI [for a successor dog]. So her last few years are hers, ours, and not working. When she got sick and I had to think about possibly going . . . to put her to sleep, I looked at mom and said, "I'm independent enough, I don't want another dog." But I thought no I have to have a dog. I haven't been without a dog since I was 12, and now I'm 24. I can't imagine going from having this to not having this [a service dog]. Whatever she does for me . . . I don't want to be screwed and not have a dog . . . because I waited [too long to request a new dog]. So I'd have to rely on people more for the little things she does and I hate that. I want the new dog . . . to pick up things cuz reaching the floor from this chair is harder, its wider and taller [than the manual chair]. And probably a golden, go places in public, and it's a safety thing.

Making the decision to get another dog when Annie became ill, and retirement became inevitable, was difficult for Jane. And even though, as she suggested, she was more independent now, the benefits of having a service dog outweighed the emotional risks of being attached to the dog. In contrast, Rick did not even consider getting a second dog. Although he identified Lacey as the loyal one, it was obvious he was also devoted to her and wanted her to have a peaceful retirement unencumbered by the intrusion of another dog. Perhaps an awareness of his own mortality and shortened life span also entered into the decision not to get another service dog.

Mark demonstrated patience and determination in his quest for a service dog.

Even though he was aware of potential drawbacks, he pursued his dream:

I knew I wanted Reba when I was in the fourth grade and saw on 20/20 a program on Canine Companions for Independence (CCI) and I wanted one then, but it wasn't convenient [to get a service dog]. It's a long arduous process and we had a lot of concerns about our mobile home

park . . . if we could have her and then when it was clear that the dog is federally protected they pushed to get me a dog then. When I was in high school we went up to Santa Rosa [training center location for CCI] and got on the list [waiting list for future recipients].

He did not indicate how long he was on the waiting list before being invited to team training; a process that lasts two weeks and teaches the individual and the dog how to work together, but it can be up to 18 months before a dog is available. He did go on to describe the team training experience:

Well it was different for me than some. They have the dorms now. CCI has changed its program, training is not a boot camp anymore, it's called team training. So it's a lot more friendly, relaxed and casual atmosphere. Y'know in our case we had people [in the class] who were very knowledgeable and it was easy to socialize and work with them. Our class was 5 or 6 people and everything that needed to work did. So we got close. We saw each other every day for two weeks, except Sunday, for training, and even on Sunday we saw others in the class. This was the first class through using the dorms. It was awesome . . .

Team training eventually met Mark's expectations, but he described initially being matched with another dog prior to getting Reba. He also demonstrated bias and possible jealousy against another classmate who he described as "too disabled to get a service dog." That person also had been initially matched with the dog (Reba) that he wanted. Of greater interest is the possibility that Mark felt he was "better" than his classmate with cerebral palsy (CP) and "deserved" the dog more than the other person did. In his words:

I was not matched with Reba. I was matched with another dog. The other dog wound up being booted from the service dog class. It would intentionally avoid doing commands. But when I came in I saw Reba and thought that's the dog I want . . . out of the whole lot I knew there were these dogs and lots of black dogs and I thought I know I'm going to get a black dog, but there was a golden [Reba] I wanted as well . . . but there was a student with severe CP [who] was not appropriate person to have a service dog, a social dog maybe, but not a service dog. It was too late to

switch them [person with CP] to another class [but they switched dogs]  
. . . so I got [Reba] and had to retrain some of her commands.

Mark maintained a presence of “specialness” in several of his stories. Rather than focusing on being different in relation to his disability, he focused on other positive traits that separate him from others. Previously he mentioned having genius level intelligence and that he should be at Berkeley or Stanford, now he talked about being a better trainer than others. Young adults in transition are often able to identify their needs, yet they may feel thwarted in their attempt to attain them (Kinavey, 2006; Lavigne & Faier-Routman, 1993; Patterson & Lanier, 1999; Stewart et al., 2001). Mark was determined to get the service dog he wanted and justified that he was the right person for her because he could “train her” better.

Betty made the decision to get a dog while in high school; however, as mentioned previously, Betty did not take Ariel to high school with her on a regular basis. She decided to wait until she went away to college to have Ariel accompany her:

ah well, a couple of times, [she went to high school] but the kids were immature about the whole thing. They tried to make her nervous and that made me nervous. I'd only just got her and had these questions . . . so I decided I would wait till college. In high school I don't advise it [taking the dog] at all, even if you are really good with the dog. Ariel and I clicked just like that and I thought we were perfect. Seven hour days straight, no breaks, [the] dog is nervous, [the] kids are immature and in high school you have cliques . . . with some certain people like they even barked at her one day. It was nuts. Here [at college] it is great. We go to class for an hour, rest for an hour its great. People will say, “Hey puppy”, or pet her a little bit, but they actually read signs and she has a little thing [patch] on her vest that says “Don't Pet Me.” As soon as they see that they stop. In high school they didn't care. [Here] they respect it [don't pet me] and I'm grateful for it. They may not like it, or understand it, but they respect it.

There was a sense of protectiveness toward the dog that several of the participants discussed. Rick described protecting Lacey in her retirement and Betty

discussed others interfering with Ariel being able to do her job. In Camp's (2001) study, she found service dog owners felt the dog was "closer than family" (p. 513). The relationship clearly goes beyond companionship and contains elements of reciprocal caring. Betty made that point clear in the following comments:

Well, more responsibilities, as far as I have to do everything for her, including taking her to the vet, except her bath and nails, she hates it and I didn't do it before. Mom does that and comes down once a month, mom did it then and that hasn't changed. . . . but everything else it's me taking care of her. And if I can't do them, I have to find someone who can because mom's not there. It went really well so far . . . it's like taking care of your own kid . . . do the best you can and she takes care of me. She had a bit of a yeast infection in her ear. So I had to put drops in. It was easy at first . . . but then every time I pulled this little thing out she'd get upset so my roommate took over for me. She would run away from me and I wasn't strong enough to hold her.

One of the advantages of having a service dog for young adults in my study was the ability to make decisions about the dog. In addition, the skills needed to navigate with a service dog, (e.g., negotiating access, arranging care, explaining the dog's role), translate into skills the young adult can use on their own behalf. For example, Betty described introducing herself and Ariel to her professors:

I took that upon myself. If I had needed them [university administration] to send a memo saying Ariel is going with me, it's no big deal they would have. But at the end of class the first time . . . I went up to the professor and said "I'm Betty and this is Ariel and she will be in your class, too. Some of them even put her on the roster.

The first day of college classes are often stressful, yet Betty was able to be assertive and notify her professors of the dog's presence. Confidence and assertiveness are skills people with disabilities need to acquire (Coakley, Holmbeck, & Bryant, 2006; Hallum, 1995; Kinavey, 2006) and in Betty's example, having a service dog encouraged her to develop those skills.

Benefits of having a service dog, such as improved self-esteem, assertiveness and improved confidence have been outlined by several authors (Camp, 2001; Lane et al., 1995; Sachs-Ericsson et al., 2002); however, because service dogs are a scarce resource, current researchers are very interested in understanding who benefits the most from a service dog and how the decision to get a dog is made (Collins et al., 2006; Coppinger, Coppinger, & Skillings, 1998; Fairman & Huebner, 2000; Whitmarsh, 2005; Zapf & Rough, 2002).

*Making the decision to attend college or obtain a job*

Blomquist (2006) reported that 35% of persons with disabilities in a national sample were working, which is about the same percentage as in 1986 before the Americans with Disabilities Act (ADA) passed. ADA provided access and protection for disabled people currently in the workforce, but has not had an impact on increasing access to the workplace for young adults with disabilities (Betz & Redcay, 2002; Buran, Sawin, Brei, & Fastenau, 2004; U.S. Department HHS, 2005). Active planning for the future, especially related to educational and vocational preferences, is vital for a successful transition into adulthood (Hallum, 1995; *Healthy People 2010*, 2002; Lotstein et al., 2005).

In their comprehensive literature review, Sachs-Ericsson, Hansen and Fitzgerald (2002), found a trend toward individuals with service dogs more likely to be employed than individuals without service dogs, but the studies had small sample sizes and inconsistent results. The participants in my study followed a similar trend. All four of the young adults had attended college, but only one (Betty) was still in school at the time of the interviews. Of the participants who had dropped out of college, Mark did not

work currently, whereas Jane worked full-time and Rick worked part-time. Both Mark and Rick had plans to return to college. The decisions regarding education, vocation and service dogs for the young adults with disabilities in this study were complicated and varied as evidenced by the following stories.

Jane was employed full-time, and Annie accompanied her to the workplace. This was Jane's third job since leaving college. During her first job after college, Jane experienced access issues related to Annie's presence at work. Kate, Jane's mother, explained the problems:

. . . applied for a job at [the local] hospital. [It] turned into a nightmare. Annie wasn't well accepted there and it was the first time we had run into access [issues] with the dog. If the dog walked too far away from wheelchair Jane got told about it. It was unbelievable.

Jane could drink at her desk but Annie couldn't have a bowl of water. It made it very difficult. They just about pushed me over the edge and Jane ended up quitting. I got some senators and people involved and told them they [the hospital] could not do this legally. I hate to use that . . . to throw legal stuff in people's faces but this was time for it.

Adjustment to workplace rules is part of the transition to adulthood for any young adult. In this case, lack of conflict in the university setting may have precipitated the conflict in the workplace. In fact, Jane had little experience negotiating conflict related to her service dog because the university made every effort to make the campus accessible for Jane and Annie. Rather than accepting the accessibility as an aid in attending classes, Jane took advantage of the situation. For example, she did not pick up after the dog and told me "the maintenance men do that, what else do they do." Now that she was in the workplace the rules changed and it was not acceptable for water splashes from the dog's bowl to go unheeded, or for Annie to sniff or to stray from Jane's side. There is clearly a need for the employer to respect the rights of the person

with a disability and the service dog, but the employee should make decisions based on those rights and not expect privileges (e.g., access for the dog, but no responsibility for the dog's presence or behavior) based on the disability status.

Jane struggled with the decision she made about going to work versus returning to school. Although she considered returning to school, she had not made plans to do so. Jane also wondered, much like any young adult, what her ideal job would be like:

My job isn't that satisfying and I don't have any schooling so I have to go with what I can get. I think about it [returning to school] once in awhile. I'd love to go into teaching or web design, staying home and doing my job from home . . . you can do that as a web designer all I need is my computer. I don't want to do IT stuff, computer programming stuff, I want the creative web stuff, it's very satisfying. I made a movie page from when I went to Titanic, and I've started one for Annie. I'm making very good money not having a degree and the type of job I'm doing it's a diddly squat job; any idiot could do my job, well maybe not any idiot . . .

Jane felt stuck in an undesirable job. Much like any young adult, she had dreams of an ideal job and if her current position remains unsatisfying and her motivation to return to school increases, perhaps she will make the transition to another, more satisfying job (Stewart et al., 2001).

The other three participants described making decisions balancing academic needs and accessibility needs. Rick chose a particular school because he “. . . wanted an accessible school and good for my major . . . telecommunications.” He described his general feelings about college life as well as specific accessibility requirements:

I may change my major to secondary education. I loved it [college] but it was stressful. I had a dorm room by myself that was very accessible; they had those cards that opened the doors with a wall unit on the door. There were several sets of doors to go thru, which was a pain so I needed help getting in and out of them, like [doing] laundry. As far as classes, I am generally speaking pretty good at hearing something and knowing it without notes, um, also I'm very good at y'know read it once---not like

real photographic memory, but not one who needs to study a lot. But sometimes I admit I didn't study at all and I did poorly, very poorly. Only time I would look at notes was if I missed them and someone else took them.

Rick made decisions about studying and socializing during college based on previous experience, and generally those choices worked for him. However, his recurrent illnesses and lack of consistent social network led to his withdrawal from school, despite maintaining good grades.

Mark started planning his college experience while still in high school and took into consideration getting a service dog and living in accessible accommodations. His experience contained all the elements researchers found essential to making a successful transition (Antle, 2004; Betz & Redcay, 2005). Despite his planning, Mark experienced life situations that did not allow him to continue with college and he also dropped out.

I had to leave [UCLA]. Mom had a spinal tumor and I took care of her. Now I [want] to return. I got Reba at the end of my second year there. Reba has only walked on campus; I got her after I had already left. I think for myself it [planning] pretty much started in high school. I already knew where I wanted to go, which is to college and then on to grad school. My family, my mom and I, decided I should take honors classes, and AP classes and I graduated with honors. I was accepted to UCLA and Berkeley and I went up to UCLA for a couple of years. It was great, the academics can't be beat . . . [but] as far as accommodations for students with disabilities it [was] pathetic. I was a ground breaker in a lot of ways. I basically had to say this is what needs to be done not just for me, but for all students, and it took many years. I was back there recently looking at dorms thinking about going back to school and y'know the stuff . . . it took awhile, but they were getting it done. Well dorm rooms for students were pretty much okay, they had a bathroom in each room and were accessible with power doors and wide doorways . . . classrooms were pretty good.

Mark clearly identified accessibility and accommodation needs related to his university experience. Mark also described financial factors related to his college choice and his need to have a high paying job, “. . . I was educating myself so I could afford

insurance, attendants and have all the things I needed to subsist. I was studying anatomical science, and want to combine anatomy, medicine and engineering. I keep up with that so I can get a good job in that area.”

The need for accessible accommodations was a thread in each of the stories. Making a decision based on accessibility may limit some academic choices, yet universities are required under ADA guidelines to maintain an accessible environment (Blomquist, 2006). Betty examined a variety of academic options before making her choice based on accessibility, academics and proximity to family. Betty was the only one to mention how her disability played a role in vocational choice:

I always knew I wanted to be a teacher and to do it right I needed to go to college. So I knew I'd go to college. As far as my disability, that is the reason why, part of the reason I want to be a preschool teacher. I want to expose them to the wheelchair and things. I've noticed when I talk to little kids before, my cousins, those I see once a week, they--- my disability doesn't come up. It's easy for them to talk to other people [with a disability] that and plus then they get used to people with a disability. My cousins accept disability and it's not an issue with them.

Second reason [I want to teach] is I want to teach little kids, and it will let me stay home. I want to stay home. I don't know if that's my values or my disability but I just want a job where I can stay home. So I'll have a home-based preschool.

. . . as far as I understand they are all teaching based schools. I didn't want to go to Evansville because it's too close to home and no really good [accessible] campus stuff yet. And Bloomington was way too overwhelming and this [school] is like a good middle . . . it's about three hours from home which is nice. Being here was a reasonable driving distance. If I got into major trouble somebody was close and when I first came up here I noticed they had good disability support services, plus they also have a note taker, [and] tables if you need them and they make sure you have what you need. Almost all the doors have those “door opener things.” Every building you can get into that way and I've noticed if I point out one that doesn't work then the next day it will work. It's not like they wait a month. That means a lot. They hear what I say.

Whereas Jane expected and sometimes demanded accommodations while in college, Betty expressed appreciation of the accommodations and did not seem to take them for granted. Attending college for these women resulted in different expectations and experiences based not on the disability or the service dog per se, but the individual personality characteristics.

It is interesting that both the women in the study wanted jobs where they could stay at home. Betty admits she did not know if it was a value-based preference or disability-related preference. Many researchers identified the difficulty people with disabilities have with transportation (Betz & Redcay, 2002; Blomquist, 2006; Kirschner, Breslin, & Iezzoni, 2007; Pierce, 1998), yet it is unclear if the desire to work from home was related to the hassles of transportation, or something more complicated such as being in control of the work environment. Jane had her own van and could easily get to and from work, yet still preferred a job she could do from home. Betty's desire to be seen and share her disability with preschoolers in a home environment was juxtaposed with not wanting to work in a public venue.

Several authors found that work trajectories vary based on age, gender, type of disability and timing of the disability (DeDanto-Madeya, 2006; DiNapoli & Murphy, 2002; Kinavey, 2006). Although meaningful work does not have to be paid, Rick made a point of differentiating his paid position from a similar volunteer position. He worked at the high school he graduated from in the role of liaison. He described it as:

I have a paid position at school, not volunteering, but same work at high school to help out but not volunteering . . . I found my niche. They didn't really have a position description for it. One kid was lost, just likes to vent, doesn't have close friends, doesn't like [her] parents, just hangs out with the wrong crowd and friends don't really care about her. She just needs to be redirected. My official title is assistant to the Dean, which

sounds either really important or really unimportant . . . basically I am a troubleshooter, a liaison between the faculty and students. I'm in a position being 20 years old that kids tell me things they wouldn't tell someone who works there. The Dean is only 30 and a graduate of [the school], he sits down and we discuss it [issues] without breaking trust kids have in me and at the same time resolve situation. It's a good deal. [This job] made me think about changing [major] to education.

Rick found his niche. He was able to work at a high school talking to younger students about their problems. His comfort with being seen was quite different from Betty and Jane, who would rather work from home. Not only does Rick want to be seen, he is putting himself in a position to see others and help them with their experience. This appears to be a remarkably mature decision reflective of Erickson's stage of generativity which usually occurs much later in life (Antle, 2004; Halfon & Hochstein, 2002; King et al., 2003). However, Rick had indicated in other ways he was aware of his shortened life span due to his muscular dystrophy, and consequently this job put him in a position to share his life lessons learned with others.

#### *Making decisions related to ADLs*

In the theme *It's different now* and *Going places*, the participants talked about accessible accommodations and accessing public venues. In this collection of *Calling the shots* stories they described the daily private activities of daily living (ADLs) related to their disability. Making decisions did not always lead to carrying out the task independently. For example, the service dog assisted with tasks that decreased reliance on others and increased feelings of independence. Likewise, Jane described a situation in which she was dependent on her mother, yet hopeful that new accommodations would provide more autonomy:

Umm, mom goes and does all my grocery shopping because we haven't, I haven't figured out . . . I can drive to it . . .but grabbing all the stuff and

getting it to the house . . . it's not a problem getting it to the car, but from the car to the house. Eventually I want to do that, but mom does right now . . . if it's not nukable I don't eat it. No pots, no pans and no boiling water, no way. Not right now anyway. Sandwiches or . . . maybe a salad. The new house will have lower counters. I have a little electric skillet for if I want to cook an egg or something. And the new house has a two burner stove with knobs in front and open on the bottom so I can roll under it. It will be a relief having my own space, catered to me . . . [I can] cook meals, do dishes, wash my own clothes, have a front loading washer.

Individual expression of values through unique choices may confuse or confound health care providers. In Jane's example, having her own accessible transportation did not lead to independence in obvious areas such as grocery shopping or visiting friends. Although mother and daughter negotiated accomplishing many ADLs, Kate told the following story as an example of how she pushed Jane to be self-reliant:

I started out at a very young age with Jane doing for herself with as limited help as possible from an adult whether it was me or whoever. She's always been very confident and in control. Not [in control] of people, but in the sense we have to do this and this and this in order to get where we are going. I told her she can do anything she wants. I've never said Jane you can't do that and I think that's kept her self-esteem up. Only once has she come home and said mom I want to do something --- I want to jump rope --- the kids laid a rope on the ground and she rolled over it. She jumped rope. The only thing she knew she couldn't do . . . these kids figured out a way and she did do it. She played pee wee softball and she'd bat and someone would run. She marched in the band, she played the bells and we built a contraption to hold the bells and I pushed her in the parade and she played right along with everyone else. A lot of times the service dog went with her. She was always very active in school.

Something as simple as involving children and adolescents in household chores was one of the most important tasks identified to ensure a successful transition (Blomquist, 2006; Hallum, 1995). Yet despite Kate's early efforts to ensure Jane's involvement in activities, she continued to assist her daughter in simple household

chores. This dynamic demonstrated that various perceptions of independence need to be accommodated, and that the definition of independence may change in various domains. Listening to individual stories gives the health care provider an opportunity to understand the young adult's unique needs rather than impose predetermined interventions (King et al., 2000; Larsen, 1998; O'Day & Killeen, 2002).

The last story in this category provides rich description regarding Mark's perception of his decision-making ability, including the barriers he encountered. The barriers encompassed attitudinal, societal and financial domains. His ability to recognize the problem was insightful, yet his feeling of powerlessness was troubling. He saw his intellectual capacity and employability as wasted without the resources to facilitate utilization.

I'm like a little corporation, what comes in goes out. I'll employ people, pay taxes and have to generate more money if I am to survive and get what I want. I think it's a waste to leave people at home getting worse. It depends on a lot . . . who gets money, prioritizing resources. Why are intellectually capable individuals not able to get an education? I have a good mind, but I was always overlooked as a kid because of my disability . . . no other reason I shouldn't have won awards, [or] been on the debate team. I was finally tested and it showed I have a great mental capacity like people who work at NASA, but I can't use it because of my physical limitations. That's frustrating . . . to know, to have someone tell you not just once but repeatedly you are . . . you have same IQ as Einstein and need to be here [college]. I don't want to live on social security checks and I don't think it's right to live below the poverty level. I want to have things for myself. I want to have a say about who will take care of me, whether I can drive, who I hire, [who] I fire.

#### *Making decisions about health care needs*

Transition from pediatric to adult health care practitioners for youth with chronic and/or physical disabilities is a national research priority (Callahan, Feinstein Winitzer, & Keenan, 2001; Scal & Ireland, 2005; U.S. Department of HHS, 2005;

Wagner, Newman, Cameto, Garza, & Levine, 2005). Although earlier research focused on identifying the ongoing special health care needs of children and adolescents with chronic illness or disabilities, the current research agenda became one of identifying and understanding their transition needs moving into adulthood (Hallum, 1995; *Healthy People 2010*, 2002; Neri & Kroll, 2003; Van Naarden Braun et al., 2006). These transition needs were broadly defined within the areas of psychosocial, environmental, vocational, educational and health care.

Mark's comments typify some of the findings regarding attitudes and barriers affecting access to health care for people with disabilities (Blomquist, 2006; Neri & Kroll, 2003; Pierce, 1998; Telford, Kralik, & Koch, 2006; Treloar, 1999; Vasas, 2005)

People have to realize we aren't all retarded [laughs]. You can have a physical problem with your body but your mind is completely there. We are very communicative . . . [I] don't have to be threatening . . . but I have to admit [I am] deeply resentful of some disabilities only because they [health care providers] have lumped us all [together] . . . [they] don't realize all of us with normal intelligence have a lot going for [us]. [There] is a negative connotation . . . People are afraid to ask questions. I'm not uncomfortable answering questions about my disability or me.

Mark's comments demonstrated his concern about being treated as a unique individual, not as just another person with a disability. He was willing to communicate with the health care provider but voiced concerns regarding their desire to communicate with him. Current research supports Mark's concern regarding the adequacy of patient-family and provider communication regarding a variety of transition issues (Blomquist, 2006; Buran, McDaniel, & Brei, 2002; Luther, 2001).

Over the last decade numerous studies identified gaps in transitioning youth from pediatric to adult health care in areas such as (a) the lack of sexual health education (Buran et al., 2002; Piotrowski & Snell, 2007; Sawin, Cox, Metzger, Horsley,

Harrigan, Deaton, & Thompson, 1999), (b) the lack of accessible health care (Neri & Kroll, 2003; Kirschner, Breslin, & Iezzoni, 2007), (c) the importance of providing youth with knowledge of their illness or disability (Luther, 2001; Patterson & Lanier, 1999; Betz, 1998, 1999; Betz & Redcay, 2005), and (d) the need to involve youth in health care decisions such as insurance (Hellstedt, 2004), treatments (Blomquist, 2006; Callahan et al., 2001), and communication with providers (Betz, 1999; Hostler, Gressard, Hassler, & Linden, 1989).

Developing programs based on federal and state mandates was the first step in addressing gaps in transition services. The next step was to put evaluation measures into place to ensure program effectiveness (Blomquist, 2006; *Healthy People 2010*, 2002; Wagner et al., 2005). Initial program effectiveness research demonstrated poor implementation and a dismal lack of coordination between educational, vocational, social and health services for youth with physical disabilities (Betz & Redcay, 2002; Blomquist, 2006; Lotstein et al., 2005; Luther, 2001).

Outcome studies identified two groups most likely to have transition plans in place: older adolescents and youth with more complex health needs. Although these two groups had transition plans, there was concern about timing that needed to be addressed by parents and health care providers (Neri & Kroll, 2003; Peterson et al., 1994). Certainly early transition planning is better than later planning; but, when a family is preoccupied with day-to-day concerns, planning for the future may be difficult. However, as the time for transition neared, and it was obvious that the young adult needed to move out of the pediatric setting, the family began to plan, albeit somewhat less efficiently (Blomquist, 2006; Neri & Kroll, 2003). Youth with complex needs were

more aware of the need for transition planning and may be better informed regarding the various entities involved in transition planning (Crittenden, 1990; Patterson & Lanier, 1999; Stewart et al., 2001); therefore making it easier for them to put transition plans into place.

Health care transition needs identified by the participants in this study ranged from making appointments, to understanding insurance benefits, to finding independent housing. None of the youth were completely independent in their interactions with the health care system, and all required assistance from parents or health care providers. The youth were involved in some aspects of health care decision-making, but they were not initiating contacts with health care practitioners. Their stories agreed with other research findings regarding health care transition needs (Hellstedt, 2004; Sawin et al., 2000; Wagner et al., 2005). Rick's description of handling health care finances showed a lack of knowledge, yet indicated empowerment regarding some decisions:

. . . my mom handles it [finances]. She tells me what needs to be done, but I'm in charge of my own health care. My mom does all that dealing with insurance and facilities. She knows all the tricks and stuff and it's a lot of work. I'm not nearly as familiar with it as mom is--there's so much to know. But medical treatment decisions are mine 95%.

Collaboration between parents, youth and health care providers was vital to successful transition planning in this study as well as others (Buran et al., 2002; Hallum, 1995; Sawin et al., 1999). In Kate's description of her involvement with Jane's health care, there was a pattern of collaboration between mother and daughter; yet, Kate clearly was still in charge:

. . . I still do that, well she has called and checked my schedule and then called but I always still go with her, and I will till she's 50 [laughs]. She goes to Riley for [spina bifida] check up and [to] family practice for general colds etc. . . . with the wheelchair she can't check [it], she tells

me [if there is a problem], there's a lot of it [the wheelchair] she can't see, like what's going on it's underneath her . . . so she depends on me and the maintenance guy at work.

Young adults exhibiting mature decision-making skills asked for help appropriately, especially with health care issues (Blomquist, 2006; Sawin et al., 1999; Telford et al., 2006). They may not know what to do, but they can garner the right the resources to make the decision. Developing decision-making skills was part of the knowledge acquisition needed for a successful transition experience. Sawin et al., suggested navigating health care issues could be approached like learning to drive. For example, new learners first drive short distances with their parents during daylight hours, and then drive during nighttime hours. Young adults could practice easier transition skills, such as learning about medications and picking up prescriptions, prior to performing more difficult transition skills such as making multiple health care provider appointments (p. 149).

Moving on to independent living is only possible if the young adult obtains knowledge of the health care system as well as other support services needed for independent living. Rick demonstrated his awareness of his changing health needs and the impact his health had on his living arrangements. He also demonstrated the eternal optimism of typical young adults who feel invincible when he says "Eventually I'll wake up one day and feel great !!" He started off by describing his arrangement for personal care while at school. . .

I had people coming in to help with physical care and friends [help with care] when they got more comfortable around me. Not necessarily around me, but being around me when I needed something, or help. . . Nursing care comes in once a day. . .

And he described being uninformed at first regarding making contacts for his living arrangements, but then is able to articulate his needs and his plan.

Voc rehab helped [with arrangements] and mom helped. I was in the dark about what I needed to do what I needed to do on my own . . . but now going back [to the dorm] I have a better idea of what I need to do. I am thinking about going into an apartment. I'll probably live with my best friend. Voc rehab pays for books and dorm, but living in an apartment has to be justified, but if nursing care gets cut then I'll need a roommate and that would justify more space and living in an apartment versus a dorm makes sense.

I got sick very suddenly. I went to bed getting over a cold and woke up and could barely breathe. It happened overnight. So I came home and spent 3 ½ weeks in the hospital with pneumonia. This whole year I have been sick and it changes throughout the day. I'll feel okay then get worse and I just have to---even though I feel good---to take cough syrup and everything just to make sure.

Knowledge of not only the primary disability but also preventing any secondary conditions (e.g., decubitus ulcers, depression, pneumonia) is necessary for the young adult to progress to independence and independent living (Blomquist, 2006; Neri & Kroll, 2003; Van Naarden Braun et al., 2006). The number of young adults surviving into adulthood that will experience normal aging is unprecedented. It is estimated 450,000 young adults with special health care needs (SHCN) turn 18 and prepare to enter adulthood every year (Hellstedt, 2004; *Healthy People 2010*, 2002; Lotstein et al., 2005, p. 1562). This number included both chronic illness such as cancer, diabetes, heart disease and cystic fibrosis, and disabilities identified as cognitive (ADHD), physical (spina bifida) or both (cerebral palsy).

Current research demonstrated that health care providers, for the most part, are ill prepared to care for the number and the diversity of these young adults (Betz & Redcay, 2005; Hellstedt, 2004; Scal & Ireland, 2005; Telford et al., 2006; Treloar, 1999; U.S. Department of HHS, 2005). Kate stated a lack of trust in health care when

Jane was in the hospital for a kidney infection, “[she was] in ICU and she wasn’t moving much and after the 2<sup>nd</sup> day I said we have to do something and she already had a huge pressure sore.” Mark expressed his concern for the health care continuity this way, “A kid who sprains his ankle can get temporary help but ongoing help [for me] isn’t available.” The transition needs of young adults are amplified by the numbers and the unknown as they age. Kate also described her fears related to Jane’s future health.

[I worry about] her health issues more than anything. She has recurrent kidney infections and the other [worry] is her shunt. You never know when it would take a turn or whatever. Her kidney function is good now, but she’s in that time frame where there aren’t that many 25 year old spina bifida kids out there. [There are] some older people [with spina bifida] but they’re really not many, and they were mildly affected. She got a shunt two years after it was invented. She got it replaced when she was 17 years old and that was the longest shunt he’d had in place out of his group and it’s a big group at Riley, but the future is unknown.

Mark’s comments demonstrated some understanding of the reimbursement dilemmas, but he also was confused and frustrated by the lack of coordination between the agencies. The lack of coordination between services was a recurring theme in the literature as well (Blomquist, 2006; Lotstein et al., 2005; Neri & Kroll, 2003; Patterson & Lanier, 1999; Pierce, 1998; Sawin et al., 1999, 2000; Tighe, 2001). Mark was concerned about “falling through the cracks” and not his getting future needs met:

I don’t have an intellectual impairment, not cerebral palsy (CP) or a developmental disability, mine is basically orthopedic and because of that services are discontinued at age 18. There are a lot of services if you are mildly retarded, or CP, but I fell through the cracks. [I] need attendants, accessible campus, adapted vehicles, and reliable public transportation. Public transportation doesn’t fit [my] needs, [it’s] difficult to get around. Attendant care and financial [support] . . . ability to succeed depends on that.

Research on self-esteem demonstrated that adolescents with disabilities who had overprotective parents actually had lower self-esteem as young adults than those

adolescents whose parents allowed some degree of autonomy and exploration (Lavigne & Faier-Routman, 1993; Sawin et al., 2000). Consequently, interventions aimed at helping young adults with disabilities to rely less on their parents (e.g., making appointments, providing transportation) are important priorities for health care providers (Buran et al., 2002; Hallum, 1995; Neri & Kroll, 2003; Telford et al., 2006; Van Naarden Braun et al., 2006).

Encouraging collaboration, such as Kate and Jane appear to have negotiated, was an important developmental milestone. However, it was evident there was tension and perhaps some sadness regarding giving up responsibilities, even as they collaborated:

Yeah she does [check herself for pressure ulcers], but if she's taking a shower I kind of look around [mom smiles and laughs] y'know quick like. [one pressure ulcer] wasn't that big but it was deep. You and me would have been screaming in pain . . . she just didn't feel it but noticed a stain on her underwear and we found it [pressure ulcer] . . . even though she couldn't feel anything of the pain from a kidney infection she could tell by the color and odor of her urine . . . she was pretty in tune with her body and she's an expert now. She tells me. "I'll call you . . . I've got a little bit of a fever, I'll call you, I'll take it [temperature] every couple of hours or I cathed [urinary catheterization] myself . . . every 2 hours not every four and I'm drinking lots of water." She's pretty much like taken over her life now. [It's] not like mom has to rush up there. But we talk every day and she knows . . . realizes I can't come every time she doesn't feel good.

Many studies have evaluated both parental and youth perspectives of the transition process, especially related to health care (Hallum, 1995; Holmbeck et al., 2006; Larson, 1998; Sawin et al., 1999, 2000; Spradley & Spradley, 1985; Stewart et al., 2001). Kate's feelings in this final story validate the need for research in that venue to continue in order for health care providers to gain a complete picture of the transition experience. Parents are obviously very involved in the health care and other transition

issues of their young adult. Until transition services are fully coordinated, either by nurses or other practitioners, parents, youth and rehabilitation service providers should continue to collaborate to provide the best care possible during this experience. Rather than create more programs, now is the time to evaluate current transition programs and adopt best practices to facilitate successful transition experiences.

### Reflection on the Findings and Discussion

Each of the participants described a distinctive story pertaining to their experience of transition. The reflection on the findings and discussion will begin with those symbolic stories and end with a summary of the themes for the young adults in transition living with a service dog.

#### *Symbolic stories*

Betty made a successful transition from high school to college, and she enjoyed being on campus, being with friends and being with her service dog. In fact, she partly attributed her success on campus to having Ariel accompany her. She felt Ariel provided her a sense of comfort and safety in her new surroundings. Betty also offered several examples of the little things that Ariel did, (e.g., picking up dropped items), that allowed them to function as team. The story of Betty introducing Ariel to her professors demonstrated the value of the team, and showcased Betty's assertiveness skills. It is never easy talking to professors, and even more difficult the first days and weeks of class, yet Betty seemed to pull this off with aplomb. Betty flourished at college as she prepared for her future vocation as a teacher.

Ostensibly, Jane had also made a successful transition from college to the workplace. She was working full-time, lived alone in her own apartment awaiting

completion of her Habitat for Humanity house, and had her own adapted vehicle for transportation. Although she did not complete her college degree, she did have three years of university education, and worked full-time. However, she stated displeasure with her job and considered returning to school.

When she was in college, similar to Betty's experience, Jane was socially active and enjoyed being on campus. Now Jane spent time either alone or with her mother. So, despite having full-time employment, independent housing and transportation, Jane frequently relied on her mother for assistance with typical household chores such as bill paying and grocery shopping.

Kate and Jane's relationship was an enigma. They both struggled with finding a balance between spending too much, or too little, time together. Even though Jane was physically and mentally capable of doing many chores and tasks, Kate facilitated everything from making physician's appointments to making grocery lists. Kate's story was highlighted by the contradiction of what she wanted Jane to accomplish and what Jane could reasonably accomplish with or without her mother's support. For now, as long as Jane had her own transportation and was employed, both considered her to be independent.

Mark had not yet made the successful transition from high school to college or college to work. Although he planned to return to college, he currently lived at home without a job. He expressed feeling excluded from opportunities available to others, both those with and without disabilities. Having a service dog was the one unique advantage he had that others did not and he used that relationship to display his team-training skills when he was in public with Reba. Mark clearly expressed his desire to

attend college because of his intellectual gifts. In his case, the service dog provided an additional impetus to return to college.

Rick made a successful transition from high school to college and to the workplace. Although he did not work full-time, he seemed to enjoy his job and to enjoy sharing his experiences with the students. Taking a so unique road trip marked his transition from depending on family for support, to utilizing peers for support. His story was the epitome of being in transition. Due to failing health, his future was unsure, so he utilized every moment to accomplish living.

#### *Thematic summary*

*It's different now* described the experience of transition and living with a service dog. Each of the participants described a unique relationship with their dog, and the meaning of having a service dog. A successful transition to adulthood meant that the service dog helped with the little things (e.g., providing safety, opening doors) so they could learn to negotiate and accomplish other tasks (e.g., meeting people, getting to class). Having a service dog allowed them to acknowledge limits, without allowing those limits to become barriers. For example, meeting people was more difficult being in a wheelchair, but having the dog accompany them facilitated interaction with others.

*Going places* described the experience of the young adults physically separating themselves from familiar support, such as family. This transition generally occurs in mid to late adolescence, but because the young adults in my study used wheelchairs for mobility, going places with family, not peers, was the norm during adolescence (Wilson et al., 2006). However, each of them described instances of being away from home, at

college or with friends, which demonstrated initiation of separation from the family and accomplishment of that transitional milestone.

*Calling the shots* described the experience of transitions in decision-making. The young adults in my study made many decisions independently (e.g., desire to get a service dog, choice of friends), as well as acknowledging the need for collaborative decision-making, (e.g., health care, ADLs, college choice). Decision-making regarding health care issues, such as the transition from familiar to unfamiliar care providers, provided the greatest opportunity for growth (Scal & Ireland, 2005). All of my participants demonstrated the ability to assertively make decisions in some instances, especially related to their service dog.

The three themes defining this study captured the variability and complexity of the transition to adulthood. Findings similar to other studies of transition were present in the current study. For example, previous authors identified gaps in transition services such as Mark experienced, (Blomquist, 2006; Patterson & Lanier, 1999; Sawin et al., 2000) and specific gaps related to health care needs such as Jane and Rick experienced moving into adult health care (Hellstedt, 2004; Neri & Kroll, 2003). Other studies focused on resilience (King et al., 2003; Nelson et al., 2004; Resnick & Hutton, 1987) similar to experiences described by Jane and Rick. Both overcame significant health issues (e.g., Rick had pneumonia and Jane had depression) that forced them to withdraw from college; but later they were able to successfully find employment.

This study also identified barriers in meeting transition needs similar to previous authors. These included, communication problems between parents and health care providers (Betz & Redcay, 2005; Buran et al., 2002; Scal & Ireland, 2005), loss of

services related to attending college and returning home (Krahn et al., 2006; Hallum, 1995; Ville & Winance, 2006) and lack of knowledge of vocational rehabilitation and transition services (Hellstadt, 2004; Ripat & Booth, 2005). The final chapter presents the significance of the findings for nursing and recommendations for future research.

## CHAPTER FIVE: SIGNIFICANCE OF FINDINGS AND IMPLICATIONS FOR NURSING

The findings from this study directly relate to the Surgeon General's report that identified four goals aimed at improving the health and wellness of persons with disabilities.

The Surgeon General's call to action encouraged health care providers to see and treat the whole person, not just the disability; educators to teach about disability; a public to see an individual's abilities, not just his or her disability; and a community to ensure accessible health care and wellness services for persons with disabilities (U.S. Department of HHS, 2005, p. 21)

This call to action is in concert with the *Healthy People 2010* (2002) goals for a healthier nation, specifically addressing the health needs of young adults with disabilities, as well as the national Healthy and Ready to Work program focused on transitioning youth with special health care needs (Betz & Redcay, 2003; Blomquist, 2003; Hellstedt, 2004).

Based on the Surgeon General's report, all nurses, as health care providers, should be prepared to care for someone with a disability. Nurses working in a variety of settings will benefit from understanding the complicated lives and needs of individuals/families with disabilities. With the growing number of younger people surviving childhood illness and disability, and older people living longer with age-acquired disability, nurses will provide care for individuals with a disability in inpatient/acute care; long-term care/assisted living, outpatient/clinic, school or work settings (Lotstein et al., 2005). Professional ethics demand that nurses treat all people with respect and dignity, which will now increasingly include those with disabilities

(Krahn, Putnam, Drum, & Powers, 2006; Telford, Kralik, & Koch, 2006). Individually and collectively, nurses could seek to understand the unique needs of people with disabilities and become aware of environmental and personal barriers that impede access to care.

Healthcare providers have traditionally depended on their own expertise in planning and developing programs. However, many transition programs developed over the last decade have been underutilized, causing health care providers to include qualitative as well as quantitative findings to determine health care and transition needs for adolescents and young adults (Betz & Redcay, 2002; Buran, McDaniel, & Brei, 2002; Wagner et al., 2005). Utilizing qualitative findings from this study will be useful to nurses and other health care providers in the quest to understand the experience of young adults.

### Significance of Findings

#### *Qualitative perspective*

This study provides nurses working with adolescents and young adults, with or without disabilities, an appreciation of the variability and complexity of transition needs. O' Day and Killeen (2002) suggested that qualitative studies are particularly useful in understanding how people make sense of their disability. The stories presented here allowed new discoveries and unexpected findings to surface. For example, driving an adapted vehicle to increase independence is taken for granted as the appropriate use of an assistive device; however my findings suggest that individual differences necessitate performing a risk versus reward appraisal of any assistive device. For example, of the four young adults in this study, the one with an adapted vehicle (Jane)

also had the least active social life. In her words, “I’m 24 and sitting home alone.” She expressed dismay at going shopping alone even though she could drive herself to the grocery store or the mall. On the other hand, Betty seemed quite satisfied with her choice not to learn to drive an adapted vehicle, at least not at this time in her life. She found getting around campus quite easy and enjoyed a sense of freedom without the burden of driving, even though her family encouraged her to learn to drive.

By allowing multiple points of view to be expressed, I identified unexpected strengths and liabilities. Although driving an adapted vehicle may be a laudable rehabilitation goal for most, these findings suggest the goal must be assessed in a larger context. Additional research could reveal a relationship between driving and socialization, for example, do young adults who drive an adapted vehicle spend less time with friends than those young adults who rely on friends/family for transportation needs?

#### *Disability perspective*

These participants expressed the importance of being treated “like anyone else” or of seeing the person first, not the disability. Other researchers also identified the societal limitations experienced by people with disabilities in wheelchairs (Padilla, 2003; Pierce, 1998). Jane and Mark both remarked that just because they were in wheelchairs did not mean they were unable to speak. As Mark stated, “I’m not stupid!” Societal attitudes, and at times health care attitudes, perpetuate a deficit perspective, despite evidence that people with disabilities have many capabilities. As the Surgeon General’s call to action states, health/wellness and disability are not mutually exclusive. In fact, fostering healthy behaviors despite having a disability is within the purview of

nursing. Good health for people with disabilities can be a normative expectation, just as seeing the person first should be a normative expectation (Krahn et al., 2006, p. 18; Tighe, 2001).

King et al. (2003) described three important processes people with disabilities engaged in to derive meaning from living with disability. These participants validated the processes of belonging, doing and knowing (self-awareness) King et al. All four of the participants attended college and described it fondly as a process of *belonging*. They were socially engaged with their peers, and the three participants (Jane, Mark and Rick) who withdrew from college recalled their campus experience longingly. In addition, while in college all four expressed a sense of *doing* something that mattered. As Mark remarked, "I should be there (Stanford or UCLA) doing that, not here." Doing activities while they were in college was easier for the young adults, despite being in a wheelchair. The youth in my study demonstrated different degrees of self-awareness or knowing. Mark exhibited a high degree of self-awareness that brought with it a sense of frustration because his life situation was not what he wanted. Rick also demonstrated a sense of self-awareness related to his worsening muscular dystrophy and shortened life span. Qualitative research studies demonstrated that living with a disability is a unique experience, with contextual and individual variations. Providing individualized transition programs is a priority for health care providers serving this population (Antle, 2004; Patterson & Lanier, 1999; Peterson, Rauen, Brown, & Cole, 1994).

#### *Transition perspective*

The most successful outcomes for young adults with disabilities resulted from early interventions and early transition planning. Several authors documented the

importance of early experiences with peers affecting later social relationships, and early participation in health care routines affecting later ability to communicate with health care providers (Betz & Redcay, 2003; Blomquist, 2006; Callahan et al., 2001; Halfon & Hochstein, 2002). None of the participants in this study were actively involved in a transition planning with health care providers. They were navigating the health care and vocational rehabilitation systems with the assistance of family rather than a transition or nurse coordinator.

At first, nurses may find the relationship between work and health outside their purview; however obtaining suitable work directly relates to promoting health as Mark so eloquently stated. He wanted to be able to complete a college degree and secure employment with benefits that would pay for disability related expenses (e.g., adaptive equipment, personal assistant). Without good health, staying employed is difficult; without good insurance benefits, staying healthy is difficult, especially for people with disabilities (Hellstedt, 2004).

For young adults to enter and stay in the workforce they must remain healthy. Nurses in rehabilitation and transition clinics can assist young adults to make appropriate vocational choices, and help build the connection between work and staying healthy. Young adults who enjoy their work and their co-workers are more likely to stay healthy (Blomquist, 2006). Nurses can become more aware of barriers for people with disabilities and assess accommodations in the workplace and the community to enable young adults to lead satisfying and independent lives. Interdisciplinary collaboration between health care, vocational, and educational services is necessary for successful

transition planning (DiNapoli & Murphy, 2002; Luther, 2001; Wojciechowski, Hurtig, & Dorn, 2002).

Choosing a vocation and finding meaningful work was difficult for the participants because of limited work experience, either paid or unpaid, prior to attending college. This pattern of limited work is typical of youth with disabilities, and one that many transition programs address (Betz & Redcay, 2002; Hellstedt, 2004; Stewart et al., 2001; Wagner et al., 2005; White & Shear, 1992). Also of concern was the 2000 census report that only 35% of all people with disabilities were working, which is about the same percentage as in 1986 before the Americans with Disabilities Act (1990) was passed (U.S. Census Bureau, 2003). Being employed is a key transition issue that affects many aspects of the young adult's life. Having early experiences with volunteering or paid work offer the youth opportunities to explore vocational aspirations and develop necessary social skills.

Blomquist (2006) revealed 83% of 650 youth in Kentucky did chores growing up, 52% did volunteer work, but only 45% had a paid job growing up compared to 80% of all high school youth. Several authors described improved independence resulted from interventions as simple as including the child or adolescent in household chores (Blomquist, 2006; Luther, 2001; Stewart et al., 2001). Two of the youth in my study (Rick and Jane) volunteered for CCI by doing public speaking at fund raising events. Betty expressed an interest in being a future puppy-raiser for CCI when she completed college. These experiences enhance adult role adaptation by providing recognition and responsibility (Halfon & Hochstein, 2002; Treloar, 1999).

Nurses working in rehabilitation and transition clinics who understand the link between postsecondary education, academic choices, and vocational choices will help young adults have a successful transition experience. Based on the current findings, the success experienced by youth with disabilities who attend postsecondary education may be a result of the social experience provided by attending college rather than the more obvious connection between college and improved job opportunities. These participants experienced numerous social advantages being in a campus environment. They had ready access to peers, shopping, cultural, and sporting events and they felt safe within the university setting.

In fact, Jane's story is a fitting example of the difference between social experiences in college versus social experiences in community living. Even though Jane did not complete college, she did obtain a job with benefits, albeit one that was not satisfying to her. However, her greater concern was loneliness and a lack of contact with peers. Despite having the tools and accommodations that should lead to successful adult role adaptation, (e.g., driving an adapted vehicle, living in an accessible house built especially for her by Habitat for Humanity, having a full-time benefited position), Jane did not have the social experience typical of many young adults. On the other hand, Jane may be typical of young adults with or without disabilities who do not engage fully in the adult social world. There are non-disabled young adults who live alone, rarely socialize and engage primarily in hobbies or family activities (U.S. Census Bureau, 2003; Wagner et al., 2005; Wilson et al., 2006). Jane's experience may be another reminder that all differences are not related to the disability; some findings are related to personality and individual traits.

Although some transition requirements, such as the need for a transition plan, the need for coordination of services and the need for adequate adult health care providers, will be similar despite the type of disability or special health care need, there will be unique issues in each population that nurses should be prepared to meet. Future research could individualize transition interventions based on unique personalities and needs rather than categorical assumptions that all young adults with disabilities need to accomplish certain predetermined goals.

#### *Health care transition perspective*

King et al. (2003) examined turning points in the lives of individuals with disabilities. They found other peoples' low or high expectations limited their participants' successful transitions. In other words, health care provider's assumptions about the person with a disability were not validated by the individual. Issues that health care providers found as problems the individual saw as opportunities or strengths (Larson, 1998). Young adults could be encouraged to focus on "this is who I am" not "what's wrong with me" (Tighe, 2001, p. 527). Nurses must consider that there is a wide variation of experience, even within young adults with disabilities.

Nurses are well suited to act as care coordinators of transition clinics like Betz and Redcay's (2002) Healthy Futures Clinic. Their clinic allows young adults an opportunity to meet both pediatric specialists and adult care generalists in one clinic setting. The health care providers worked together and learned from each other. Youth 18-25 years old should not be attending pediatric clinics, but most adult health care providers and facilities are not prepared to care for their special needs (Kirshner, Breslin, & Iezzoni, 2007). Collaborative research on the needs and outcomes of

transition services is vital to understanding the successful transition of these young adults. For example, maintaining services while moving from home to college and back home was a significant burden for the young adults in my study. The young adults in this study did not have the skills to negotiate a fragmented system; so either we need to fix the system or provide them with skills training or both (Krahn et al., 2006; Lotstein et al., 2005).

One of the biggest challenges for nurses and others in the health care system will be staying informed regarding health care needs and assuring current and future health care providers are also aware of those needs. Bachman et al. (2006) studied providers' perceptions of their ability to care for people with disabilities. Even though the ADA passed more than 15 years ago, providers were unaware that their health care facilities were not accessible; furthermore, the providers themselves felt ill-prepared to care for people with disabilities. Many young adults who have transitioned to adult health care providers reported a decrease in the quality of care (Callahan et al., 2001).

Young adults growing old with spina bifida who acquire arthritis will look different than a typical patient with age-acquired arthritis. Understanding the medication interactions of the current aging population is difficult, and as a population of young adults with disabilities and chronic illness enters the health care system with disease specific treatments, and problems, understanding medication interactions will be minor compared to the other unknown interactions. Nurses will need to take an active role in educating their patients as well as themselves regarding the health care needs of this burgeoning population (Krahn et al., 2006; Neri & Kroll, 2003; Piotrowski & Snell, 2007).

Blomquist (2006) and Wagner et al. (2005) found adolescents and young adults with disabilities engaged in risk behaviors at a similar rate as their non-disabled peers. Of special note was the risk for unplanned pregnancy, domestic violence and substance abuse (Sawin, Cox, & Metzger, 2000; Young et al., 1997). These risks are especially worrisome given the inexperience with interpersonal relationships the young adults in this study, as well as other studies, demonstrated (Kinavey, 2006; Lotstein et al., 2005; Patterson & Lanier, 1999; Sawin et al., 1999). Assumptions or attitudinal barriers about the sexual or relationship capability of young adults with disabilities may prevent nurses from providing anticipatory guidance about these issues. However, providing education/information about interpersonal relationship risks, would clearly benefit some young adults with disabilities.

Future studies could focus on the barriers within transition services; (i.e., the programs exist but are not being accessed by young adults and their families.) On a positive note, future research focused on successful programs would be beneficial for new programs and existing programs that are unsuccessful. It also is imperative that programs focus not just on youth with disabilities during transitions, but also on universal transition issues that allow youth with and without disabilities to get together and problem-solve. Youth with disabilities need access to peers without disabilities and nurses could creatively seek ways to make that a reality. For example, transitioning to adult health care is not easy for youth without disabilities. They frequently use urgent care, they are unlikely to have a primary care provider, and they are the age group least likely to be insured (Hellstedt, 2004; *Healthy People 2010*, 2002). I believe nurses will continue to creatively provide care for youth in transition, with or without disabilities.

### *Service dog perspective*

One of the more interesting pieces of information uncovered during this study was the lack of acknowledgement of service dogs in any research other than those studies aimed at the service dog relationship. Only two studies referring to service dogs surfaced among the hundreds of studies reviewed for this paper. In a study on aging with multiple sclerosis, one of the participants commented that she would consider getting a service dog so she would be less dependent on her children. The concept of independence is present in her statement; however the age group was reversed compared to my study. Rather than young adults relying less on parents, this middle-aged woman wanted to rely less on her young adult children, and thus considered getting a service dog (Fong, Finlayson, & Peacock, 2006).

Service dogs were also mentioned in a report addressing ADA issues and domestic violence shelters. The author presented recommendations that would accommodate women with disabilities in domestic violence shelters. For example, not only does a shelter need to provide access for a woman coming to the shelter in a wheelchair, but they also need to be prepared for a woman who may present with a service dog (Dubin, n.d.). This report pointed out a significant gap in research related to interpersonal violence against people with disabilities and the feelings of safety consistently reported by service dog and companion animal studies. There is growing concern regarding reports of domestic violence and abuse, especially for women with disabilities, and this would be a fruitful area for research (*Healthy People 2010*, 2002; O'Day & Killeen, 2002; Piotrowski & Snell, 2007; U.S. Census Bureau, 2003; Young et al., 1997; Zitzelberger, 2005).

Although studies of human animal interaction have become more commonplace, there are fewer research studies on service dog teams than on other types of human animal interaction (Barker, Rogers, Turner, Karpf, & Suthers-McCabe, 2003; Hines, 2003). It is unclear why there are so few health care studies related to service dogs, but perhaps it is because the people seeking a service dog are generally healthy and not actively involved with either rehabilitation or acute care researchers. However, with the increasing number of people with disabilities and the increasing burden to society for costs related to disability, any cost-effective intervention (e.g., service dog) should be seriously investigated.

Coppinger, Coppinger, and Skillings (1998) expressed concern regarding service dogs pulling wheelchairs and the strain it placed on the dog. Various types of harnesses are adapted for such use, but concern for the welfare of the dog was rarely addressed in studies of service dog benefits (Lane, McNicholas, & Collis, 1995; Sachs-Ericsson, Hansen, & Fitzgerald, 2002; Zapf & Rough, 2002). Veterinarians, service dog providers and health care practitioners, especially therapy services, could collaborate to evaluate the benefits and risks for both the individual and the dog in service dog placement.

Transitioning to adulthood is a stressful time for young adults, especially those with chronic illness or disability (Hallum, 1995; Luther, 2001; Patterson & Lanier, 1999; Stewart et al., 2001). Nurses could suggest getting a service dog as an intervention for some young adults to decrease stress during this time. Unfortunately, existing studies have not identified who may benefit the most from having a service dog. One consistent finding revealed peer relationships improved after acquiring a service dog; both the number of social contacts and the number of friends increased in

the service dog groups (Collins et al., 2006; Collis & McNicholas, 1998; Valentine, Kiddoo, & Lafleur, 1993). Because service dogs increase social interaction, potentially they could reduce depression and anxiety and improve social skills (Bergin et al., 1988; Sachs-Ericsson, Hansen, & Fitzgerald, 2002), and therefore benefit those individuals at risk for depression.

Although Collins et al. (2006) used standard measures such as the Rosenberg Self-Esteem scale and The Center for Epidemiologic Studies-Depression (CES-D) scale to predict community participation, until more researchers measure similar variables, it will be difficult to establish a pattern of reliable benefits related to service dogs. We do know that service dogs make meeting people easier and that youth with disabilities are at risk for social isolation. Further study is needed to follow a line of inquiry establishing the relationship between the amount or intensity of social contact due to the service dog and the degree of influence on well-being, depression or loneliness.

Rew's (2000) study of homeless adolescents identified their pets as a major source of comfort. The adolescents stated the pets provided relief from loneliness and also helped them stay healthy. Loneliness is a concept that could be included in future service dog and companion animal studies. It may be a more robust variable than social contacts related to the benefits of having a service dog, especially in at-risk populations.

Rew's findings are similar to the health-related finding reported by Lane et al. (1995), who found 47% of the participants self-reported improved health, even though they had disability conditions that were unlikely to change. This phenomena deserves further attention to determine whether the improved health is perceived or actual and whether it is due to a general feeling of well being or a specific health variable such as

decreased stress. Another possibility is that the responsibility they had for the pet/service dog led to improved self-care. This was true for Jane, in my study, when she stated that her suicidal thoughts abated primarily because of her concern for Annie, her service dog.

Another significant finding related to the young adults' use of the service dog to learn relationship reciprocity. Caregiving and reciprocity are skills not often available to youth with disabilities; they tend to be on the receiving end, rather than the giving end, of relationships (Camp, 2001; van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006). However, these participants clearly demonstrated caregiving and reciprocity in their relationships with the service dog. Most youth with disabilities have fewer friends and fewer intimate friendships. Perhaps the service dog is a bridge to making deeper connections with people.

Several of the participants demonstrated an awareness of their disability as more or less visible when the dog was present. Further study could answer questions such as: does the dog make the disability more visible or does the dog, by doing the everyday things, make the person more visible and the disability less visible? The participants in the current study expressed feeling different now that they had the service dog. If someone wanted a service dog to help with tasks, but felt dependent on the dog rather than self-sufficient by accepting the service dog's help, then that person may not be a good candidate for a service dog. The relationship between visibility, identity and stigma would be new areas of exploration for young adults with service dogs, but these are concepts that could inform not only service dog providers but also transition and

health care providers as well (MacLeod & Austin, 2003; Sanders, 2000; Zitzelberger, 2005).

### Implications for Nursing Research

#### *Service dog studies*

The existing service dog studies have not investigated physiological health variables related to having a service dog. Longitudinal studies of health, both psychological and physiological variables, would be beneficial in understanding the benefits of service dog across the life span. For example, is there a critical period when acquiring a service dog is most beneficial? For example, does a young child with a congenital disability benefit more than an older adult with newly acquired deficits following a stroke? Health maintenance variables such as medication usage, health care provider visits (Siegel, 1990) and satisfaction with health (Lane et al., 1998; Rew, 2000) would be of particular value to nursing and health policy. Collins et al. (2006) and Sachs-Ericsson et al. (2002) pointed out that the most interesting link to health and service dogs may be that it does not need to be a service dog at all; in fact any companion animal may provide benefits to people with disabilities. Collins et al. suggested further research was needed to determine if the benefits of living with a service dog were related to constant companionship (which could also be accomplished by a pet) or the fact that the animal was a specially trained service dog with access rights to public places.

Another possible conceptual framework related to service dogs is ambivalence. Sanders discovered ambivalence in the study of K-9 police officer's relationship with the canine partner. Some of the day was spent with a highly trained dog that had

potentially lethal deterrent capabilities and the rest of the day was spent with the same dog off-duty at home with family and friends. Existing service dog literature has not tapped into the working dog literature for conceptual frameworks, except in rare cases (Coppinger et al., 1998; Duncan, 1998). Putting the service dog in the context of a working dog and examining variables related to such a relationship may be more beneficial than studying the relationship from a companion animal or pet perspective.

Perhaps there is reluctance on the part of researchers to focus on the more objective working aspects of a service dog, rather than the subjective social/companionship aspects. The more recent studies from physical therapy and occupational therapy have started down that path by comparing the service dog to other types of assistive devices (Camp, 2001; Fairman & Huebner, 2000; Hanebrink & Dillon, 2000; Ripat & Booth, 2005). The combination of understanding the service dog as an intervention designed to provide specific assistance and understanding the service dog as a working dog could advance the knowledge of the service dog role significantly.

#### *Service dogs within the context of transition*

Two other areas for future studies related to service dogs and young adults are resilience and family adaptation. Both concepts are identified frequently in the disability literature, yet neither has been studied in either the service dog or companion animal literature (Barker et al., 2003; Beck & Katcher, 2003; Betz & Redcay, 2005; Buran et al., 2003; Holmbeck et al., 2006; Sachs-Ericsson et al., 2002). All of my participants shared stories of the dog's impact on their family, and Camp's (2001) respondents called their service dogs "closer than family." In addition, resilience is not only an

individual characteristic but also one found in families. Service dogs are a scarce, yet potentially valuable intervention, for young adults in transition. It is important to understand family dynamics that could promote or negate service dog benefits before promoting service dogs as an intervention. Currently, there is very little screening before service dogs are placed with a person with a disability (Duncan, 1998; Coppinger et al., 1998; Zapf & Rough, 2002). Future interdisciplinary research, involving nursing, occupational and physical therapy and veterinarians would assist in proper placement of service dogs, especially in light of the high demand for this scarce resource.

This study will be useful to professionals who place service dogs with persons with disabilities, lay persons concerned about the shortage of service dogs, rehabilitation specialists who desire appropriate interventions and nurse researchers who want to understand the human animal bond. (Rintala, Sachs-Ericsson, & Hart, 2002; Zapf & Rough, 2002). Very few qualitative studies exist in the human animal interaction literature, but qualitative studies could help identify important person/dog traits for future research. Areas that would be well-suited to future qualitative research include: (a) feelings when retiring/replacing a service dog and reasons for not obtaining a successor dog, (b) concerns being placed on a waiting list for service dog, (c) who decides NOT to get a service dog, (d) difficulties with access with a service dog, (e) what is the impact of retirement or death of a service dog on the individual and the family, and (f) unsuccessful or failed service dog matches.

#### Implications for Nursing Education

Nurses have the opportunity to advance the goals of *Healthy People 2010* and the Surgeon General's call to action by including the needs of young adults with

disabilities in nursing and medical school curricula. Nursing students and other health care students need opportunities for collaborative interdisciplinary training and assessment of disability awareness, especially related to barriers to access, (e.g., attitudinal barriers or physical barriers). Students could have collaborative or interdisciplinary clinical experience in acute care settings as well as outpatient and clinic settings to improve their understanding of the needs of young adults with disabilities. A collaborative model would improve their ability to understand the roles of the practitioners that direct care during the transition period.

Furthermore, current adult health care providers lack knowledge regarding disability and disease specific information to adequately care for young adults with special health care needs as they move from pediatric to adult health care providers. Many studies on health care transition focused specifically on the need to provide ongoing education to health care providers. In fact, in several of the studies the youth also identified concerns that adult providers would not understand or provide for their needs (Bachman et al., 2006; Betz, 1999; Betz & Redcay, 2002; Patterson & Lanier, 1999).

Over 15 years ago, a seminal issue of *Holistic Nursing Practice* provided nurses a variety of information about the human-animal bond, including Manor's (1991) discussion of including the human-animal bond in nursing curriculum. Annually, from 2000-2006, I provided a human-animal bond lecture in an Alternative and Complementary Therapy course at Purdue University School of Nursing, Fort Wayne, IN. During each two hour lecture, I provided the students with research related to companion animals, animal-assisted therapy and service dogs, including my own

research. As future research defines the benefits of the human-animal bond and the usefulness of service dogs as an intervention for people with disabilities, nursing education, both academic and continuing education, could integrate evidence-based findings into the curriculum.

At the end of this journey I am amazed and overwhelmed by the amount I have learned from my participant's stories. Even more so, I am grateful for the opportunity to continue this line of inquiry. Even though I did not actively work on the dissertation during a 3 year period, I was in fact, sharing my thoughts and ideas. My nursing students learned about my research with service dogs and young adults with disabilities in every class I taught. Students from the school of nursing, as well as other schools, learned about persons with disabilities and service dogs every time I brought a service dog puppy to the university for socialization. Consequently, I increased awareness about people with disabilities and service dogs, even if only for a small group.

I will end my paper like Padilla (2003) ended hers, with a quote from Soren Kierkegaard from an unknown source, shared by her interviewee, "Life is not a problem to be solved but a reality to be experienced" (p. 422). Truly, I am privileged to present the transition experiences shared by my participants that will hopefully stimulate future research about the way young adults with disabilities experience life.

## Appendix A

### Letter of Invitation to Participants

Date  
Address  
Zip

Dear Participant,

I am conducting a study to learn about the experience of youth living with a service dog. Currently, there is a lack of information about young adults with disabilities and their service dogs. Therefore, I am inviting you to participate in a research study conducted by Susan J. Modlin and the School of Nursing at Indiana University. We hope that the information gained in this study will be useful to all young adults with disabilities and the people they come in contact with; such as, health care providers, teachers, dog trainers and family members. We want to be able to understand the experience of young adults with service dogs as they become more independent.

We would appreciate your willingness to participate in this important study. The study involves an interview that will last approximately 1-2 hours. The interview will be done in-person; in your home or another convenient place you may chose. I will ask questions about what your day is like, and how you and your service dog go about your daily routines.

Your participation is voluntary. You do not have to participate in the study. If you decide not to participate, it will not affect your service dog team status in any way. I have enclosed a consent form to participate in the study. If you would like to participate in the study, please sign and return the consent in the enclosed envelope to: Susan Modlin, 196 Blue Ridge Rd., Indianapolis, IN 46208. If you have any questions please feel free to call or email one of us at

Principal Investigator: Dr. Melinda Swenson 317-274-0045

Co-Investigator: Susan J. Modlin 219-338-1954 or smodlin@iupui.edu

Sincerely yours,

Susan J. Modlin, RN, MS  
School of Nursing  
Indiana University

## Appendix B

Informed Consent

Study No.9901-05-B

### IUPUI and CLARIAN INFORMED CONSENT STATEMENT FOR

Living with a service dog: The experience of youth

You are invited to participate in a research study to learn about the experience of youth living with a service dog. You were selected as a possible subject because you are a young adult and have a service dog. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Susan J. Modlin, RN, MSN and Dr. Melinda Swenson and the Indiana University School of Nursing at Indiana University Purdue University at Indianapolis.

#### **STUDY PURPOSE**

Your participation in this study will help me and other health care professionals understand the role of service dogs. In addition, this research may help trainers and health care professionals make the right kind of decisions about who should get a service dog

#### **NUMBER OF PEOPLE TAKING PART IN THE STUDY:**

If you agree to participate, you will be one of **8** subjects who will be participating in this research.

#### **PROCEDURES FOR THE STUDY:**

If you agree to be in the study, you will do the following things:

I will ask questions about what your day is like, and how you and your service dog go about your daily routines. I want to know about what it is like to be you, in your own words.

I will ask questions and tape record your answers as we talk together. First, I will call you and determine the best time for me to come to your house so we can talk. I may also talk to a sibling or to one of your parents. We will find a comfortable spot to talk, just the two of us, and your dog, too, of course. We will probably talk for about 1-2 hours. Sometimes I will ask questions, but mostly I will want you to tell me your story of having a service dog. You can write the story out before I come, or have notes to refer to, or show me pictures, or you can just think of things to say the day I come to do the interview. You can do whatever makes it easiest for you to tell me about your experience. When we are done talking I'll give you time to think of anything you want to add. While completing the interview, you can tell the researcher that you feel uncomfortable or do not care to answer a particular question.

#### **RISKS OF TAKING PART IN THE STUDY:**

Although there is not any known risk in answering questions like the ones I will ask, you may feel uncomfortable or ill at ease about something you said. *If you have questions or if you have anything to add, please contact one of the researchers. Our names and phone numbers are listed below.*

**BENEFITS OF TAKING PART IN THE STUDY:** Although there is no direct benefit to you for participating in this study, your information may help future young adults with service dogs. You may benefit from participating in this study because you will feel good about yourself as you tell your story.

**ALTERNATIVES TO TAKING PART IN THE STUDY:**

Your participation is voluntary. If at any time you change your mind about participating in the study, you can decide not to be interviewed, or you can decide not to have your interview included.

**CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. Your name will not be used when the study results are discussed, and all of your information will be kept confidential, however, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and databases in which results may be stored. Susan Modlin, co-investigator, will listen to the audio tape recordings obtained during the interview and transcribe the audio tapes. The audio tapes will be kept in a locked cabinet until the end of the study (data published) at which time they will be destroyed. Only the co- investigators will have access to the tapes.

I may want to videotape or observe you and your service dog as you go through a typical day. If you are interested and willing to help with that part of the study, there is space provided below to indicate your interest, and a separate consent form to sign. Susan Modlin, co-investigator, will watch the video tape recordings obtained during the interview and analyze the tapes. The video tapes will be kept in a locked cabinet until the end of the study (data published) at which time they will be destroyed. Only the co-investigators will have access to the tapes.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, study sponsor, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP), that may need to access your medical and/or research records.

**COSTS**

There are no costs to you to participate in this study. If you voluntarily choose to meet at a location other than your home, you will have transportation costs to that location.

**PAYMENT**

If you agree to participate in the study you will receive a \$15 gift certificate to Borders Bookstores (or similar establishment in your area).

**CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study or a research-related injury, contact the researcher Susan Modlin at **260-515-1822 or smodlin@iupui.edu** If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949.

**VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with any service dog organization.

**SUBJECT’S CONSENT**

In consideration of all of the above, I give my consent to participate in the Service dog study. I have had an opportunity to ask questions and any questions have been answered satisfactorily. I understand that I can withdraw at any time without anything bad happening as a result of that decision. I will be given a \$15 gift certificate for my participation in the study.

I will be given a copy of this informed consent statement to keep for my records.

SUBJECTS SIGNATURE: \_\_\_\_\_

Date: \_\_\_\_\_

(must be dated by the subject)

SIGNATURE OF PERSON OBTAINING CONSENT:

Date: \_\_\_\_\_

Principal Investigator: Dr. Melinda Swenson 317-274-0045  
Co-Investigator: Susan J. 260-515-1822 or smodlin@iupui.edu

## Appendix C

Informed Consent

Study No.9901-05-B

### IUPUI and CLARIAN INFORMED CONSENT STATEMENT [Parent] FOR Living with a service dog: The experience of youth

You are invited to participate in a research study to learn about the experience of youth living with a service dog. You were selected as a possible subject because you are a parent of a young adult who has a service dog. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Susan J. Modlin, RN, MSN and Dr. Melinda Swenson and the Indiana University School of Nursing at Indiana University Purdue University at Indianapolis.

#### **STUDY PURPOSE**

Your participation in this study will help me and other health care professionals understand the role of service dogs. In addition, this research may help trainers and health care professionals make the right kind of decisions about who should get a service dog

#### **NUMBER OF PEOPLE TAKING PART IN THE STUDY:**

If you agree to participate, you will be one of **8** subjects who will be participating in this research.

#### **PROCEDURES FOR THE STUDY:**

If you agree to be in the study, you will do the following things:

I will ask questions about what your day is like, and how you go about your daily routines interacting with your brother/sister and their service dog. I want to know what it is like for your family to have a service dog living in the household.

I will ask questions and tape record your answers as we talk together. First, I will call you and determine the best time for me to come to your house so we can talk. I may also talk to another member of the family as well as your sibling. We will find a comfortable spot to talk for about 1-2 hours. Sometimes I will ask questions, but mostly I will want you to tell me your story of having a service dog. You can write the story out before I come, or have notes to refer to, or show me pictures, or you can just think of things to say the day I come to do the interview. You can do whatever makes it easiest for you to tell me about your experience. When we are done talking I'll give you time to think of anything you want to add. While completing the interview, you can tell the researcher that you feel uncomfortable or do not care to answer a particular question.

#### **RISKS OF TAKING PART IN THE STUDY:**

Although there is not any known risk in answering questions like the ones I will ask, you may feel uncomfortable or ill at ease about something you said. *If you have questions or if you have anything to add, please contact one of the researchers. Our names and phone numbers are listed below.*

**BENEFITS OF TAKING PART IN THE STUDY:** Although there is no direct benefit to you for participating in this study, your information may help future young adults with service dogs. You may benefit from participating in this study because you will feel good about yourself as you tell your story.

**ALTERNATIVES TO TAKING PART IN THE STUDY:**

Your participation is voluntary. If at any time you change your mind about participating in the study, you can decide not to be interviewed, or you can decide not to have your interview included.

**CONFIDENTIALITY**

Efforts will be made to keep your personal information confidential. Your name will not be used when the study results are discussed, and all of your information will be kept confidential, however, we cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published and databases in which results may be stored. Susan Modlin, co-investigator, will listen to the audio tape recordings obtained during the interview and transcribe the audio tapes. The audio tapes will be kept in a locked cabinet until the end of the study (data published) at which time they will be destroyed. Only the co- investigators will have access to the tapes.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and his/her research associates, the IUPUI/Clarian Institutional Review Board or its designees, study sponsor, and (as allowed by law) state or federal agencies (specifically the Office for Human Research Protections (OHRP), that may need to access your medical and/or research records.

**COSTS**

There are no costs to you to participate in this study. If you voluntarily choose to meet at a location other than your home, you will have transportation costs to that location.

**PAYMENT**

If you agree to participate in the study you will receive a \$15 gift certificate to Borders Bookstores (or similar establishment in your area).

**CONTACTS FOR QUESTIONS OR PROBLEMS**

For questions about the study or a research-related injury, contact the researcher Susan Modlin at **260-515-1822 or smodlin@iupui.edu** If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IUPUI/Clarian Research Compliance Administration office at 317/278-3458 or 800/696-2949.

## **VOLUNTARY NATURE OF STUDY**

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with any service dog organization.

## **SUBJECT'S CONSENT**

In consideration of all of the above, I give my consent to participate in the Service dog study. I have had an opportunity to ask questions and any questions have been answered satisfactorily. I understand that I can withdraw at any time without anything bad happening as a result of that decision. I will be given a \$15 gift certificate for my participation in the study.

I will be given a copy of this informed consent statement to keep for my records.

SUBJECTS SIGNATURE: \_\_\_\_\_

Date:

(must be dated by the subject)

SIGNATURE OF PERSON OBTAINING CONSENT

Date: \_\_\_\_\_

Principal Investigator: Dr. Melinda Swenson 317-274-0045

Co-Investigator: Susan J. 260-515-1822 or smodlin@iupui.edu

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## CURRICULUM VITAE

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### **Education**

- 2008, March            Doctor of Philosophy, Nursing Science  
Indiana University, Indianapolis, IN
- 1994-1996            Rehabilitation Psychology Minor  
Purdue University, Indianapolis, IN
- 1983, August        Master of Science, Nursing  
University of Wisconsin-Madison, WI
- 1977, May            Bachelor of Science, Nursing  
Purdue University, West Lafayette, IN
- 1975, May            Registered Nurse, Diploma  
Uniontown Hospital School of Nursing, Uniontown, PA

### **Professional Experience**

- 2006-Present        Director, Nursing Education  
Renown Health System, Reno, NV
- 2003-2006            Staff Nurse, Inpatient Psychiatric Hospital  
Northeastern Center, Auburn, IN
- 2000- 2006            Assistant Professor, Nursing  
Indiana University Purdue University, Fort Wayne, IN
- 1989-1993            Assistant Professor, Maternal Child Health  
Purdue University, West Lafayette, IN
- 1988-1989            Perinatal Nurse-Preterm Birth Home Care  
Tokos Medical Corp., Orange, CA
- 1987-1988            Clinical Nurse Specialist and Clinical Nurse Researcher  
High Risk Obstetrics  
University of California-Irvine (UCI), Orange, CA
- 1982 -1987            Perinatal Nurse Specialist and Clinical Trials Coordinator  
Corometrics Medical Systems, Inc., Schaumburg, IL
- 1977-1982            Labor and Delivery Nurse Clinician, Various locations

### **Adjunct Teaching Experience**

- Spring 2000            Research Methods in Nursing  
Indiana University, IUPUI, Indianapolis, IN
- 1994-1996            Experimental Psychology and Life Span Development  
Purdue University, Psychology Department, IUPUI
- July 1986            Clinical Instructor-Obstetrics, Medical Student Summer Elective;  
July 1987            University of California Irvine Medical Center, Irvine, CA

### **Presentations**

- Meyer, L., Carlson, C., Modlin, S. & Sedlmeyer, R., (2003, April). *A web-accessed database for evaluation of nursing students' clinical experiences and skills.*  
Demo-dialogue workshop presented at Educational Design conference  
sponsored by UIC Nursing Institute, Oakbrook, IL.
- Modlin, S. J. (2003, May). *Making transitions: Young adults with disabilities who have service dogs.* Paper presented at the Delta Society Annual meeting, Seattle, WA.

### **Research and Training Experience**

- 2000                    Midwest Alliance for Health Education Fellow
- 1999-2002            Grant Consultant for Indiana Youth Institute
- 1999-2000            Research Fellow, Adolescent Medicine, Riley Hospital and  
Indiana University School of Medicine
- 1998-2000            Research Assistant, School of Nursing, Indiana University  
Area of Study: Adaptation of Teens with Spina Bifida
- 1996-1999            Research Fellow, School of Nursing, Indiana University  
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- 1996                    Research Assistant, School of Nursing, Indiana University  
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- 1987-1988            Clinical Research Coordinator, Obstetrics and Gynecology,  
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## **Publications**

Meyer, L., Sedlmeyer, R., Carlson, C., & Modlin, S. (2003). A web application for recording and analyzing the clinical experiences of nursing students. *CIN: Computers, Informatics, Nursing*, 21(4), 186-197.

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