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Mentoring youth with disabilities: the mentor's lived experiences

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MENTORING YOUTH WITH DISABILITIES:
THE MENTOR'S LIVED EXPERIENCES

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Friends

Laura Brackin has been my mentor through graduate school and my profession. Thank you for the many phone calls offering advice and encouragement. You helped me envision and cross the finish line.

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ABSTRACT

Studies have demonstrated the benefits of mentoring as a successful intervention for youth in programs such as Big Brothers and Big Sisters. Limited research is available which describes the experiences of the mentors who participate in a program specifically for youth with disabilities. Youth with disabilities experience unique challenges as they work towards academic goals and independent living. Findings from this study will provide a insight into the lived experiences from the mentors' perspective.

The methodology used for this study was a single interview with five adult mentors of youth with disabilities. Qualitative interviews were conducted with each mentors to describe their lived experience of participation in the mentoring program. Mentors were recruited from Partners for Youth with Disabilities (PYD) in Boston, Massachusetts. Mentors were asked about the process of recruitment, mentor-youth match characteristics, activities, training and support (from program administrators), benefits to the mentor and challenges encountered.

Findings from this study indicate the primary source of recruitment of mentors was through staff and organizational affiliation. The mentors-mentees match process including similar interests, disability and geographic proximity should continue. Further exploration is needed about utilization of training and support. Mentors in this study rarely attended PYD's events. The mentors' initiated the majority of communication and activity planning. Mentees' needs at various ages generated different responses and challenges. Overall, the mentors found their mentoring involvement mutually beneficial.

One unexpected discovery was the length of the mentoring relationships for these mentor participants far exceeded the national averages. Mentors were involved with mentees from three and twelve years.

Implications would indicate further studies with mentors and mentees with disabilities. The unique nature of the needs in their relationship needs to be explored to provide mentoring programs administrators, mentors and funding sources information to develop and support successful relationships.

CHAPTER 1

INTRODUCTION

Mentoring is a practice which has been utilized for hundreds of years. The term "mentor" has been adopted from Homer's character in Odyssey. "Odysseus, Kin of Ithaca, went to fight in the Trojan War, leaving his wife and infant son Telemachus at home. He appointed his old friend Mentor as guardian to his son and to the royal household" (Colley, 2001, p. 182). The practice of mentoring has developed over years from informal relationships to formalized mentoring programs which are located in diverse environments, such as workplaces, communities and schools. More recently, mentoring programs are facilitated through technology resources. Through these mediums and environments, mentoring relationships are formed to address specific goals such as academics, career growth, life skills, and leadership development.

Some mentoring programs focus on specific populations, including at-risk youth or individuals with disabilities. "Big Brothers Big Sisters has been shown to have a significant and positive impact on the lives of children, according to the first-ever nationwide impact study of a mentoring organization" (Tierney, Grossman, & Resch, 1995, p. 1). Mentoring programs serving youth populations address a variety of age related issues including peer pressure, decision-making, goal setting, and life skills.

Within the last several years disability service providers have acknowledged the merits of mentoring and begun to develop mentoring programs to serve youth with disabilities. Due to the unique circumstances of the youth, often adults with disabilities are recruited to serve as mentors. Youth with disabilities require mentors who can speak to their specific challenges and experiences. Mentors address such topics as independent living, disability management, disclosure, accommodations, assistive technology as well as academics, careers, leadership, and life skills. An example of a mentoring program is Partners for Youth with Disabilities.

This program "provides unique role model relationships by carefully pairing "mentoring" adults from the community who have a disability with youth who have similar disabilities. This program is designed to encourage a social relationship between mentor and mentee whereby they can identify common ground and work on individual mentee goals" (Axelrod, et al. 2005, p. 2-2).

The National Mentoring Research Advisory Council for National Mentoring Partnership has conducted several comprehensive studies describing multiple aspects of mentoring. Research to describe the experiences of the mentors and protégés provides a foundation for program development components such as recruiting, training and support (National Mentoring Partnership, n.d. a). A substantial amount of research exists to describe specific aspects of mentoring, such as the formal and informal, group and one-to-one, at-risk youth, and career focused mentoring. Many studies evaluate the impact on the mentee/protégé from participating in mentoring. However, information gathered to date from the mentor's perspective is primarily limited to antidotal information. The scholarly research that has been identified on mentoring from the mentor's perspective offers a broad description of any type of mentoring relationship. Dr. Du Bois and Dr. Rhodes address the "Urgent Need for Mentoring Research" (Dubois & Rhodes, 2004, p. 1) in their Research Agenda. They suggest "researchers examining these models should investigate relationship processes from both the mentors' and mentees' perspectives, and they should attend carefully to patterns of stability and change in relationship over time, including how the length of a relationship affects outcomes" (p.3)

The National Mentoring Partnership conducted a national poll on mentoring whereby one component was to describe adults who have mentored or were willing to mentor. This study addressed the demographics of adult mentors, duration of mentoring, types of relationships and the characteristics of the youth they mentor. Many mentoring components were analyzed however the only mention specific to individuals with disabilities was in the special population category. This demographic question described special populations, such as mentees in foster

care, mentees in juvenile justice system and mentees with disabilities. Of mentors surveyed,

23% were mentoring a youth with a physical disability and 83% of adults surveyed indicated that

they would be willing to do so (National Mentoring Partnership, n.d. (b), Special Populations,

Chart 4).

Problem Statement

Mentoring is based on a relationship between two individuals, the mentor and the mentee.

The process of recruiting, matching, training and supporting participants is managed by

mentoring program administrators. Program administrators need to examine recruiting, criteria

for matching the adult mentor with a youth mentee, support and training offered, communication

and activities and long-term outcomes. Feedback from all stakeholders is considered as programs

are developed and supported.

Both mentors and mentees need to understand the benefits and challenges of participation

in this relationship. Each individual enters a relationship with different expectations and

requirements. These expectations may evolve as the relationship matures.

The problem is that little is known about the mentoring experiences from the perspective

of the mentor, with or without a disability, working with a youth with disability. Research needs

to be conducted from the perspective of the mentor regarding, recruitment, matching mentors

with mentees, and the training and support needed, so that we may fully understanding the

mentoring relationship.

Purpose of This Study

The purpose of this study is to describe the lived experiences of mentors of youth with

disabilities and what program administrators can do to assist in the success of developing mentor

– mentee relationships.

This study will answer the following guiding research questions:

1. Mentor Recruitment – How are mentors recruited to volunteer? What are their expectations?

2. Mentor-Mentee Match Characteristics – What do the adult mentor and youth mentee have in common?

3. Support and Training – What preparation did the mentor receive before becoming a mentor? What support did they receive throughout their participation?

4. Activities – What time commitment was involved? Where and how did you communicate with the mentee?

5. Benefits / Challenges – What are the rewards and challenges from participation?

This study will contribute to methodology for development of mentoring models servicing youth with disabilities by developing mentoring relationships with adults with disabilities. Information can be used by mentors and professionals involved in mentoring youth with disabilities.

Significance of This Study

The results of this study will contribute to the scholarly literature on mentoring program components which develop mentor - mentee relationships that will result in positive long-term outcomes for youth and adults with disabilities.

Audiences who could benefit from the results of this study are stakeholders in the mentoring programs such as mentors, employers, program administrators and funding providers. Mentors will be able to evaluate the benefits and challenges when considering participation. Program administrators can address concerns through on-going training and support. Funding providers can evaluate timelines and resources required to support successful relationships.

Rationale for This Study

Dr. Jean Rhodes, Professor of Psychology at the University of Massachusetts and Dr. David DuBois, University of Illinois have been conducting research on the mentoring of children and adolescents for more than ten years. Their research includes extensive analysis of the Big Brothers Big Sisters national impact and a national research agenda for youth mentoring. Dr. Rhodes and Dr. DuBois identify priority areas for future research which states "researchers need to rigorously evaluate strategies for recruiting, training and retaining mentors" (DuBois & Rhodes, 2004, p.3). Additionally the research agenda addresses the unique needs of special populations.

> A number of mentoring program models specifically tailored to young people with special needs appear promising but lack strong research support. To help ensure positive effects of mentoring for special populations, priority should be given to rigorous evaluation of these types of programs (DuBois & Rhodes, 2004 p.3).

Furthermore, "researchers examining these models should investigate relationship processes from both the mentors' and mentees' perspectives" (DuBois & Rhodes, p.3). "One of the most important reasons for bringing the practice of mentoring into alignment with a solid research base is to ensure that mentors and mentoring interventions *do no harm"* (DuBois & Karcher, 2005, p.9).

Previous research studies have presented data about the outcomes for youth who participate in mentoring programs. Research and best practices of mentoring program development and implementation is available (Axelrod et al. 2005). However, there is little published research regarding the perceptions of mentors, particularly those who work with youth with disabilities. Program administrators need to know what the mentors know, about the relationship in order to secure funding, recruit volunteer mentors, effectively match adults with youth, develop mentor/youth training, facilitate on-going support and record outcomes. "First,

mentoring research needs more process oriented data. What happens in interactions between

mentors and youth" (Larson, 2006, Conclusions, para. 2)? "How do the experiences and actions

of mentors and mentees influence each other" (Larson, para. 3)?

Over the past 20 years, the federal government has recognized a deficit in services for

transition-aged youth with disabilities and increased funding to programs serving this population.

During the same time period, the mentoring movement has made great strides. In the 1980's,

MENTOR/National Mentoring Partnership was formed to build federal, state and local initiatives

which would connect youth with mentors (National Mentoring Partnership, n.d. c). In 1983,

Partners for Youth with Disabilities (PYD) started a mentoring program for youth with

disabilities (Axelrod, et al. 2005). PYD was the program chosen for this study, however other

mentoring programs were considered. The University of Minnesota Institute for Community

Integration's program "Connecting to Success involves youth with disabilities in an e-mentoring

project that holds high expectations of youth while helping them develop social competence,

academic motivation, career awareness, and improved skills in reading, writing, and technology"

(Connecting to Success, 2004, para. 1).

Definitions of Mentoring

The formation of mentoring relationships both through formal and informal means is

integrated in our society. The definition of mentoring is adapted by the organization or the

individuals participating. This researcher discovered many definitions of mentoring for use in

different contextual environments. Federal agencies are often the funding source of formal

mentoring programs. For the purpose of this research and the target population, a definition

from the Office of Disability Employment Policy, a division of the Department of Labor will be

highlighted.

> A mentor is a person who through support, counsel, friendship, reinforcement and
> constructive example helps another person, usually a young person, to reach his or

her work and life goals. Mentoring relationships provide valuable support to young people, especially those with disabilities, by offering not only academic and career guidance, but also effective role models for leadership, interpersonal and problem-solving skills (United States Department of Labor, Office of Disability Employment Policy, 2005).

Definitions of Disability

Disability implies a loss of ability; however to what significance does the loss impact the life of an individual? Several definitions will be offered for reference in this research to highlight the perceptual and contextual contingencies from government agencies.

National demographic and population statistics are determined by the United States Census Bureau. The following definition was retrieved from the United States Census, noting the difference in definition over the past thirty years:

- In the 1970s, the concept of a disability referred to an underlying physical or mental condition. A person with leg paralysis would have been considered disabled based solely on their physical condition.

- Today, disability is seen as a complex interaction between a person and his or her environment. The same person with leg paralysis may be considered disabled due to their physical impairment as well as the barriers in the environment that prevent full social participation. (United States Census Bureau, 2004, Disability Overview, para. 1)

U.S. Census disability data is collected though surveys whereby individuals self-assess their circumstances and respond to the questions based upon their life experiences and perceptions.

Depending upon the circumstances that the term disability is referenced the definition varies. "Disability is an umbrella term and does not provide a single way to determine disability status. Thus it is important to state clearly what aspect of the disablement process is being captured by a specific set of questions." (United States Census Bureau, 2004, para. 2)

Many definitions of the term disability are for determination of benefits and community services. Medical coverage and cash assistance are examples of benefits received by persons

determined eligible, thus meeting the definition of disability. The Social Security Administration

provides cash assistance for individuals meeting all of their eligibility criteria.

> The definition of disability under Social Security is different than other programs.
> Social Security pays only for total disability. No benefits are payable for partial
> disability or for short-term disability.

> Disability under Social Security is based on your inability to work. We consider
> you disabled under Social Security rules if you cannot do work that you did
> before and we decide that you cannot adjust to other work because of your
> medical condition(s). Your disability must also last or be expected to last for at
> least one year or to result in death (Social Security Online, n.d., para. 1)

The American with Disabilities Act of 1990 provided legislation offering certain protection

from discrimination. The broad definition of disability has left the judicial system flexibility for

interpretation. The ADA says:

> An "individual with a disability" is someone who has a physical or mental
> impairment that substantially limits on or more major life activities, has a record
> of such impairment or is regarded as having an impairment.
> "Physical impairment" is defined as "any physiological disorder, or condition
> cosmetic disfigurement or anatomical loss affecting one or more of the following
> body systems: neurological, musculoskeletal, special sense organs, respiratory
> (including speech organs), cardiovascular, reproductive, digestive, genitourinary,
> hemic and lymphatic, skin and endocrine."
> "Mental impairment" is defined as "any mental or psychological disorder, such as
> mental retardation, organic brain syndrome, emotional or mental illness and
> specific learning disabilities" (Dickson, 1995, p.7)

Research Definition of Terms

For the purposes of this study, the following researcher developed definitions will be utilized:

- Mentor – an adult who has volunteered to offer guidance, support, and encouragement to a

  youth thus developing opportunities for personal and/or professional development.

- Protégé, mentee, youth – all terms will be utilized interchangeable and refer to the younger

  person who is the focus of the mentor.

- Disability – a self reported limitation which affects one or more life activity.

Limitations of This Study

The scope of this research is limited by the input of five individuals who were recruited from a sample of convenience. All five individuals are mentors from Partners for Youth with Disabilities; therefore reflect the experiences from only one organization. The individuals volunteered based upon the referrals from Partners for Youth with Disabilities program administrator.

The definition of disability for this research is all encompassing. Individuals who self report as having a functional limitation in any area are considered in this population.

CHAPTER 2

LITERATURE REVIEW

The literature review includes discussion about disabilities, statistical data demonstrating the need for supportive youth programs, why mentoring is an appropriate response, types of mentoring programs and the rationale for choosing the mentoring program Partners for Youth with Disabilities (PYD) for this study.

Individuals with Disabilities

Statistics documenting the diversity between individuals with and without disabilities vary due to differing definitions of disability and collection methodologies, yet the numbers all indicate an extensive gap. For example, Steinmetz's conducted a Survey of Income and Program Participation (SIPP) in 2002, which asked about a person's ability to perform life activities. The study reports about the U.S. civilian, non-institutionalized population and addressed the concerns of individuals with disabilities. According to this report, 51.2 million (18.1% of the population) members of our society are citizens and consumers with disabilities (Steinmertz, 2006).

Some statistical data about youth with disabilities is determined through the educational system. Special education services offer students with disabilities accommodations or supported services. Youth transitioning from the educational system to higher education and employment are typically between the ages of sixteen and twenty-one years old. "Among the 25.1 million people 15 to 21 years of age, 12.1 percent have a disability, and 3.2 percent have a severe disability" (Gould, 2002, para. 11).

Individuals with disabilities experience greater gaps in basic life activities such as educational attainment, employment and independent living. The adverse consequences of managing additional challenges and poor decisions are higher dropout rates, unemployment, long-term dependence upon public assistance and lower participation in higher education.

Table 1: Characteristics of the Civilian Non-institutionalized Population by Age, Disability Status, and Type of Disability: 2000

	Total		Males		Females	
	Number	Percent	Number	Percent	Number	Percent
Population 5 years and over	257,167,527	100.0	124,636,825	100.0	132,530,702	100.0
With any disability	49,746,248	19.3	24,439,531	19.6	25,306,717	19.1
Population 5 to 15 years	45,133,667	100.0	23,125,324	100.0	22,008,343	100.0
With any disability	2,614,919	5.8	1,666,230	7.2	948,689	4.3
Sensory	442,894	1.0	242,706	1.0	200,188	0.9
Physical	455,461	1.0	251,852	1.1	203,609	0.9
Mental	2,078,502	4.6	1,387,393	6.0	691,109	3.1
Self-care	419,018	0.9	244,824	1.1	174,194	0.8
Population 16 to 64 years	178,687,234	100.0	87,570,583	100.0	91,116,651	100.0
With any disability	33,153,211	18.6	17,139,019	19.6	16,014,192	17.6
Sensory	4,123,902	2.3	2,388,121	2.7	1,735,781	1.9
Physical	11,150,365	6.2	5,279,731	6.0	5,870,634	6.4
Mental	6,764,439	3.8	3,434,631	3.9	3,329,808	3.7
Self-care	3,149,875	1.8	1,463,184	1.7	1,686,691	1.9
Going outside the home	11,414,508	6.4	5,569,362	6.4	5,845,146	6.4
Employment disability	21,287,570	11.9	11,373,786	13.0	9,913,784	10.9
Population 65 years and over	33,346,626	100.0	13,940,918	100.0	19,405,708	100.0
With any disability	13,978,118	41.9	5,634,282	40.4	8,343,836	43.0
Sensory	4,738,479	14.2	2,177,216	15.6	2,561,263	13.2
Physical	9,545,680	28.6	3,590,139	25.8	5,955,541	30.7
Mental	3,592,912	10.8	1,380,060	9.9	2,212,852	11.4
Self-care	3,183,840	9.5	1,044,910	7.5	2,138,930	11.0
Going outside the home	6,795,517	20.4	2,339,128	16.8	4,456,389	23.0

Note. (United States Census Bureau, 2000)

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Educational Attainment

The National Council on Disability prepared a comprehensive report on the status of students with disabilities in the United States to examine the impact of Education for All Handicapped Children Act in 1975. This legislation "guarantees a free appropriate public education to all students with disabilities" (National Council on Disability, 1989, para. 3).

> The Education of Students with Disabilities: Where Do We Stand? – A Report to the President and the Congress of the United States – A good education is a ticket to success in our society; it is a predictor of success in later life, in terms of employment, income, and independence. When we examine the education status of a group of individuals, we are also, in most cases, examining predictors of their future. A good education can mean the difference between a life of dependence and unemployment and a life of independence and productivity. In a society too frequently preoccupied with defining people in terms of their *disabilities*, a good education offers people an opportunity to define themselves in terms of their *abilities* (National Council on Disability, 1989, para. 1).

Students with disabilities are entitled to special education services such as individually designed instruction at no cost to parents. This report indicates 40% of all persons with disabilities aged 16 and older did not complete high school. (para. 10)

Five years later, Gould reports high school graduation rates for students with disabilities in comparison with their peers in general education. "National research data indicate that while only 27% of students who receive special education graduate with diplomas, 75% of their peers in general education – who do not receive special education – graduate with diplomas" (Gould, 2002, para 9). Students with disabilities who are unable to complete high school requirements and obtain a diploma are offered alternate completion options, which vary by state. Most states offer the standard high school diploma, if exit requirements are achieved, or a certificate of completion. The certificate of completion indicates time spent in school; however this would not qualify them to be a graduate.

Post secondary education reveals further gaps between students with and without disabilities. "Only 27% of those who complete high school are enrolled in post-secondary education compared to 68% of the general student population" (Gould, 2002, para 9).

Table 2: Basis of Exit for Students Who Receive Special Education in the United States During the 1996 to 1998 School Years

School Year	% Students 14 Yrs. and Older Who Exit with Diplomas	% Students 14 Yrs. and Older Who Drop Out	% Students Who Moved, Not Known To Continue	% Students 14 Yrs. and Older Who Returned to Regular Education	IDEA Annual Report Year
1996	27	17	13	15	1998
1997	27	18	12	14	1999
1998	27	17	13	12	2000

Note. In school year 1996, there were 441,812 students reported to have exited special education in the United States and outlying areas. In 1997, that number increased to 463,025 students. In school year 1998, that number increased to 486,625 students. The following statistics provide information on the 'Basis of Exit' data reported over the last 3 years by the U.S. Department of Education's Office of Special Education Programs (Gould, 2002, para. 7, table 1).

The transition process for students with disabilities usually is guided by special education teachers and rehabilitation professionals. Patton conducted a feasibility study involving employees with disabilities assisting youth transitioning from school to work. One of Patton's considerations for additional research:

> Many teachers and rehabilitation counselors graduate from university-based training programs and proceed directly into positions where they must assist handicapped individuals in preparing for careers. Studies have shown that these professionals are unsure of opportunities in industry and are reluctant to initiate contact with industry representatives. (Patton, 1985, p.3)

Youth with disabilities transitioning from the educational environment to pursue educational, career or independent living goals face tremendous challenges. Responding to these challenges, the vocational rehabilitation (VR) agencies offer services to support persons with disabilities seeking employment. Most of their consumers are adults however "a recent longitudinal study of state VR programs found that approximately 13 percent of all VR clients

are transition-age youth." (Wilson, 2003, p.44) Recognizing that state agencies cannot meet all of the youths' needs,

> RSA (Rehabilitation Services Administration) recently launched an initiative to connect students with disabilities with mentors who have similar disability and who possess the practical knowledge and personal experience necessary to help student effectively transition to adulthood and overcome the attitudinal and environmental barriers that are so pervasive" (Wilson, 2003, p.44)

Research has indicated that mentoring at-risk youth does improve educational attainment. In a Big Brothers/Big Sisters research study conducted in Philadelphia's public schools, one of the benefits to a youth mentee was an increased participation in higher education. This study reported "85% of mentored youth attended college the year after graduation" (Grossman & Johnson, 1998, p. 39) as compared to "64 percent of the comparison group" (p.39).

Employment

Many factors influence an individual's ability to secure employment. Educational attainment is one consideration which has demonstrated a strong impact on employability. In one study,

> only 15.6% of persons with disabilities who have less than a high school diploma participate in today's labor force; the rate doubles to 30.2% for those who have completed high school, triples to 45.1% for those with some postsecondary education, and climbs to 50.3% for disabled persons with at least four years of college (Yelin & Katz, 1994, p.38).

The American with Disabilities Act (ADA) "was signed into law by President George Bush on July 26, 1990. Its purpose it to provide equal opportunities in all aspects of life for America's 43 million people with disabilities." (Dickson, 1995, p. 3). Title One of the ADA addresses situations involving employment of Individuals with Disabilities. Disability

definitions utilized in the ADA have been adapted by other federal agencies for use in collection

of demographic data related to employment.

The disparity in unemployment for people with disabilities is described by the Economics

and Statistics Administration in the Bureau of the Census. "A person is considered to have a

disability if he or she has difficulty performing certain functions, or has difficulty performing

activities of daily living, or has difficulty with certain social roles" (United States Department of

Commerce Economic Status Division Bureau of the Census, 1997, p. 1). The statistics show a

dramatic difference between those with a disability and those with a severe disability. In this

report, a person with a severe disability is defined as someone who "is unable to perform one or

more activities, or who uses an assistive device to get around, or who needs assistance from

another person to perform basic activities" (United States Department of Commerce Economic

and Statistics Administration Bureau of the Census, p. 1)

> In the prime employable years of 21 to 64, for example, 82 percent of people
> without a disability had a job or business compared with 77 percent of those with
> a non-severe disability, and 26 percent of those with a severe disability (p.1).

This report further describes how an individual's limitations factor into employment. Sensory

limitations pose a greater barrier to employment than mental or physical difficulties.

Table 3: Kinds of Disabilities and Employment

Disability (persons 21-64)	Percent Employed (persons might have more than one disability)
Difficulty hearing	64.4
Difficulty seeing	43.7
Mental disability	41.3
Difficulty walking	33.5

Note. (United States Department of Commerce Economic and Statistics Administration Bureau
of the Census, 1997, p. 2)

Therefore, given the data from these two reports, the unemployment rate of individuals

with disabilities far exceeds the national average.

Societal attitudes could be another factor influencing employment. "It is interesting to note that the term dis-ability, literally "lacking ability," suggests an implicit human capital perspective on the nature of the problems facing persons with a disability" (Potts, 2005, p.21). When employers consider applicants, they evaluate the match between job requirements and abilities. This is just another factor contributing to the need for interventions for youth with disabilities to learn how to self-advocate and strive towards post-educational goals.

Why Mentoring?

Adult mentors have shared their experiences and knowledge with a younger mentee throughout history. A relationship is developed which helps to guide and motivate the mentee through new experiences or challenges. "Mentoring is a fundamental form of human development where one person invests time, energy, and personal know-how assisting the growth and ability of another person" (Shea, 2002, p.3). The term mentor is associated with advisor, coach, role model, and peer supporter. "The mentor relationship requires a high level of involvement, commitment and time leading to linkages at a deeply personal and professional level, and it extends well beyond the initial interaction" (Whelley, Radtke, Burgstahler, & Christ, 2003, p.43).

> History and legend record the deeds of princes and kings, but in a democracy each of us also has a birthright, which is to be all that we can be. Mentors are the special people in our lives who, through their deeds and work, help us to move toward fulfilling that potential (Shea, 2002, p.3).

Today, mentoring occurs throughout society. The relationships are formed through formal programs in schools, workplaces and community programs. Informal mentoring relationships develop through family, friends, churches, sports and extracurricular activities. Mentoring has become a growing trend in the workplace. Teachers, nurses, architects and other professionals form mentoring relationships to transition to a new position or encourage career progression.

Mentoring is sometimes intermingled with definitions of coaching and role models. Mentors blend the roles of advisor, counselor, coach, role model and peer supporter. Coaching usually includes skills instruction and encouragement, such as sports coaches. Educators, health professionals and agency administrators serve as advisors in their area of expertise.

Role models are perceived by the individual as "an object of admiration, emulation and respect" (Whelley, et al. 2003, p.44). Mentors who become role models for youth with disabilities "succeed because of the emotional attachment that is formed" (Whelley, et al. p. 45).

> When the mentees are "able to observe people with similar disabilities as they successfully pursue education and careers that might otherwise have been thought of as impossible. In these instances, the role model is expanding the perceived range of careers considered possible by young people with disabilities." (p.45)

Peer supporters "can serve some of the same critical functions as mentors." (Whelley, et al. 2003, p.45) Peer relationships are perceived as less threatening therefore "there is an increased likelihood that communication, mutual support and collaboration will naturally occur." However, peers lack the experience that an adult mentor can provide.

> Research clearly indicates that Mentors play a critical role in the lives of youth and that having a positive relationship with a caring adult can be a critical factor in helping youth rise above difficult life circumstances to lead healthy, fulfilling and successful lives" (Snowden, 2003, p. 40).

The outcomes of mentoring programs for special populations have attracted the attention of national leaders.

> Over the past decade, tremendous strides have been made in documenting the success of mentoring. The National Mentoring Partnership, Secretary of State Colin Powell and America's Promise have all made extraordinary efforts in bringing mentoring to the fore of the nations' consciousness as the premier way to serve youth" (Snowden, 2003, p. 40).

In 1904, Big Brothers and Big Sisters created a mentoring program for disadvantaged youth which is now the largest worldwide, formal mentoring program (Tierney, et al. 1995). Since the 1980's many youth mentoring programs have developed and grown. Momentum

increased with the President's Summit on the Future of America. The United States brought

national attention to the mentoring movement in 1997, whereby summit attendees encouraged

mentoring programs for at-risk youth (Axelrod, et al. p. 1-3).

President George W. Bush brought additional attention to mentoring and proposed funding

for mentoring children of prisoners in his State of the Union Address on January 28, 2003.

> Tonight I ask Congress and the American people to focus the spirit of service and
> the resources of government on the needs of some of our most vulnerable citizens
> -- boys and girls trying to grow up without guidance and attention, and children
> who have to go through a prison gate to be hugged by their mom or dad.
> I propose a $450-million initiative to bring mentors to more than a million
> disadvantaged junior high students and children of prisoners. Government will
> support the training and recruiting of mentors; yet it is the men and women of
> America who will fill the need. One mentor, one person can change a life forever.
> And I urge you to be that one person. (The White House, 2003, para. 30)

In response to President Bush's statements, Geoffrey T. Boisi, chairman and co-founder of

MENTOR, highlights the need for volunteers willing to get involved in a mentoring relationship.

> The President's goal of matching an additional million children with mentors
> would be a tremendous stride forward in our efforts to close the mentoring gap.
> The President's words also affirm the importance of high-quality mentoring
> programs that provide training and support for mentors. MENTOR estimates that,
> of the 17.6 million young people who need mentors, approximately 2.5 million
> are in formal, high-quality mentoring relationships – which means that 15 million
> young people still need mentors (National Mentoring Partnership, 2003, para. 4).

President Bush continued his support of mentoring in the United States by proclaiming

January, 2006 as National Mentoring Month.

> During National Mentoring Month, we recognize the many individuals who
> dedicate their time, talents, and energy to help children develop character and
> integrity. (The White House, 2005, para. 1)
> Mentors are soldiers in the armies of compassion, sharing their time to help
> provide a supportive example for a young person. Mentors help children resist
> peer pressure, achieve results in school, stay off drugs, and make the right
> choices. Many people become mentors because of the impact of a mentor in their
> own lives, creating a chain of compassion over the course of generations. (The
> White House, 2005, para. 2)

I, GEORGE W. BUSH, President of the United States of America, by virtue of the authority vested in me by the Constitution and laws of the United States, do hereby proclaim January 2006 as National Mentoring Month. I call upon the people of the United States to recognize the importance of mentoring, to look for opportunities to serve as mentors in their communities, and to observe this month with appropriate activities and programs (The White House, 2005, para. 6)

National attention to the mentoring movement addressed the needs of many populations which might benefit from this type of intervention. Mentoring programs often have more youth wanting to participate than available mentors. Recruiting efforts could be strengthened if the mentors had a clear understanding of their involvement. Additionally, mentoring program support staff would also benefit from an understanding of all facets of mentoring participation.

In 2005, MENTOR, which is the National Mentoring Partnership, conducted national poll on the current state of mentoring. The key findings were as follows:

- 3,000,000 adults have formal one-to-one mentoring relationships with young people; an increase of 19% since 2002.
- 96% of existing mentors would recommend mentoring to others.
- 44 million adults who are not currently mentoring a young person would seriously consider it.
- While the average mentoring relationship lasts 9 months, 38% last at least one year
- The majority of mentors are willing to work with youth in unique or difficult situations, including children of incarcerated parents, youth with disabilities and immigrant youth (National Mentoring Partnership, n.d. (b), p.ii).

Mentoring youth in special situations such as children of immigrants or mentee's in the juvenile justice system are addressed in the Special Populations section of the report, Mentoring in America, conducted by the National Mentoring Partnership. This is the only area of the report which speaks to individuals with disabilities. Two categories, special education and physical disability relate to this study. Mentors surveyed were asked if their mentee was in this situation category and if they would be willing to mentor a youth in this situation. For

example, 24% of respondents mentored a youth with a physical disability and 83% indicated

they would be willing to do so (National Mentoring Partnership, n.d. b).

<center>Why Mentoring for Youth with Disabilities?</center>

At-risk youth and special populations, such as children of prisoners and youth with

disabilities, are examining the factors which contribute to successful outcomes. The long-term

goals of a mentoring program are to improve the lives of youth with disabilities though shared

experiences with peers and adults with disabilities, such that youth will build self-esteem,

independent living, leadership, education, and career development. The adults who guide a

youth's life include family, educators, VR counselors, and medical staff. Each adult has a

different role and responsibility to the youth. As primary caretakers, family members provide for

the daily needs, financial support and some advocacy when time and energy permits.   Educators

focus on the academic progression, while medical staff on health matters. "Most vocational

rehabilitation (VR) counselors act as advisers to their clients and are not able to make the time

commitment to one student to be a mentor" (Whelley, et al. 2003, p.49).

> Long-term mentoring relationships have been known to be highly effective in
> assisting individuals with disabilities to excel in education and employment, as
> the mentor is personally vested by providing a nurturing and stimulating
> relationship conducive to personal and professional growth (Whelley, et al. 2003,
> p.43).

Many transition programs provide training to improve specific skills. "On a daily basis,

students with mild disabilities confront social and academic difficulties with teachers and peers

in the general education setting" (Campbell-Whatley, 2001, p. 212). Solutions to these

challenges require unique attention and need to be customized for each individual. Youth who

are matched with an adult and develop a relationship during this time of transition, are exposed

to additional opportunities. "Youngsters participating in mentoring programs have higher self-

<center>20</center>

esteem, higher grade point averages, better attendance and fewer suspensions" (Campbell-

Whatley, 2001, p. 211).

Many of us have experienced the benefits of networking. The ability to connect with

through networked introductions often reveals opportunities for career and social development.

"Disabled individuals do not have well developed networks in business, particularly in

connection with successfully employed disabled persons" (Patton, 1985, p.4). However,

mentoring helps to build relationships thus developing their social capital and social networks.

The "concept of social capital as a key to employment has been largely ignored by those

assisting persons with disabilities to find employment" (Potts, 2005, p.22). Furthermore, "if

disability narrows the set of jobs one is qualified to fill, then having the right channels of job

contacts to get access to that smaller set of job opportunities may be even more crucial to

employment success" (Potts, p.22). Mentors serve a vital role in building social capital.

"Building and maintaining social relationships requires interaction with people" (p.23).

Development of social capital (networking) is important to employment success. As the

common expression affirms, "It's not what you know, but who you know!" "Social capital is the

set or network of social relationships by which most people find employment" (p.21).

Additional considerations must be evaluated for youth with disabilities participating in a

mentoring program. "A major goal of transition is for the youth to understand and be able to

discuss their disabilities" (Sword & Hill, 2003, p.17). Accommodations, academic limitations,

social complexities, and disclosure are a few areas of consideration for a mentoring relationship

(2003). Sword and Hill discuss how mentors influence mentees employment options. "Mentors

and employers learn about the students' capabilities in spike of any disabilities they may have.

This, in turn, prepares youth to be part of the future workforce, and gives employers a potential

solution for labor market issues" (p.15). Thus, mentoring can be a dynamic catalyst for the

achievement of transition goals. Mentors with disabilities are called upon by mentees with

disabilities for specific support.

Funding opportunities and programs have been developed due to some national responses

to the needs of youth with disabilities.

Disability Mentoring Day began in 1999 with fewer than three-dozen student
participants as part of a White House effort to increase the profile of National
Disability Employment Awareness Month (NDEAM), celebrated every October.
In 2005, 9,000 youth with disabilities participated nationally and in 20
international locations (United States Department of Labor Office of Disability
Employment Policy, n.d. para. 3).

Partners for Youth with Disabilities (PYD) began in 1983 to form mentoring relationships

between youth and adults with disabilities (Axelrod, et al. p. 1-4). Originally developed for face

to face and group mentoring, PYD has expanded its programs to include the development of a

web-based electronic communication portal. PYD received funding in 2001 to pilot electronic

mentoring from the U.S. Department of Commerce, National Telecommunications and

Information Administration, and the Technology Opportunity Program (Axelrod, et al. p. 1-5).

PYD uses a multifaceted approach to recruitment of mentors, including
advertising though disability-related publications; networking with state agencies,
schools, hospitals, human service agencies, independent living centers, VR
commissions, and others; presenting information at statewide conferences; and
through direct mail campaigns. Youth and mentors go through the application
and screening process to enable PYD staff to make the most appropriate matches
(Snowden, 2003, p. 40).

Mentee Benefits

Research indicates the effectiveness of mentoring programs to assist youth with the

successful transition to adult life. The benefits to youth who develop a relationship with an adult

mentor vary based upon the duration of the mentoring relationship, the mentor-mentee match

process, and many other factors in the process. A closer look at some mentoring research

discloses similarities and differences in the benefits reported.

The largest national mentoring program, Big Brothers, Big Sisters, reports the benefits for the youth participants are:

- 46% less likely to begin using illegal drugs;

- 27% less likely to begin using alcohol;

- 52% less likely to skip school;

- 37% less likely to skip class;

- More confident in their schoolwork performance;

- Able to get along better with their families. (Tierney, et al. 1995, Results Section)

Group mentoring offers the opportunity of mentoring to more youth when volunteers are in short supply. A 2002 study of three group mentoring programs evaluated the benefits and challenges of this type of mentoring experience. "One very important benefit, and one most often cited by youth and mentors, is improvements in social skills." (Herrera, Vang, & Gale, 2002, p.5) The youth and mentors reported improvement in relationships with other people in their lives such as teachers, parents, and peers.

The benefits of mentoring youth with disabilities are not as well documented. Joanne Wilson, Commissioner Rehabilitation Services Commission reports,

> My own experiences, research and the successes of mentoring programs around the country demonstrate that mentoring is effective in helping youth with disabilities gain confidence, increase their academic performance a obtain experience in the workplace – all of which lead to increased opportunities to find meaningful employment and independence for these students. (Wilson, 2003, p.44)

Mentor Benefits

Research from the mentor's perspective includes analysis of formal and informal mentoring, youth mentoring, and organizational mentoring. Mentors demographics, motivations, and benefits are considered. In most of this research, discussion does not address disability issues.

Dr. Jean Rhodes article, "What's in it for Mentors?" researches the mentor's perspective. She asks, "Do volunteers derive any benefits from mentoring?"

> The potential rewards to mentors are rarely considered in youth mentoring. Instead relationships are conveyed mainly in terms of the mentor selflessly giving to the mentee in a decidedly one-sided relationship. It would be a mistake, however, to assume that mentors stand nothing to gain. In fact, when mentors don't derive benefits, relationships are at greater risk for early termination. One-sided relationships drain mentors of enthusiasm and leave mentees feeling burdened by the imbalance. Alternatively, when mentees see that admired adults find it personally rewarding to spend time with them, they feel a new surge of self-worth and empowerment (Rhodes, 2004, para.1).

Dr. Rhodes refers to Friank Riessman's helper-therapy principle where he states that "people help themselves through the process of being genuinely helpful to others" (Riessman, 1965, p.27). She refers to this as "a form of "cultural capital," that helped them to make sense of their own past (sometimes difficult) experiences and current challenges; gain insight into the day-to-day lives of youth; and develop positive, more reciprocal relationships with youth" (Rhodes, 2004).

In another study by the Commonwealth Fund in 1998, telephone interviews were conducted with 1,504 adults. The participants had mentored at least one person age 10-18 during the past five years through formal programs such as Big Brothers/Big Sisters or local programs and informal mentors. The following are a few of the results (McLearn, Colasanto, & Schoen, 1998):

- Adults are motivated to mentor because they believe the young person needs help (43%), they want to do good for others (27%), and they want to work with young people (17%) (McLearn, et al., 1998, p. 80)

- Formal mentors who received training are more likely than are formal mentors who received no training to teach social skills (85% vs 66%) (p. 80)

- 71% of mentors provide cultural, social or entertainment opportunities that wouldn't normally be available to the youth (p. 79 Table 7)

- 73% of the 1,504 mentors surveyed reported that their experience had had a "very positive" effect on their lives (p. 81 Table 8)

- 91% stated that they are likely to recommend mentoring to a friend, with the majority stating this is very likely (59%) (p. 81 Table 8)

- Amount of contact – on average about 10 hours per month - 62% talking on the phone, 4% communicate with email (p. 77)

The survey conducted by the National Mentoring Partnership entitled, Mentoring in America 2005, asks one thousand adult mentors about their motivation and satisfaction thus further reinforcing earlier studies.

- 82% want to help young people succeed
- 76% want to make a difference in someone's life
- 43% want to give back to the community
- 96% would recommend mentoring to others
- 33% non-mentors would consider mentoring on-line (National Mentoring Partnership, n.d. (b), p.8)

Mentors who work with youth with disabilities have a limited voice in the publications found by this researcher. The experiences of mentors and mentees with disabilities need further attention.

<div align="center">Types of Mentoring Programs</div>

Mentoring programs require different resources and have different geographic limitations, therefore various models or combinations of the models are developed. In each model the mentors and youth develop their relationship over a defined period of time with a focus on social skills, academics, independent living and/or career goals. Youth may be matched with an adult or peer mentor.

Face to face communication is the traditional definition of mentoring. Mentors and youth meet in person as well as communicate by means of telephone, electronic mail and letters.

Group mentoring involves several mentors and youth participants. Activities may take place at a school, workplace or community organization. In a study examining three group mentoring programs, "Groups range in size from two to 32 youth, but average about 10. More than half of group mentors work with at least one other mentor on a team" (Herrera, et al. 2002, p.3).

Employment based mentoring programs match a veteran employee with an employee who is learning new skills or interested in developing their career.

Electronic mentoring also known as e-mentoring or telementoring, is becoming a popular model for youth programs. Youth communicate with their mentors via email, list serves, chat rooms or instant messaging. The benefits of electronic mentoring include increased communication, improved educational outcomes and increased employment opportunities.

Geographic, time and transportation barriers from traditional mentoring models are minimized with technology. "Adult mentors and youth protégés will be able to email 24 hours a day, seven days a week, now matter where they are, so long as they have access to a computer" (National Mentoring Partnership, n.d. (c)).

> Computer-mediated communication (CMC), where people use computers and networking technologies to communicate with one another can connect people separated by time and space who might not otherwise meet. The removal of social cues and social distinctions like disability, race and facial expression through text-only communication can make even shy people feel more confident about communicating with others. Adaptive technology makes it possible for anyone to participate in CMC regardless of disability. The combination of adaptive technology and Internet communication can help overcome the geographic, temporal, and disability-related barriers to establishing peer support groups. There is some evidence that CME can reduce social isolation and allow independent access to information resources. With CMC, it is not uncommon for a student who cannot speak with his voice to become the most vocal in a conversation. One participant notes that he appreciates that this type of communication "kinda hides what type of disability you got" (Burgstahler, 1997, Section Computer Mediated Communication).

Geographic boundaries and participant time constraints are noted as barriers to face-to-face mentoring. Many volunteers and youth are balancing family responsibilities and career/academic obligations. This contributes to the amount of time they can dedicate to a mentoring relationship. Access to a computer eliminates the geographic and time boundaries, thus providing the opportunity for supplementing communications between the mentor and youth.

Positive educational outcomes and use of technology are expected to increase future employment and earning opportunities. Access to technology "can provide students and teachers with a large body of easily accessible information; create opportunities to reinforce learning basics, new and higher-order cognitive skills' and increase student interest and motivation" (Eamon, 2004, p. 93).

Furthermore, technology has transformed communication methods in the community. Youth who lack access to or skills in using IT such as electronic mail, instant messaging, listservs and chat rooms are at a social disadvantage. Youth have found electronic mail and instant messaging an appealing method of communication.

Blended Model of mentoring This study focuses on the relationships from mentoring programs using a combination of electronic mentoring and face to face communication.

Additional considerations must be evaluated for youth with disabilities participating in a mentoring program. A major goal of this time of transition needs to be understanding of disability issues. Disability awareness and management need to become part of the program. Mentors need to be prepared to address potential barriers or limitations of the youth. Resources for accommodations, such as interpreters or transportation may need to be addressed (Sword & Hill, 2003)

Mentoring Programs

Many mentoring programs serving youth with disabilities combine/blend multiple types of mentoring activities to maximize the benefits to both youth and mentors. Program descriptions resulting from this research:

Partners for Youth with Disabilities (PYD), Boston has received funding from the U.S. Department of Labor's Office of Disability Employment Policy to act as an intermediary organization that will provide support to community-based organizations throughout the country that are starting, sustaining or expanding mentoring programs for youth with disabilities. Partners for Youth with Disabilities program provides a monitored network for youth to communicate with peers and mentors across the country (Axelrod, et al. 2005). PYD's mentoring model has been replicated in Illinois, Washington D.C., New York, and California. PYD is a national leader in the field of mentoring youth with disabilities and has received the following acknowledgements:

- 2005, Citizens Bank and New England Cable News selected PYD as a Champion in Action. This prestigious honor comes with $25,000 in unrestricted funding and publicity from NECN

- 2005, The Boston Foundation and the Boston After-School for All Partnership awarded PYD its Best Practices Award in Teen Programming in the Category of "Caring Adults."

- 2001, PYD Mentor Match Program awarded Grand Prize by the National Organization on Disability (NOD) for the NOD/United Parcel Service Community Service Awards (Partners for Youth with Disabilities, n.d.)

Other programs which were evaluated for this research were Check and Connect (Check & Connect, n.d.) located at the University of Minnesota and the DO-IT program at the University of Washington in Seattle (Do-It, n.d.). The Check & Connect program at the University of

Minnesota has specifically researched and targeted the needs for youth with disabilities. This program coordinates activities between mentors and youth in the school system and additional individual interventions as needed (Check & Connect, n.d.).

Disabilities, Opportunities, Internetworking & Technology (DO-IT) was initially funded in 1992 by the National Science Foundation to increase participation of students with disabilities in higher education, DO-IT has been recognized for its innovative program. Mentors are matched with mentees with similar disabilities. Most mentoring takes place via electronic communications and projects using the Internet, discussion groups with common concerns. "Scholars also practice disclosing their disabilities as well as negotiating and testing the effectiveness of adaptive computer technology and specific accommodations in job settings" (Kim-Rupnow & Burgstahler, 2004, p. 2).

CHAPTER 3

METHODOLOGY

The purpose of this study was to describe the lived experiences of adult mentors who have mentored youth with disabilities. To accomplish this objective, qualitative methods were utilized. This chapter provides the methodology for multiple participant interviews. The data collection process involved recorded interviews, which required some accommodations. Data analysis utilized the comparative method (Rubin & Rubin, 1995). Each interview was repeatedly reviewed for connections between the participants' responses thus illuminating common themes. The study results will contribute to the discussion of mentoring program development and support for mentors of youth with disabilities.

Every mentoring relationship is unique; however description of their experiences provides factors for consideration for program development, volunteer recruitment, training and on-going support. Mentoring program administrators can evaluate these mentor's experiences as they develop supporting programs. Additionally, the results will provide adults considering volunteering to mentor a window for consideration of this commitment.

Qualitative Design

This study utilizes a qualitative design to expand understanding of the mentoring relationship from the perspective of the adult mentor. Conversational interviews allowed for a comfortable atmosphere which created an open exchange of viewpoints. Guiding questions provided a framework to address the researcher's questions. As the participants' reflected upon their lived experiences, they provided insight to the researcher. The researcher explored emerging questions. Sensitivity to the mentor's willingness to participate and individual situation was also a consideration during the interviews.

Population and Sample

The researcher evaluated mentoring programs across the United States which specifically offered programs for youth with disabilities. Some of the criteria for program evaluation included accessibility and cooperation of program staff, duration of program operation, types of programs offered, and recognition within the community.

Partners for Youth with Disabilities (PYD) program was selected for this study because the staff graciously offered to cooperate and assist with the research; PYD has sustained their mentoring programs for over 25 years; PYD has been nationally recognized; and has incorporated many successful program elements to serve youth with disabilities. In the past few years, PYD developed a blended mentoring model which includes face-to-face activities as well as a secure, monitored online community. Partners Online not only facilitates communication between adult mentors and youth participants, but between parents, peers and partner programs. Features include chat, discussion forums and mail which are completely accessible (Section 508-compliant) for users of assistive technology.

The researcher met program administrators during an association conference years ago and continued an on-going discussion about replication of their program in Louisiana. Several telephone discussions and e-mail messages generated the foundation for research inquiry. A formal e-mail inquiry to the mentoring program administrators requesting permission to participate in this project was sent along with a follow up telephone call to clarify the research objectives and methodology. PYD agreed to post an invitation to mentors on their internal website and facilitate introductions to the researcher.

The accessible population for this study included five adult mentor volunteers. Mentors were recruited from the mentoring program, Partners for Youth with Disabilities (PYD), for participation in this research. The criteria for participant selection included:

- Active with PYD within the period of 2004 – 2006
- Have mentored a youth for at least one year
- Utilized the blended mentoring model (face-to-face and online communication).

Informed Consent

The internal review board of Louisiana State University and A & M College granted approval to conduct this study (IRB # 3388). There is no known risk for participation. Participants received a copy of the informed consent provisions through electronic mail and were verbally advised of their role in participation.

Confidentiality

Interviews were conducted in a manner which provided utmost confidentiality and sensitivity for the participants. Audio tapes and transcriptions were securely maintained by the researcher. For referencing purposes, alias identification replaced actual names of participants and any persons referenced in their interview.

How Mentors Were Recruited to Participate?

Partners for Youth with Disabilities (PYD) posted an invitation on their internal web site in the format of an e-announcement to all mentors. The announcement included a brief description of the research project. Mentors were asked to respond to the researcher with their email address and telephone number. (See Appendix C)

The e-announcement solicited two participants. The remaining three participants were obtained by networked introductions. An administrator introduced the researcher to two participants at the National Conference in Boston. The final participant was an administrator herself who had mentoring experience.

Data Collection

Guiding questions (Appendix A) were developed to by the researcher to capture and describe the experiences of mentors. These questions were developed to initiate a discussion and

stimulate an open discussion about the mentoring experience. Questions were grouped to correspond with research objectives.

To verify content validity, a draft of the questions was distributed and evaluated by the Genelle Campbell Thomas, PYD, Director of National Initiatives and Strategic Partnerships and Dr. Krisanna Machtmes, Assistant Professor of Human Resource Education and Workforce Development.

Guiding Questions

Demographic Background information (Table 4) was gathered through the conversation about the gender, age, employment, academic background and disability of the mentor. The guiding questions were used as conversation starters. As the participants shared their experiences, often their response would answer more than one question.

Guiding questions related to four areas of interest:

1. Describe the how the mentor became involved with the mentoring program.

    a. Tell me about how you became involved as a mentor.

    b. Who did you talk to when deciding whether or not to participate?

    c. What were your expectations?

2. Describe the characteristics and process of matching mentors with a youth.

    a. What characteristics do you have in common with the youth protégé?

    b. How do you feel adults and youth should be matched for long-term relationships?

3. Describe mentor's experiences from participating in a mentoring program (training, support, activities).

    a. What support and preparation did you receive as a mentor?

    b. What activities did you participate with your youth mentee?

    c. How much time per month do you spend mentoring?

d. Do you email, phone and/or have face-to face meetings with youth?

e. Were accommodations needed to facilitate this relationship?

f. How did you arrange for these accommodations?

g. Did you talk about disability management, disclosure?

4. Describe the mentor's benefits/challenges of participation.

a. What was the most rewarding about being a mentor?

b. What were the challenges?

c. What would you say to someone considering volunteering to participate as a mentor?

d. Would you volunteer again?

e. Is there anything else you would like to tell me about your mentoring experience?

Participant Interviews

After mentors were identified for participation, three telephone, one face-to-face and one electronic (instant messaging) interviews were scheduled. Each mentor was electronically contacted with the date, time, confirmation of telephone number, communication accommodation clarification and a copy of the informed consent documentation. They were also informed that a second contact might be scheduled, if further clarification warranted. Accommodations were arranged to facilitate communication with mentors unable to access the telephone.

All participants were informed of the interview protocol and that the conversation would be recorded to develop a transcript. Additionally they were offered the option to end the interview at any time. Each interview required individual attention to schedule and facilitate to be described in the analysis section. While interviewing the researcher took notes and audio-recorded the conversation. Transcripts were completed within a few days of the interview in the

privacy of the researcher's home office. This allowed for reflection of the conversation and

insight into the experiences of each relationship. Participants' and persons named by the

participant received alias identification. Participants received an electronically mailed copy of

the transcript for their review. Only one participant submitted edits to the transcript which were

grammatical and not content related. Transcripts were sent to the major professor for review and

input.

Data Analysis

Each interview transcript was analyzed to extract demographic data (table 4). This data

was not asked directly but gathered conversationally. Background data such as gender and

approximate age of both the adult mentor and youth mentee was straightforward. Information

about the duration of the mentoring relationship required some calculation, such as subtracting

the age of the youth now from their age when first matched. It was the conscious decision of this

researcher to describe the mentor's and mentee's disability only if they included information in

their responses which would indicate a description. In all five interviews, some description of

disability characteristics was provided for the mentor and youth.

Each transcript was reviewed repeatedly. Demographic data was extracted and

summarized in a table. Responses to the guiding questions were organized by question and

participant response. Each interview was summarized along with the researchers perceptions of

the environment. As themes emerged, statements which contributed to the theme were

highlighted.

The five interviews were analyzed for re-occurring themes using the comparative method.

Emerging themes and their implications were described with all receiving equal attention to the

significance of the contribution.

CHAPTER 4

ANALYSIS OF THE DATA

The purpose of this study was to describe the experiences of adult mentors who participated in a mentoring program for youth with disabilities. Five mentors participated in qualitative interviews with researcher developed guiding questions to generate discussion. The process of data analysis began with verbatim transcription and repeated review of the transcripts by the researcher. Each transcript was read and reviewed multiple times which provided the researcher with insight to organize the data and become familiar with each response. Some responses were applicable to multiple questions. Some spontaneous participant responses were not relevant to that specific question however contributed to their description of this experience.

This chapter will introduce the reader to each participant. I answered any questions they asked me about my research and affiliation with PYD. My intent was to generate a comfortable, friendly conversation which was sensitive to respecting the duration of the interview and clues indicating closure of the topic. All of the participants were eager to share their experiences.

All five mentor participants had more than one year of experience as a mentor for PYD. Several mentors had more than one experience mentoring a youth. Two mentors had been mentored prior to volunteering themselves.

Responses to each of the guiding questions are organized with responses. Due to the conversational nature of the interview, some questions were not asked because previous responses addressed the issue.

Guiding Questions with Participant Responses

1. Describe the how the mentor became involved with the mentoring program.

    a. Tell me about how you became involved as a mentor.

Todd: As a child I was on the waiting list for Big Brothers/Big Sisters and never received a mentor. There were some disabilities in my family, so I needed somebody I could relate to. When I was twenty, I had a car accident. It was severe. They gave me a small chance of living. I had to learn everything all over again. I had a spinal cord injury so I could not do much for a long time. In the hospital they did everything for me. Towards the end of rehab I made a phone call to the Independent Living Agency. That was the beginning of my mentoring experience. I was matched with somebody who ended up having the exact same injury as me. At first I didn't think a similar disability was a big deal. I would have taken help from anybody because I was so sick. I just wanted to go back to being independent, but did not think that was a possibility till I met him. I was especially unsure of what I was capable of and he was in a similar situation. At the time I was not comparing myself, but to see someone with the same injury maintaining their independence was encouraging. Because if I did not meet him, I would not believe on my own that I could be independent. The idea of listening well, withholding judgment, and being a role model goes a long way in relating to others and my mentor taught me that. (Todd's mentor was with him five years.) He was there every step of the way. He saw me get my first apartment. He gave me advice about how to stay independent. I did not take all of his examples but it was a blessing having someone to compare notes with. Most of my life I felt like I was alone but it was heartening to know there was somebody I could call.

I kinda wanted to be a mentor anyway. I was the youngest in my family and feel I have a lot to offer to kids. I was working in the same building and I heard about them (PYD). I think it's a big deal mentoring specifically for disabilities because it's hard to find people to relate to on a peer level. Like most of the non-disabled people are big on sympathy and stuff. Just to somebody to relate to as a peer.

Gary: I was a mentee first. George Donahue was my mentor. So when I was old enough, I wanted to be a mentor to a little kid like George was to me.

Lucy: In this area, everyone knows everyone and the director asked me to come to a workshop. Partners asked me to speak at a parents meeting. One of the parents thought that I would be a good mentor for her daughter.

Jean: I was directing a program called the "Young Entrepreneurs Project"and through that project we taught business skills to young people. We taught them entrepreneurship skills knowing that those skills were transferable to any career. We created an adult ed program and we also hooked up mentees with mentors. One of the young women in the project received a mentor and they had a successful relationship but her mentor moved and because I was the one who had done the original match and I had gotten to know this young woman, about a year later, she wanted a mentor again. So I said I would do it because we had a pre-established relationship, and she had a social services career interest. So that's how that happened.

Sandra: Well, I like working with young people and I made a personal decision a long time ago, before I might have know all the implications of that decision that I would not want to have a child of my own because I did not want my PCA's being my primary caretaker. So I have nieces and nephews, that kind of thing but I don't have as many young people in my life as I might like. I would like to be a mother if that would be possible but it did not seem to be. It didn't feel that is was going to be the type of experience I wanted it to be so that is wasn't for me and actually back when Partners got started – a long time ago – I had a friend who worked for Partners and I would go to things and she would talk to me about Partners. I thought for the longest time that I did not have enough time to do this. I don't have enough time to devote to do a good job. So finally I don't know what changed but I decided if I am going to do this, I am going to do it now so in 1994 or 95 – I am not sure exactly when I applied to Partners. Then I found out that the

person I knew there just left to take another job, then she asked why I didn't start before this –
but I said, I did not know you were going to leave. But any way, that's how and a little bit of
why I got into Partners but I don't remember exactly what year I started and it was awhile before
I got matched.

They interview you and they ask you what age range you are interested in working with. I think
in the beginning I was hoping to get matched with someone a bit younger but I have been happy
matched with Mary and I think we have one of the longest running relationships in Partners. It's
been eleven years now. We did the interviewing and a query check and at first they were going
to match me with someone else but that never worked because the girl who was coming to meet
me – there was a storm and she could not come and meet me. Then she had to have a bunch of
surgeries and so we never did get matched. I never met that person. Then a while later, after I
got a different staff member and everything, the staff member I had left for medical leave, then I
did get matched with Mary. Then a few years ago, I'm not really good on what year, but there
was a year that I was matched with someone else, along with Mary. That did not last as long
because mostly because of where we both lived and our schedules did not match. But I think
that Partners does works intensively to make sure the matches will last. Takes a long time to
make sure the people are compatible and that kind of thing.

(age when matched) She was twelve, and going to be thirteen in 3 weeks

       b. What were your expectations?

Todd: I did not expect anything and I think that's why it is so successful. I started out with the
attitude that I am just there for him and not looking to get something in return. I was just
offering myself in anyway that I could be helpful. To my surprise the mentee that I've had since
2004 – I got hit by a car in my wheelchair and he visited me in my hospital and we listened to
music together. It's not as extensive as my mentorship that I had with the Independent Living

but I'd like to seek out a closer affinity. He's doing great transitioning to adulthood and he has more luck with girls than me. Hence he is not as needy as I was, but I would like to seek out a more challenging mentorship.

It's still nice to know that I can be there if he needs anything.

Gary: Participant did not respond.

Lucy: Well, I thought I would be helpful for a younger person. I thought it might be interesting to do.

Jean: I probably did. I think I thought it would be regular relationship – we'd see each other a lot and be a typical mentoring relationship.

Sandra: I going to give you an answer to your question and you can tell me if it the answer to your question that wanted or if there is a better question down the line. I am not sure exactly what I expected when I became a mentor. It was just I just wanted someone, a younger person to do things with and hang out with. At that time I was working as a peer counselor and I wanted to be able to offer support and guidance to a younger person and I think that kind of expectations did get met. I don't remember if I had some other expectations too. I think that now it might be a little bit more of a challenging time to work with Mary than in the beginning. Now I think I would like to help her – pretty soon she is going to move into her own housing and she is going to college, but a little bit at a time and I would like to help more with her the obstacles that she is going to face and that kind of thing. But sometimes I can't tell when I talk to her how much she is really comprehending and synthesizing what I say. How much she is going to have to learn when she gets there. I think that some challenging times like a few activities, one activity that we did with partners that we sort of both got lost on either side, just didn't turn out to be what either of us expected. I think that sometimes it's challenging because some of us, some of our disabilities are similar and such in way that I don't have a good sense of direction and neither

does Mary. So if you limitation are similar sometimes things happen like you both get lost where you are going or you there was a mix up because of the signs and that kind of thing. You have to be careful that so far both wheelchairs are out of power at the same time. Mary called her nephew to come with the van and stuff like that. Overall, working with Mary has been a joy and I do consider Mary more like a sister than like a mentee person. Anyway, I think that sometimes there are challenges. With the other youth person that I worked with we had challenges because her parents were divorced, my parents are divorce too, because she is younger she was sometimes at her mom's house and sometimes at her dad's house and we had a hard time making our schedules match and we also had a hard time because we live far away from each other and we had a hard time finding activities where we could meet. So we sort of lost touch. We didn't last very long. I hope that I had an impact on her but I'm not sure if we were matched that long to have that much of an impact on her life. That was probably too much information.

2. Describe the characteristics and process of matching mentors with a youth.

Todd: Well, I told them I'd like to find somebody not too far away, preferably with physical disability and also not too young so that I could talk them through things, you know.

The said this kid is 15 minute drive from you but it's different now because I'm in Boston. He is in the suburbs and I was in the suburbs. He has trouble traveling. It's kinda hard to see him. I travel to go see him but it's more of a strain for him to see me.

Yes, then they say, "Here is a couple matches that you might be interested in" or it may be just one good match idea. Then everybody meets together and they talk about the ground rules and all that. The first time it's important to feel it out. Maybe at the first meeting you might decide this is not going to work based upon each person's preferences. But they have the meeting to tell them that they meet once a month and talk once a week and all that. Talk about the ground rules

– no alcohol consumption, etc. so everybody knows what's going on. That's so it starts a meaningful relationship from the beginning. Both know what the expectations are.

Gary: I have two mentees, they are both (have the same name). One lives in Town A, MA and one lives in Town B, MA (Gary was a youth mentee participant at PYD, then became a mentor)

Lucy: She was 12 and I was 28.

Jean: (About the career focused mentoring program) Now it is an inclusion program but at the time it was youth primarily with learning disabilities or behavioral or psychiatric issues.

I would say she was 18. She was a Senior in high school. Now she is about 21. I have to admit as I mentioned in my email, it might be good to have this type of experience because we still talk and communicate but it was not the most rewarding situation, I would say.

I do not have a disability but because of this program with a career focus, we had our mentors with and without disabilities because the common connection was the career interest.

We were matched in 2003 and we still communicate a little bit.

Sandra: (described in a previous question) It was just I just wanted someone, a younger person to do things with and hang out with. At that time I was working as a peer counselor and I wanted to be able to offer support and guidance to a younger person and I think that kind of expectations did get met. I don't remember if I had some other expectations too. I think that now it might be a little bit more of a challenging time to work with Mary than in the beginning. Now I think I would like to help her – pretty soon she is going to move into her own housing and she is going to college, but a little bit at a time and I would like to help more with her the obstacles that she is going to face and that kind of thing. But sometimes I can't tell when I talk to her how much she is really comprehending and synthesizing what I say. How much she is going to have to learn when she gets there. I think that some challenging times like a few activities, one activity that we did with partners that we sort of both got lost on either side, just didn't turn out to be what

either of us expected. I think that sometimes it's challenging because some of us, some of our disabilities are similar and such in way that I don't have a good sense of direction and neither does Mary. So if you limitation are similar sometimes things happen like you both get lost where you are going or you there was a mix up because of the signs and that kind of thing. You have to be careful that so far both wheelchairs are out of power at the same time. Mary called her nephew to come with the van and stuff like that. Overall, working with Mary has been a joy and I do consider Mary more like a sister than like a mentee person. Anyway, I think that sometimes there are challenges. With the other youth person that I worked with we had challenges because her parents were divorced, my parents are divorce too, because she is younger she was sometimes at her mom's house and sometimes at her dad's house and we had a hard time making our schedules match and we also had a hard time because we live far away from each other and we had a hard time finding activities where we could meet. So we sort of lost touch. We didn't last very long. I hope that I had an impact on her but I'm not sure if we were matched that long to have that much of an impact on her life. That was probably too much information.

        a.   What characteristics do you have in common with the youth protégé?

Todd: Well, I think age is an important consideration. Because at each stage of development, kids go though very different things. Like, a seven year old, I'm sure it's obvious to you, would have different goals than a 18 year old. But if somebody does not know a lot about development, for them to say they'll take any age, they might not know what they are getting in to. Compared to a 7 year old and 18 year old. There's very different things on their mind.

So, at first I was interested in somebody older but now I'm more flexible. I tried picking up a new mentee a few months ago and he was 14 and he had cerebral palsy. He had the same thing as my other mentee but this one did not use a wheelchair. It is not my first impression, but I

think that was a barrier between us because he may have had trouble relating to me in some ways. I hate to blame on the disability, but I learned it helps. I don't think he was as comfortable because he's trying to stay walking and me being in a wheelchair may be something he's not ready to relate to.

Gary: With both of my mentees, we like to go bowling, and we like to go to the Red Sox games and we like to do other stuff together.

Lucy: (The mentee) was still growing up. A teenager. We would hang out. Go to the movies, go to dinner or both. We would chat about all kinds of things. School, independence. Both the youth and I have spina bifida. The same disabilities. We both like movies and eating out.

Jean: Well we probably had very little in common. We both live in Boston. We have a similar race – both Caucasian. She was interested in business and social services. That's about it. (knowing this was a career focus match, I explored interests) I wouldn't say hobbies were in common, socio economic status not in common, our upbringing was definitely not in common.

Sandra: Well, we have similar disabilities. I think that is the case of most Partners matches. We love some of the same things and we seem to be pretty compatible thinking of each other's schedules. There are some times when we are both busy and we don't see each other a lot. Then are some times that we see each other 2 times in 8 days or something like that. Because depending upon what we are doing. So I try to keep her updated on the things I am doing and let me know if she needs some support. That is basically what we do now and what we found what works best for us. I don't know if we ever have a weekly time that we called every single week, even in the beginning, but we stay in touch and things work well for us.

I think we find different things we have in common at that we want to do different times. We don't always do the same things. Like next Friday is the Disability Mentoring Day and

something at Partners, I forgot what they call it, but we are going to that. She comes to my house to eat and talk. Or I go to her house to eat and talk or we watch movies or eat lunch or something. Sometimes she likes to do art and I like to do art also. So for last Christmas and people's birthdays, I was doing ceramic type stuff. She came over to do some ceramics near a studio near my house. The nice part about it was for our birthdays I gave Mary something that I made for friends and she gave me something she had done in art class. We did not know that we were going to do that, it just turned out that way. I think that was nice coincidence. Sometimes because the difference in our ages, everything you do in common, you don't have to have everything in common but you just find that you both like OK to do together. Mary and I do lots of different things. Sometimes we go shopping. Or one year we went shopping for Christmas stuff and sometimes we do different things and every once in awhile I forget for what – I think we were at a Peace rally once and there was one time that we just happened to run into each other at the same thing but sometime we don't always know what each other is doing but I think we find enough things that we want to do together that we do together and sometimes when Mary, a lot of years ago when she lived in a rental house she had a pool, so we went swimming in her pool once and then now she is taking swimming lessons again so in a few weeks I might go where she is going swimming so we can go swimming together.   And we both have cats. She came over to meet my new kitten and that kind of thing. One day I went over to her house to cook dinner and spend time with her.

b. How do you feel adults and youth should be matched for long-term relationships?

Todd: (in addition to phone and email) Yeah, but I visit him too though. I visit him more than I should because we are supposed to both invest in this. (if both do not invest) Then it's not a mentorship. It's feeding into disability. For him to not be disabled, he needs to get out and

experience, you know. For me to just go out to him, that's like serving him. It's not helping him

out. He has enough people doing things for him. He has PCA's all the time.

(side note of career-focused match criteria) Only if that is something that the mentee says he

wants to do. Like I mentioned before in the development process. A ten year old may not care

at all about careers. He just wants to have fun. I try to customize every match. Part of my job at

Partners right now is that I look through the files and find out what each person really wants.

What I try to focus on is all the different criteria together, not just one or two things. Age, where

they live, and disability are relevant, but its always flexible…for example if they live far but are

a good match they might meet online or something. I try to give people as many options as

possible. Having them choose what they want is key.

Gary: Having things they like to do together in common. Besides bowling and Red sox, we all

like going to the Science Museum or one time I went to a track meeting with Austin of Braintree

to watch our sisters. I went to the Tall Ships with Austin of Wellesley. I took both of them to

the Quincy Dinner theater to see a funny play.

Lucy: Both the youth and I have spina bifida. The same disabilities. We both like movies and

eating out.

Jean: I know that PYD typically matches people with similar disabilities, but this case this is not

true. I do not have a disability because of this program with a career focus. We had our mentors

with and without disabilities because the common connection was the career interest.

Sandra: They interview you and they ask you what age range you are interested in working

with. I think in the beginning I was hoping to get matched with someone a bit younger but I

have been happy matched with Mary and I think we have one of the longest running

relationships in Partners. It's been eleven years now. We did the interviewing and a query

check and at first they were going to match me with someone else but that never worked because

the girl who was coming to meet me – there was a storm and she could not come and meet me. Then she had to have a bunch of surgeries and so we never did get matched. I never met that person. Then a while later, after I got a different staff member and everything, the staff member I had left for medical leave, then I did get matched with Mary. Then a few years ago, I'm not really good on what year, but there was a year that I was matched with someone else, along with Mary. That did not last as long because mostly because of where we both lived and our schedules did not match. But I think that Partners does a really , works intensively to make sure the matches will last. Takes a long time to make sure the people are compatible and that kind of thing.

3. Describe mentor's experiences from participating in a mentoring program (training, support, activities).

   a. What support and preparation did you receive as a mentor?

Todd: I participated in couple trainings and I go to the events. For me individually and personally, I've had experience mentoring other kids in groups through the "Making Healthy Connections" program. So I learned about what the needs are of kids in transition. He was born with his disability. I learned about others with disabilities at Partners programs, at previous work, and in my studies.

I'm also applying to be the Mentoring coordinator at Partners. I want to help them match people up.

Two people are matched up and they go over personal ground rules and everything. Every few months, the mentors have the option to go to a training to learn more about how to better serve the kids.

(Youth programs) Yes, couple different programs. Making Healthy Connections – very successful program and I was happy to be a part of it because the kids learn from each other and

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exposed to many different topics. The guest speakers also contribute and are usually themselves people with disabilities or in the field. Thus, the kids learn from all different people and not just their mentor. There are all the different possibilities, like driving and learning about speaking up about themselves – from advocacy to talking to their doctor. Basically trainings about being independent. A lot of kids with disabilities used to having their parents speak for them. Their parents also have their own meeting. They can learn how to be better parents for the kids and let them have control of their lives.

The parents have guest speakers too. A lot of times the same person that speaks to the kids also speaks to the parents. ½ and ½, but the parents have their own meeting with other parents. The kids meet with other kids with disabilities. There are 2 facilitators. Our job is to find guest speakers to come in and talk about different topics.

Another program is the Youth Leadership Forum. Many kids that participate end up being candidates for the youth forum.

That's where kids try to become leaders and …..I'm sure you know about it.

Gary: Actually, I think the best training for me, was my John. He was my mentor and I am copying what he did for me.

Lucy: No, we did not do any of the PYD stuff actually. We did not go to the parties

Jean: I did not take the training because I ran the training.

(Mentee's involvement in PYD activities) Not any more. She's older now.

Sandra: Now more than in the past, or maybe it was in the past but I don't remember, about once a year or once every 6 months someone calls me up and says, "what are your goals, long-term and short-term goals?" Sometimes I get frustrated because my goal working with Mary is to let her know that I am around and to make sure that I have met my expectation for her are realistic so that when she faces, even if we are not matched any more, because she is getting

older and technically we might not be considered matched or not but I try to stay in her life. But I don't know if technically they will keep us matched because she is 23 now. They (PYD) stop the matches before that I think. I want my expectations to be realistic because I know that she is coming into a time in her life where is she does successfully move out of her parents house it's going to be very different for her and sometimes I think I have more perspective than some of her other case managers working with her. I get a little nervous for her as she makes this transition. I don't often know what her goals are because we don't talk like that when she comes over. And so I don't know if I have all the information to answer all the questions . And I sometimes don't know, I mostly just follow Mary. But I don't know when I am supposed to ask anybody at Partners anything. I think the conference was a good thing, I really wanted to go to the conference it was a good thing to get different people's experiences from different states and stuff. On what they had done and that kind of thing but is hard to know how to put in practice with Mary. Because she will ask me things like having PCA's is stressful. That is what she was talking yesterday and I was like, yeah, well if you are going to live on your own, your are going to need more PCA's that you have now because your mom and dad are not going to be around to help you as often. And so, even if you live close to them. So I think that she listens to me but I don't know how she took it in and digested it or something. It is hard to know how much of an impact I am having on Mary because we are very connected and we want to stay that way. So but I don't often know how much support I am supposed to expect from the staff at Partners and what that support is and how to access and it might be just as much my problem as it is their's, I just don't know when to ask for help sometimes.

b. What activities did you participate with your youth mentee?

Todd: I don't expect him to come all the way to Boston but I could meet him at a movie theatre or something. That's something we need to work on. Part of the reason it's not working is

because he's real concerned about money, and traveling is added cost. I could present the

problem to Partners and they might be able to pay for transportation but it's only a few dollars

for transit and he should put that in his budget if he wants a successful mentorship.

I was there to support him when performed in plays. I went to watch him in plays but after those

events he chose not keep up the relationship. So, the more exposure I have to disability the more

I feel like similar disabilities are relevant to successful pairing

Gary: With both of my mentees, we like to go bowling, and we like to go to the Red Sox games

and we like to do other stuff together.

Lucy: Go to the movies, go to dinner or both. We would chat about all kinds of things. School,

independence.

(For twelve years) Yes, on and off. I do find that I have to do most of the work to keep in touch.

We do stuff with her family sometimes or with her relationship with her sister sometimes. We

talk about what classes she was taking. She was diagnosed with a learning disability, and there

were some issue with that, so we talk about that.

I tried to bolster her mom. It is very clear to me that educators are clueless when it came to

knowing about living with a disability and independent living. They don't understand how

people look at you. The youth was talking about what it's like when you walk in the room and

how people look at you. The special education teacher said that she was not aware that people

looked at you differently. I think that somewhere in special education training there would be

some discussion about stigma. What kids can do when they are stared at and deal with peoples'

reactions.

Jean: We ended up meeting a couple of times. The initial time we went out to lunch in Boston

Common. We walked around and then went to lunch. After that she continually cancelled and

no showed so it ended up being a phone and email relationship.

Sandra: I think we find different things we have in common at that we want to do different times. We don't always do the same things. Like next Friday is the Disability Mentoring Day and something at Partners, I forgot what they call it, but we are going to that. She comes to my house to eat and talk. Or I go to her house to eat and talk or we watch movies or eat lunch or something. Sometimes she likes to do art and I like to do art also. So for last Christmas and people's birthdays, I was doing ceramic type stuff. She came over to do some ceramics near a studio near my house. The nice part about it was for our birthdays I gave Mary something that I make for friends and she gave me something she had done in art class. We did not know that we were going to do that, it just turned out that way. I think that was nice coincidence. Sometimes because the difference in our ages, everything you do in common , you don't have to have everything in common but you just find that you both like OK to do together. I don't think that, …Mary and I do lots of different things. Sometimes we go shopping. Or one year we went shopping for Christmas stuff and sometimes we do different things and every once in awhile I forget for what – I think we were at a Peace rally once and there was one time that we just happened to run into each other at the same thing but sometime we don't always know what each other is doing but I think we find enough things that we want to do together that we do together and sometimes we .. or when Mary , a lot of years ago when she lived in a rental house she had a pool, so we went swimming in her pool once and then now she is taking swimming lessons again so in a few weeks I might go where she is going swimming so we can go swimming together. And we both have cats. She came over to meet my new kitten and that kind of thing. One day I went over to her house to cook dinner and spend time with her.

        c.   How much time per month do you spend mentoring?

Todd: Lately I have been trying to make more of a commitment because like for awhile he was independent with everything but he is 24 now – but he does not have much family and most of

his time is with his PCA. So recently I been spending a few hours a month visiting him but before that it was every few months.

We mentioned about both people investing, but I on a side note, as long as I keep the attitude that I am there for him, it makes it a lot easier to be a mentor. For example, I'm not looking out to see what I'm doing this weekend. I try to think on his behalf. I picture the mentoring relationship with him in the driver's seat. If he wants to go a few months without, then that's fine with me. I'm letting him direct. I worked in Independent Living for a couple years. I learned about the importance of giving people choices. I don't get discouraged if he is not in a big hurry to see me. I go at his pace. I try to keep the idea of consumer directed in mentorships as well as Independent Living. That's how it works for me when I was being mentored. The most important thing he told me was when "tell me leave and I will." Gave me the choice to see him or not. So that is an important thing that I try to keep up. It's like giving him the choice to see me.

I don't want to force him, you know. Just because I'm bored or have nothing to do on a particular weekend, I won't be greedy. I just wait till he wants to see me.

Gary: With both of my mentees, we like to go bowling, and we like to go to the Red Sox games and we like to do other stuff together.

Lucy: About one day per month.

Jean: We would talk probably once a month.

Sometimes more often, sometimes not. It definitely did not turn into a … It turned into an e-mentoring relationship, actually.

And I am not sure. I never talked to her about why that happened. I think that in some way, it fit her needs. She was already a young adult with relationships in her life. She has a mother at home, she has girlfriends. I think what she wanted was that if she had an issue or a career thing

come up she needed someone to bounce ideas off of. Because I don't think that is what she had in her life. That is what our relationship became.

Sandra: There are some times when we are both busy and we don't see each other a lot. Then are some times that we see each other 2 times in 8 days or something like that. Because depending upon what we are doing. So I try to keep her updated on the things I am doing and let me know if she needs some support. That is basically what we do now and what we found what works best for us. I don't know if we ever have a weekly time that we called every single week, even in the beginning, but we stay in touch and things work well for us.

d. Do you email, phone and/or have face-to face meetings with youth?

Todd: Yeah, but I visit him too though

Gary: Neither one is on line. They haven't found a good way to communicate on the computer yet. I communicate with them via their mothers and my mother.

Lucy: (Partners online or email use) No, not really.

Jean: (from previous question) She continually cancelled and no showed so it ended up being a phone and email relationship. We would talk probably once a month.

Sandra: Participant did not respond.

e. Were accommodations needed to facilitate this relationship?

Todd: That's something we need to work on. Part of the reason it's not working is because he's real concerned about money, and traveling is added cost. I could present the problem to Partners and they might be able to pay for transportation but it's only a few dollars for transit and he should put that in his budget if he wants a successful mentorship.

Gary: For me, personally, I have a Mac computer with Discover Ke:nx. It is a keyboard simulator and a word predictor. I can do this on my own, but it would be very slow. I am

dictating to my mother now and she is typing my words. I get tired, especially at this time of night.

I communicate with them via their mothers and my mother.

Lucy: Not really. We just walk slow.

Jean: No

Sandra: No

       f.   How did you arrange for these accommodations?

Todd: not applicable

Lucy: not applicable

Gary: (in reference to his mother typing for him in the IM screen) this is the fastest way, right now. Assistance from his mother and from the mentee's parent

Jean: not applicable

Sandra: not applicable

       g.   Did you talk about disability management, disclosure?

Todd: The best thing about Partners are the amount of services that are available to kids. They can express themselves theatrically they can do that. If they want to be part of a group and not speak up they can do that. We don't force people to talk. We try to encourage but we don't single anyone out.

Gary: PYD taught me that I can advocate for myself, and I can do anything I want, despite my CP. By the way, my two mentees, both have CP, also. I am 27; my two mentees are both 13 and both have CP. What a coincidence, that I would meet two guys with CP and they were both 6 years old when I meet them. PYD introduced me to the one in Town A, and my sister, introduced me to the one in Town B.

And John has been my mentor for about twelve years.

Lucy: (Expanding on her comment about independence) She and I were opposites in some respects. She likes to be helped and I hate to be helped. I resist being helped, if I can, graciously.

One thing was to get her more physically independent. So I would say, "Why don't you carry the popcorn at the movie? Or why don't you try this or that." I tried to encourage her in that respect. We would talk about school, friendships or lack of friendships at school.

I did go to a transition meeting.

Jean: We did not**.**

Sandra: I help her with whatever she asks me.

Yes, I tell her this is what happened to me and some of it worked out well and some of it was good and some wasn't – that kind of stuff. I would tell her whatever comes up and every once in a while something will happen like she won't have a reaction to something that I said - what I would expect so every once in a while I will talk to her parents or something. When Mary was a lot younger, she was very sick. She was in intensive care for a month or something and we did not know if she was going to be OK or not and then she got out of intensive care and I went to see her at Children's. I was talking to her and she starting crying. Because I have a background in peer counseling, usually when she gets upset or crying, I just listened to her cry. But that time I just went and got her parents right away because I couldn't tell if she was in pain or if she was suffering, or if she was crying because she was frustrated or what. So I just went and got her parents. Now I think, there has been occasions when sometimes her reactions to what I suggest are not exactly what I would expect. She starts getting upset about something that I didn't really mean to upset her at all and sometimes I will change the subject. I say, we don't have to do that. Because if that is going to stress you out that is not what I intended so we can just do something different. It is sort of a balancing act – figuring out when I want Mary to feel like she can talk to

me about anything but I don't want to necessarily get her upset. Sometimes as she is getting older it is harder for me to figure out what exactly is going on with her sometimes. We are pretty close so we muddle though like anyone and most of the time is turns out great.

4. Describe the mentor's benefits/challenges of participation.

      a.   What was the most rewarding about being a mentor?

Todd: The fact that what makes it rewarding is that I don't always need a thank you. Just to know that I am there as a resource. It's not necessarily a good mentoring relationship if I'm talking to my mentee every day. Just know that I'm there if they need something is encouraging. I can be a resource and positive role model and example for somebody.

Gary: Both mentees don't talk, but they work hard at being advocates.

Mentee in Town B is the first kid to be on a baseball team in Town B in a wheelchair.

Lucy: She finished college. We had many discussions about going to college and I think that I was helpful to her mom about the challenges of college. Also, I was not a parent at the time, so this youth broadened my horizons with kids in general.

She works at a nursing home as a social worker. One time we had a talk about lunch times. Before she worked in a family business, and they could take as long as they liked for lunch. In this job they need to get back, so we talked about that.

Jean: (expanding upon her comment about the relationship not being rewarding for her or the mentee) Maybe she got what she needed, but it definitely never turned into, you know- we would see each other regularly and that sort of thing. It was more that she ended up calling and we would talk if she needed career advice or things like that. Or she would email. Now we just email. It never became a regular thing.

It helped me have more empathy for mentors. It's harder than it looks.

Well I guess this is one, but not a great one. It's just that in my profession I have to work with volunteers so often, it made me appreciate the role of a volunteer more and appreciate the difficulty in mentoring. Up until that point, I had never been an actual mentor. So I could talk to these issue like how a teenager is going to test your boundaries and things like that. I had never actually had it happen to me, so it gave me a better sense of that.

(Career Goals) Well right now she is studying to be a first grade teacher. She is in community college. (Did the mentor assist with educational decision?) I don't know. I don't think so.

(Did the mentee's family influence educational goals?) They definitely were not.

Sandra: Overall working with Mary has been a joy and I do consider Mary more like a sister than like a mentee person.

I really love Mary a lot so I think of her as part of my family, not exactly my family, but almost.

   b. What were the challenges?

Todd: Working out the details, like who's going to meet who when and where are we going to go. I think as long as we are enjoying each other, it's not so critical the exact activity. You have to be careful about some things. Like movies, find out about the movie first so that the rating is something worth considering.

Gary: I go to Massasoit Community college during the day, and I am tired at night.

Gary is non-verbal. He uses a footswitch.

Lucy: We had some differences. We can't expect that we are alike and respect the ways that they are not like you. For example, she was a risk adverse kid and I am a risk taker. I would encourage her to take more risks if the demands were appropriate.

Jean: There were so many. Another challenge was that she had a history of being involved with abusive men. So she would often turn to me, not even turn to me, involve me indirectly in things like – she would send out a mass email like so and so is doing this and … I saw this pattern

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develop with all the boyfriends that she had and it was very negative. One time she even had to go to court to get a restraining order and all these things. That was a major challenge for me, trying to see what my role was in that, given we did not have a strong relationship. Given that I was still an adult in her life, so that was a huge challenge to navigate that.

(expanded) Basically as soon as I got an email, I would call or and I would say, I got this email and I'm a little concerned and wondered if you wanted to talk about it and she would share things with me and I would try to always do, and I would say, "the great thing is that there are counselors out there who can help with this." And I would always explain this as her reaching out for support and professional help instead of putting my – what I really wanted to say was – there is obviously a pattern and you really need help and I sound a little judgmental and I tried to keep that out of it. Instead, I said, there are people out there who can talk to you about this and I relayed a negative experience I had with somebody and how I got professional help and how that helped. I tried to be non-judgmental and maybe share something of myself to make her feel that she wasn't out of the norm, that she wouldn't feel threatened by getting helped. So she was already 18, so I couldn't tell her parents or anything. I think that if you had a minor, in that situation, it might be different.

I just always tried to recommend professional help. We were just talking and emailing and so it was just a really tricky situation.

Sandra: To let the person go at their own pace and to figure out when to push and when not to push and when to advise and when to leave them alone and stuff.

Well that is what I do, I don't know if that is what everybody does but that is what I do. And sometimes I do it because Mary is really smart but she has some cognitive deficits. And she her parents have really exposed her to many things. She'll go to speakers, even in different countries where her grandparents are from and stuff like that. Her one grandparent is from Samoa or

something like that. She does amazing things but she has been very sheltered from certain things so that she does not actively seek information all the time. I am just a little worried about her living on her own and it's going to be a rude awakening. But I guess it is a little bit for everybody and I hope that I tell her that living on your own. I can't always be there physically but you can always call me if you have a question or something. I hope that whether you have your own kids or you have someone else close to you, you will try to prevent them to go through some of the things you went through. But they have to figure out some things on their own. I think that is one of the challenges we have now. That is why I said that working with Mary is a little more difficult now than in the past. Because in the past she was younger and we used to just do things together and now I sort of want to be there to inspire her more but I don't know whether she is ready to hear it so.

        c.   What would you say to someone considering volunteering to participate as a mentor?

Todd: It takes a little bit of homework to be a mentor. You don't want to influence them in a bad way.

I have never been a parent but I have a cat and I know from my own experience what works. Like being a parent, not only doing for them but guiding them. I hate giving advice. I would rather ask them questions and let them come to their own conclusions.

I tried to touch on this a little bit. I try not to measure all my goals too definitely because that sets me up for failure. I just try to be there when they need it. I don't try to well they use the word in the business world – micro management. I try not to get too much in the details. I try to let the child create his goals instead of me imposing what I want on to him. I let him choose how this relationship works.

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Yeah, that's the term like consumer control. And learned helplessness. If somebody is used to having things done for them a lot. Especially with the person that I mentor, if he gives in then he wouldn't have control over anything. Even if I give him a choice if he wants to go the mall or a movie, that gives him a piece of dignity and he feels like he has some control in the world. If you can think of any other questions, I would be happy to answer them. It's hard to consolidate a couple years. You asked me what I get out of it. I just enjoy what ever comes my way. I don't in it for what I can get out of it. I'm in it to be there for him.

Gary: He needs one more semester and he will have a Certificate in Micro-Soft Office Specialist and then on to an associate.

Lucy: Watching this teen go through difficult times brought up uncomfortable memories of my own adolescence. That memory was difficult at times.

Jean: Well, I think the biggest thing is for me, you can't take anything personally. So, if you mentee does not show up or if your mentee doesn't call you back, you just can't take it personally. And that is really hard not to do. Even though I know that, I found myself taking it personally. I would think she doesn't like me… and here I am telling everybody else how to be a mentor. So I would just say, you can't take it personally. They are just a teenager and teenagers function at a whole range of levels. And the teen that I was hooked up with happened to be from a family that social skills are really lacking and some of those skills she had not learned yet.

Sandra: Well, I think sometimes figuring it out, like I am figuring out whether I am seeing her enough or doing things as we are supposed to do it on schedule or something. But that does not really work for me. It seems that we see each other a lot. We see each other when it is necessary. I will tell her that you have to call me, I don't just have to call you. You need to call me and tell me when you need to talk to me. Cause sometimes I forget to call you on the specific time when I am supposed to. But I think that if you are going to be a mentor you have to do it

because it is what you really want to do. Think about how your life intersects with the other person. You have to realize that the other person is not going to be there to fill all of your other expectations. The mentor, the person mentoring learns as much from that person as you can teach. I found that in peer counseling too that you get experiences and you help people and you always get something back from them no matter what it is, even if it is difficult. That it is not for everybody. And it depends upon the match and I still sometimes feel like I should have kept up better with the person that didn't work out that well. She said she wanted to be paired with somebody. But then she did not want to come to each other's houses and stuff. Then she did not call after that. Then I thought it had been too long. Then I feel like that maybe I should try to call her and try to track her down and see how she is doing. So she know that I remember her. I happen to be kind of hard on myself. I am like that and I want to do a good job. I really love Mary a lot so I think of her as part of my family, not exactly my family, but almost. So that way you have to be careful not to, you know, keep your expectations so that you won't get disappointed too much. You are not too hard on yourself if things don't go the way you expected them to all the time.

        d. Would you volunteer again?

Todd: I would like to find somebody I could spend more time with because I have more time to invest.

I think I would make a good mentor because I try to withhold judgment. I am somebody who will listen.

Gary: Gary wants you to know that he and John are still mentor/mentee matches. He and John meet every Thursday night during the summer at the park to listen to the concerts and play chess in the park.

Lucy: Participant did not respond.

Jean: Oh yes, I think I would like to do it again. For me, I think it might be easier for me with a child. A younger child, because I think my expectations for a teenager were too high. I thought they would call me back and do this and that. With and 8 year old, I'm not going to have that expectation.

Sandra: Then a few years ago, I'm not really good on what year, but there was a year that I was matched with someone else, along with Mary. That did not last as long because mostly because of where we both lived and our schedules did not match. But I think that Partners does a really , works intensively to make sure the matches will last. Takes a long time to make sure the people are compatible and that kind of thing.

      e. Is there anything else you would like to tell me about your mentoring experience?

Todd: Can you do me a big favor? Can you give me a copy of your notes? I want to use that when I'm giving speeches and stuff. Can you send a copy to PYD? They would be interested in hearing it too.

I don't want to be anonymous. I want Partners to hear what I have to say.

Gary: (In reference to the National PYD conference) We are going to be there on Thursday, only. Just to hear Brook Ellison speak at the lunch. Just hope to meet you next week. On Wednesday, that is the only day we are going. We will be in the back of the room, because Greg don't eat, he has a g-tube, so we aren't going to the lunch, jus to the speech by Brooke Ellison. He has met her before at Harvard and want to hear her and her mother again.
Greg said look for the 27 year old guy, with black hair that is starting to go gray with a g-tube and a trach. Thanks, Good night.

Lucy: Watching this teen go through difficult times brought up uncomfortable memories of my own adolescence. That memory was difficult at times.

Jean: I guess the only other thing is that I can see why it is important to have support and have a case worker check in with you. And that might have been another barrier to my success, that because I was an employee, no one ever checked in with me about my mentee. They just assumed I was fine, because one of the mentoring staff. So anytime I needed support, I would reach out. I had to be the one to reach out. That verified to me the importance of regular mentor support. Outreach to the mentors and making sure that the employees are on top of that and even if it is a long-standing or if someone works for the organization or someone you think is fine, that check in is just as important as the mentor you knew from nowhere.

Sandra: No, I don't think so. I gave you a lot of information. Everybody's experience is different. In working with Mary, I don't know how much longer they will officially consider us matched. I think I am going to stay in her life regardless and eventually if she goes off to college somewhere else, right now she is taking 2 classes at a time, but if she moves away, then I might with someone new. I worry about having enough time for the new person and still having time for Mary. So I have not decided about that. I know that before when I had a different mentee. All I know is that it is different and I got lucky with Mary. Maybe when we first met we did not have as much in common when we first met but my expectation in the beginning might have been different than now but I don't think that – I think we both got very lucky in our experiences and that not necessarily going to last as long as I would like. I hope people that are going into mentoring will give it a chance for what they give the person and what the person will give to them.

<div align="center">Participant Interview Summaries:</div>

Todd: Todd was the first respondent to the PYD announcement on the Partners Online discussion board. He phoned me in the evening and was very excited about sharing his experiences with me. The request for participants was timed to correspond with committee

Table 4: Demographic Description of Mentor Participants

	Psuedo Name	Gender	Approx. Age During Relationship	Number of Years as a Mentor	Mentor Disability
Mentor	Todd	Male	33-38	5	Spinal Cord Injury Mobility
Mentee		Male	19-24		CP (PCA)
Mentee		Male	14		CP (is mobile)
Mentor	Gary	Male	20-27	7	Cerebral Palsy Non-Verbal
Mentee		Male	6-13		CP, non-verbal
Mentee		Male	6		CP, non-verbal
Mentor	Lucy	Female	28-40	12	Spina bifida Spina bifida
Mentee		Female	12-24		Learning Disability
Mentor	Jean	Female	20's	3	None
Mentee		Female	18-21		Learning Disability
Mentor	Sandra	Female	20-30's	11	Mobility (has PCA)
Mentee		Female	12-23		Mobility (has PCA)

approvals. Due to some unexpected delays, the time between the participant invitation and scheduling of interviews was longer than anticipated. Todd agreed to postpone scheduling our discussion until approvals were complete. We communicated through electronic mail to coordinate a date and time for telephone interview. While researching the Partners Online portal, I had noticed many posts from this participant. He was very active in the open discussion forums.

The telephone interview was scheduled and conducted on September 6, 2006 from 8:45 until 9:25, Eastern Time. I phoned him from my home office to his residence. The interview protocol was reviewed and Todd gave permission to record the conversation. Todd spoke with incredible enthusiasm in his voice and eagerness to share his experiences.

Todd is 38 years old, holds a bachelor's degree in Psychology and works part-time. A car accident in 1998 caused a severe spinal cord injury which limited his mobility. While crossing the street in his wheelchair, he was once again involved in a car accident in 2004.

In the interim, 1998- 2003, Todd had called the Independent Living agency and been matched with an adult male mentor who also had a spinal cord injury. His mentor was with him during his extensive recovery. Todd says, "I had to learn everything all over again." The impact of his mentor is visible in his statement, "At the time I was not comparing myself, but to see someone with the same injury maintaining their independence was encouraging. Because if I did not meet him, I would not believe on my own that I could be independent." For five years, Todd and his mentor maintained their relationship. "He saw me get my first apartment." He gave me advice about how to stay independent. I did not take all of his examples, but it is a blessing having someone to compare notes with. Most of my life I felt like I was alone, but it was heartening to know there was somebody I could call."

Todd became involved with PYD when he was working in the same office building. "I was working in the same building and I heard about them. I think it's a big deal mentoring specifically for disabilities because it's hard to find people to relate to on a peer level. Most of the non-disabled people are big on sympathy and stuff."

Todd requested a youth mentee who lived near him and was "not too young." Todd was matched with a male, age 21 in 2004. This relationship is active today. Todd obtained a second mentee, age 14, a few months before this interview in 2006. After the first match, Todd was involved in a second car accident. His mentee visited him in the hospital during his recovery. Todd's first experience as a mentor "is not as extensive as my mentorship that I had with the Independent Living mentor, but I'd like to seek out a closer affinity. He's doing great transitioning to adulthood and he has more luck with girls than me. Hence, he is not as needy as I was." Todd and his mentee occasionally communicate on the phone or electronic mail. Todd visits him at his home; however he would like his mentee to join him for activities such as a movie. He believes that the cost of transportation is a potential barrier to his mentee traveling to meet him. The youth mentee is 24 years old now and Todd spends a few hours of month visiting him.

For the second match, Todd was matched with a 14 year old male. In reference to how they were matched, Todd said, "He had the same disability as my other mentee but this one did not use a wheelchair. It is not my first impression, but I think that was a barrier between us because he may have had trouble relating to me in some ways. I hate to blame on disability, but I learned it helps. I don't think he was as comfortable because he's trying to stay walking and me being in a wheelchair may be something he's not ready to relate to." Todd went to see this mentee perform in plays and continues to develop the relationship.

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The benefits of being a mentor were intrinsically rewarding. "I don't always need a thank you. Just to know that I am there as a resource. I can be a resource and a positive role model and example for somebody."

The greatest challenge is coordinating activities. Details such as location, transportation, and activity have been difficult to confirm. Todd tries to respond to the needs of the youth and not "micro manage." "I try not to get too much in the details, I try to let the child create his goals instead of me imposing what I want on him. I let him choose how this relationship works." Freedom of choice is a strong message that Todd wanted to share. "If I give him a choice if he wants to go to the mall or a movie, that gives him a piece of dignity and he feels like he has some control in the world."

Todd's enthusiasm remained throughout the interview. He was anxious to receive a copy of the transcripts and asked that I share them with PYD. I told him that I would send him a copy, however it would be his choice to share with administrators at PYD. I later learned that he posted a copy on the internal Partners Online web portal.

I had the privilege of meeting Todd in person during the National Conference in Boston. **Gary**: This participant responded to the PYD online invitation to participate. In his first email Gary told me that he was non-verbal and suggested we "chat" using one of three instant messaging tools. At the time I was waiting for final approval from my committee, so I asked him if we could schedule in a few weeks. He was agreeable. In the interim, I created an instant message (IM) account with AOL. I am familiar with IM as a parent, but not as a frequent user. I practiced with my children a few times to familiarize myself with the program. Using electronic mail, an online interview was scheduled at a date and time of his choice.

The interview occurred at the scheduled time, Thursday, September 7, 2006, 8:00 – 9:00 pm, Eastern Time. Microsoft Word was open along with the IM program. I had planned to copy

and paste the conversation from IM to MS Word, saving every few minutes, as backup of the transcript.   We both typed greetings and proceeded with the questioning. I noticed that responses were slower than conversations were with my children. In a few circumstances, the delay between my questions and his responses prompted a different response than the question asked.

Gary is a male, approximately 27 years old. He attends community college and is working towards a certificate in Microsoft Office Specialist. Gary has cerebral palsy and is non-verbal.

Gary had been mentored as a youth though PYD. This twelve year relationship continues today. Gary and his mentor meet weekly to play chess in the park and listen to music. Because of this mentoring relationship, he wanted to mentor a youth "when I was old enough." In preparation for becoming a mentor, he stated that "he was my mentor and I am copying what he did for me."

Gary's first youth mentee was six years old when he met him through his sister. He was matched through PYD with a second youth mentee in the past year. They both have gender and disability in common. All three are male and have cerebral palsy. Ironically, both youth have the same first name. He differentiates them by the area they live. It was my impression that Gary and both youth were all non-verbal because he told me that he communicated through his parents and their parents. Gary uses a footswitch. He has been mentoring the first youth seven years and the second youth a few months.

Gary believed that he and his mentees enjoyed similar activities. He said that they all enjoyed baseball and bowling. He has participated in a variety of face-to-face activities with both youth mentees.

> "Besides bowling and Red Sox, we all like going to the Science Museum or one
> time I went to a track meeting with _____ to watch our sisters. I went to the Tall

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> Ships with _____. I took both of them to the Quincy Dinner theatre to see a funny play."

No electronic communication was utilized between the adult and youth. Gary utilizes assistive technology to use the computer. He uses "a Mac computer with Discover Kenx. It is a keyboard simulator and word predictor. I can do this on my own, but it would be very slow." Neither youth mentee uses the computer. Gary told me that "they haven't found a good way to communicate on the computer yet. I communicate with them via their mothers and my mother."

In response to my question about training from PYD, he said, "PYD taught me that I can advocate for myself, and I can do anything I want, despite my CP." Gary also stated that although both youth were non-verbal "they work hard at being advocates."

I sensed a desire for closure in the conversation and Gary had told me that he was tired earlier in the interview. We concluded with a quick comment about the upcoming conference. I told him about my participation and Gary told me that he was coming to hear one of the keynote speakers. To identify him, he told me to look for "the 27 year old guy with black hair that is starting to go grey with a g-tube and a trach." Unfortunately, I did not connect with Gary at the conference.

The conversation with Gary was amazing. I was overwhelming impressed with his ability to develop communication strategies which enable him to assist young people and work towards achieving higher education goals.

Lucy: I was invited to be a presenter at the National Mentoring Conference for Youth with Disabilities in Boston on September 13-15, 2006. During this conference, a mentor was introduced to my by a PYD administrator. The administrator was my point of contact on this research and was prepared to introduce me to some mentors who might be interested in participating. In the exhibit area, the administrator introduced me to Lucy. She also shared with

me that Lucy has multiple graduate degrees and is currently pursuing a PhD. Thus our connection as students developed. I introduced myself and my research. Lucy suggested, "no time like the present" therefore we coordinated a meeting in the lobby coffee shop in 15 minutes. There was ample time before registration opened for the conference.

Lucy is a female, approximately 40 years old who holds multiple graduate degrees in social sciences. She is currently pursuing a doctorate. Lucy has spina bifida and walks with a cane.

After reviewing the interview protocol, Lucy requested that her name not be used to protect her privacy and of the youth mentee. I reassured her that individual identities would be protected.

Lucy was recruited to become a mentor due to her involvement with PYD's staff. She said, "in this area, everyone knows everyone." Lucy's intention to "be helpful to a younger person" matched her with a female youth, age 12. They were matched based upon gender and disability. Age appropriate activities included movies, eating out or both. During this time the primary focus of conversation was school activities for the youth. Lucy mentioned independence as a topic of discussion which differentiated them in personalities. "She likes to be helped and I hate to be helped." To encourage physical independence, Lucy would make suggestions such as, "why don't you carry the popcorn at the movie?" Lucy also offered support to her youth mentee in regards to others' responses to persons with disabilities. The youth told Lucy that, "they (special education teachers) don't understand how people look at you." A conversation between Lucy and the youth's teacher revealed that teacher was unaware that public glances were a concern to students.

Their twelve year relationship continues "on and off." Lucy "finds that she has to do most of the work to keep in touch" yet also states that they usually get together about one day per

month. Neither the mentor nor the youth participated in PYD's online community, workshops or activities.

As a mentor, Lucy felt that she contributed to the youth's ability to complete her college education. "We had many discussions about going to college and I think that I was help[ful to her mom about the challenge of college." Lucy's mentee is currently working as a social worker in a nursing home whereby Lucy continues to "coach" her about workplace issues. On one occasion they discussed lunch protocol. When the mentee worked in the family business, lunchtimes were flexible, however in her current environment, there were different expectations. Throughout this relationship some differences surfaced. "For example, she was a risk adverse kid and I am a risk taker." Reflecting on the stages of the mentoring relationship brought up Lucy's own teenage memories. This experience was difficult for them both.

At this point in the interview, I sensed closure. Lucy wanted to protect her privacy and the relationship with this mentee. The interview concluded with explanation of emailing the transcripts and an expression of appreciation.

Jean: This mentor volunteer is also a staff member of PYD. She and I have had previous conversations about PYD's programs and she was familiar with my research. Jean offered to participate in this interview because her mentoring experience was a result of career focused program, thus different than the majority of mentoring relationships at PYD. We scheduled a telephone interview on Columbus Day (October 9, 2006, 9:00 am), both of us working from our home/office. She mentioned that we would be interrupted for a few minutes when a package was scheduled to arrive. As anticipated, the package came to the door and 30 seconds later, she was back on the phone.

Jean understood and agreed to the interview protocol and recording the call. Jean had previously told me that she was part of the career focused mentoring program at PYD.   This

program called, "Young Entrepreneurs Project" taught business skills to young people. Jean was

an instructor. One young woman's mentor moved out of the area during the program and

because Jean had a pre-established relationship with this young woman, she offered to serve as

her mentor. Jean's background in social services interested this young woman. Other than their

common career interest, gender, race and geographic proximity, Jean felt they had little else in

common. A difference she noted was socio-economic and "up-bringing." This match began in

2003 and they continue to communicate occasionally through 2006.

Jean's mentee was 18 years old and a senior in high school when she was matched as her

mentor. Early in the relationship they had lunch together and walked around Boston Common.

"After that she continually cancelled and no showed." Their sporadic relationship was

maintained through telephone calls and electronic mail messages. Jean says, "It never became a

regular thing." Recently, "it turned into an e-mentoring relationship, actually."

As the facilitator of mentor training, Jean was aware of the mentoring process. She

witnessed many types of relationships and her expectation was to have a "regular relationship

whereby we'd see each other a lot." Jean stated that her mentee had relationships with her

mother and other friends. The mentee turned to Jean with career questions. "I think that what

she wanted was that if she had an issue or a career thing come up, she needed someone to bounce

ideas off of. Because I don't think that is what she had in her life. That is what our relationship

became." The mentee is currently studying elementary education in a community college.

When I asked Jean if she believed she was influential in her mentee's participation in higher

education, she said, "I don't think so." She also said that the mentee's family was not

encouraging her to attend college.

It is my intuition that although Jean's impression of the relationship was not successful that

if I had the opportunity to talk to the young woman she mentored, she would offer additional

perspective. As perceived by the mentor, the youth was involved in negative behaviors, lacked

supports and positive role models. Despite this, she is pursuing a teaching degree. The mentor

may not have been the only reason, but possibly a contributing factor.

Professional benefits were the outcome of Jean's participation as a mentor. "In my

profession I have to work with volunteers so often, it made me appreciate the role of a volunteer

more and appreciate the difficulty in mentoring." "It's harder than it looks." Another benefit

was learning about adolescence. "I could talk to the issues like how a teenager is going to test

your boundaries."

Challenges included some sensitive situations whereby her mentee confessed negative

situations. "That was a major challenge for me, trying to see what my role was in that, given that

we did not have a strong relationship." The age of the mentee was perceived to contribute to the

challenge. "Teenagers function at a whole range of levels." Due to the challenges Jean

experienced she recognizes the value of mentor support. As an administrator, she was not

assigned a case worker. When she needed support, "I had to be the one to reach out." On-going

mentor support, despite the length of the relationship, was declared important to Jean.

Jean would volunteer to mentor again. She would tell others considering mentoring that

"you can't take anything personally. If your mentee does not show up or if your mentee doesn't

call you back, you just can't take it personally. And that is really hard not to do."

The interview concluded with an explanation of the next steps and appreciation for her

time and participation.

Sandra: Sandra was introduced to me through a PYD administrator at the Boston conference.

She asked for my phone number to contact me when she was ready to participate. A few weeks

after the conference I phoned her determine if her interest continued. Sandra was interested in

sharing her experience; therefore we scheduled a telephone interview for Saturday afternoon,

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October 21, 2006. I asked her for her email address in order to send the interview protocol, however, she informed me that she did not have access to email unless her PCA was available. She was also experiencing technical difficulty receiving messages. We agreed to communicate using the telephone.

Sandra is a female in her early thirties who worked part time as a peer counselor for 15 years. She is currently looking for another position. Sandra has a mobility disability and employs the services of a Personal Care Attendant.

I telephoned Sandra from my home office to her apartment at the scheduled time. She initially asked me to phone her back in 20 minutes to allow her to finish another task. The interview began with a review of the protocol and permission to record the conversation. Sandra had discussed this interview with her mentee and asked if she had any thoughts to contribute. Her mentee did not have any comments.

For each question, Sandra responded at length with examples and descriptions. Her stories were delightful and passionate about her relationship with her mentee. Their relationship has lasted eleven years. Through the years, their experiences have developed a family oriented relationship. "I really love her a lot, so I think of her as part of my family, not exactly my family, but almost."

Sandra's offer to volunteer as a mentor rooted from a personal decision "that I would not want to have a child of my own because I did not want my PCA's being my primary caretaker." She was recruited by a friend who worked at PYD. This friend invited Sandra to PYD events. Initially she felt she did not have enough time to devote to a mentoring relationship, however eventually she decided to apply. She was first matched with a youth who dropped out of the program due to health concerns prior to meeting Sandra. After PYD staff changes and some passage of time, Sandra was matched with her current mentee (around 1994-95).   A few years

later, Sandra was matched with third youth. This match did not last due to geographic distances and schedule conflicts. This interview focused on the current mentoring relationship which has lasted eleven years.

Sandra and her mentee were matched based upon gender and similar disabilities. The youth mentee was twelve years old when they first met. They "love some of the same things and seem to be pretty compatible thinking of each other's schedules." They have been involved in many different activities over their eleven year relationship. Some examples include participation in 2006 Disability Mentoring Day at PYD, attendance at a peace rally, visiting each other's homes, working on arts and crafts, watching movies, swimming and shopping.

When asked about her expectations of mentoring, Sandra responded, "I just wanted someone, a younger person to do things with and hang out with." She also wanted to "offer support and guidance, and that expectation did get met." Over the years the relationship has grown and has recently become more challenging. She is going to college and considering moving out of her parents' home. Sandra is concerned about her transition to independent living. This transition would include an increased dependency upon personal care attendants (PCA). Sandra's mentee told her that "having PCA's is stressful." Sandra tried to explain the process of leaving parents and living independently, however she was not sure if here message was understood. The balance of the relationship is sensitive to the situation and age of the youth mentee. "Let the person go at their own pace and to figure out when to push and when not to push and when to advise and when to leave them alone."

Sandra believes that their common disabilities allow her to assist with some challenges and pose a unique twist in other situations. During one activity their limited sense of direction got them lost and both wheelchairs were out of power at the same time. Sandra encourages her

mentee to call her when she would like to talk or schedule an activity, however Sandra initiates most interaction.

Support from PYD has continued throughout the eleven year mentoring relationship. Once or twice a year a staff member contacts Sandra to reevaluate goals. Sandra did not have specific goals, "my goal is to let her know that I am around." As challenges arise with the relationship, Sandra was unclear of the role of PYD administrators. "I don't know how much support I am supposed to expect from the staff at Partners and what that support is and how to access. It might be just as much my problem as their's because I don't know when to ask for help sometimes."

Sandra's advice to people considering mentoring would include setting realistic expectations, and making a personal commitment. "I think that if you are going to be a mentor you have to do it because it is what you really want to do. Think about how your life intersects with the other person. You have to realize that the other person is not going to be there to fill all of your other expectations."

The personal benefits of volunteering to mentor cannot be measured, only described. Sandra's experience has developed into a family-like bond. "The mentor, the person mentoring learns as much from that person as you can teach."

<center>Themes</center>

The themes which emerged as a result of this research provide insight in to the lived experiences of adults who mentor youth with disabilities. Some themes are consistent with documented mentoring experiences. Additional themes illuminated the specific nature of the relationship between mentors and mentees with disabilities. Analysis of the themes corresponds to the sequence of the guiding questions.

Table 5: Themes and Descriptions of the Mentors' Lived Experiences

Theme	Description
Recruitment	Networked introduction
	Knew a staff or participant of PYD
Expectation	Desire to help younger person
Mentor-Mentee Match	Same gender
	Similar disability
Support and Training	Rarely attended PYD's workshops
	Limited relationship with a PYD staff member after the initial match
Mentor-Mentee Activities	Mentors were responsible for sustaining the relationship
	Age appropriate
	Hobbies and interests of participants explored
	Time commitment varied
	Frequency of contact varied
	Mentors reacted to clues by mentees
	Disability management was addressed when requested
Challenges	Age related (teenagers)
Benefits	Would mentor again

Mentors were recruited for participation through networked introductions. Each of the mentors participating in this study became involved in the program due to a personal connection to a staff member or PYD participant. Within the community of disability service providers, such as Independent Living agencies and vocational rehabilitation services, the staff frequently shares opportunities and information. One mentor mentioned that "everyone knows everyone" when asked how she became involved in the mentoring program.

The mentors' expectations about becoming involved with a mentee centered on the desire to help a younger person. Each mentor was willing to dedicate time and effort to developing a relationship with a youth.

PYD's criteria for matching mentors with mentees are based upon their experiences as mentoring program administrators. All mentors were matched with a mentee of the same gender. Four of the mentors shared a similar disability as their mentee. The mentors' ability to talk about their personal experiences with concerns related to their disability was an important

consideration in development of a mentoring program for youth with disabilities. The mentors who participated in this research stated that they responded to any questions their mentee generated, disability or otherwise.

The mentors participating in this study had multiple years of experience. Their experience ranged from three to eleven years. The mentors were all aware of the programs and special events, yet indicated that they rarely attended the trainings and workshops offered by PYD. When challenges arose in the relationship, the consensus was that they were not aware of what types of supports were available and how to access them. Also noted was their admission that they did not seek assistance.

In all five mentor-mentee relationships, the mentor assumed the majority of responsibility to sustain relationship. The mentor's commitment and dedication to developing the relationship was a common response. The mentor initiated communication and activities, coordinated the details and maintained the relationship. The frequency of contact was driven by the clues provided by the mentee. Each mentor remembered times when their relationship would hibernate for a few months. The rekindling would be prompted by a conversation or event in the mentor or mentee's life.

Throughout this process, each mentor encouraged independence through conversations and activities. Each mentor addressed some aspect of advocacy and independence as related to the goals of the mentee. The mentors' relationship with the mentees developed mutual trust and confidence due to the length of their commitment. The mentors' intuition and knowledge of the mentee provided them some framework to guide the conversation. For example, as some of the mentees encountered questions about independent living, they asked their mentor questions about this transition. Another mentee solicited career advice from her mentor as she exited high school.

One common challenge discussed by the mentors was dealing with age related issues. Those who had begun their relationship with a younger child noted that their activities were socially oriented. As the youth became teenagers with transition decisions, such as education, careers, and peer relationships, the mentoring relationship became more challenging.

The mentors expressed the desire to continue their present mentoring relationship and consider mentoring another youth. Based upon the duration of the relationships, the assumption is made by this researcher that although unstated, substantial intrinsic satisfaction was derived as a result of serving as a mentor.

CHAPTER 5

SUMMARY

This research process began due to my involvement in a training program for adults with disabilities. My participation in this program was enlightening in many ways. I have been touched by the courage, compassion and motivation of many people who have intersected with my life, yet none to the degree that some of these individuals reached. I had the privilege to build relationships with individuals who have experienced challenges which appear insurmountable. Despite their situation, they radiate optimism and hope.

Throughout this training program, one barrier that was a common thread for most of the participants' was a lack of the appropriate supports in the community and in their personal lives. Due to circumstances, they had a limited social network and social confidence. It has always been evident to me that my personal and professional success is linked to the people who have crossed my path. This prompted me to wonder how to help them build a network of supports as they transitioned into the workforce. People need people. Mentoring relationships provided adult mentors and youth mentees an opportunity to share their unique stories and experiences. Throughout their journey, they needed a partner and a voice to build community awareness and opportunities.

Upon learning about mentoring programs specifically developed for youth and adults with disabilities, I began my journey to assist with the development of a mentoring program for youth with disabilities in Louisiana. This journey included discussions with local non-profits and state agencies about the need for supports, descriptions of the barriers transition age youth encounter, and best practice mentoring program design components.

Research is available about the experiences of youth who have participated in mentoring programs. Very little research is published about the experiences of youth with disabilities who

have been mentored and even less documentation exists about the mentors' experiences. Thus, this research will continue the discussion.

Summary of Research

The primary purpose of this study was to describe the lived experiences of adult mentors involved in a mentoring program for youth with disabilities.   In chapter one, I described the need for this research. The need for supports for transition age youth with disabilities is significant. The barriers they encounter as they leave the educational environment to live independently and join the workforce are numerous. Research along with my personal discovery indicates that the demand for mentors far exceeds the adults willing to volunteer (National Mentoring Partnership, 2003).

Disability definitions were reviewed from several perspectives. Disability is contextual and is often categorized and measured for determining benefits or legal protections. Disability advocates would ask that individuals are first considered for their contributions and abilities. For this research, the disability is defined by the individuals self assessment and participation in the program.

Mentors are adults who have volunteered to offer guidance, support, and encouragement to a youth thus developing opportunities for personal and professional growth. The mentee is the youth who is the focus of the mentor.

The guiding study questions were:

1. Mentor Recruitment – How are mentors recruited to volunteer? What are their expectations?

2. Mentor-Mentee Match Characteristics – What do the adult mentor and youth mentee have in common?

3. Support and Training – What preparation did the mentor receive before becoming a mentor? What support did they receive throughout their participation?

4. Activities – What time commitment was involved? Where and how did you communicate with the mentee?

5. Benefits / Challenges – What are the rewards and challenges from participation?

In chapter one, I also described the significance of this study as having the potential to contribute to the conversation about mentoring program components which will assist with development of relationships resulting in positive long-term outcomes for mentors and mentees with disabilities.

Chapter two reviews the literature regarding the diversity in our population between individuals with and without disabilities. Persons with disabilities experience gaps in life activities such as independent living, educational attainment and employment. Literature suggests, one intervention proposed to reduce these gaps is mentoring. Mentoring has received national attention and funding and is considered an appropriate response to the challenges facing transition age youth with disabilities. Descriptions of mentoring programs targeting youth with disabilities is summarized.

In chapter three, I described the methodology utilized to conduct this research. This was a qualitative study with mentors who were recruited from the mentoring program, Partners for Youth with Disabilities in Boston (PYD), Massachusetts. Each participant agreed to participant in the interview and audio taping. Five interviews were conducted by me, the researcher. The interviews were transcribed, reviewed and analyzed for emerging themes.

Chapter Four introduced the mentor participants to the reader. Interviews were conducted conversationally and responses to the guiding questions often prompted spontaneous reactions. The mentors participating were all open to sharing multiple aspects of their relationships. Their

responses were analyzed for emerging themes. The emerging themes were mentor recruitment, mentor match characteristics, utilization of supports, activities, challenges and benefits.

Findings

The findings are organized as they correlate with the guiding questions. Comparisons are made between relevant research presented in chapter two and participant responses.

The mentors in this research became involved with mentoring through a personal connection to a program staff member or participant. The National Mentoring Partnership study in 2005, notes that 50% of mentors became involved through a personal connection with someone who already mentors (National Mentoring Partnership, n.d. b, p. 8). Two of the participants had been the focus of a mentor, a mentee, prior to becoming a mentor. One of these mentors received their mentor through PYD. In the same study, 41% of mentors were recruited through participation in an organization (p.8). The research and my findings suggest that the primary source of recruitment of mentors is through personal connections and affiliation with organizations.

When asked about expectations about the mentoring experience, the mentors' responses indirectly indicated that they wanted to help a younger person. They were unsure of the specific expectations of the relationship, however followed up with a comment about their willingness to become a part of another person's life. Mentor responses included, "I started out with the attitude that I am just there for him and not looking to get something in return." Another said, "I thought I would be helpful for a younger person" or "I wanted to be able to offer support and guidance to a younger person." Research confirms the motivations of mentors are consistent with the responses of these mentors (McLearn et al, 1998; National Mentoring Partnership, n.d. b)

Mentors were matched with a youth mentee based upon criteria developed by PYD program administrators. Factors such as gender, hobbies, geographic proximity career interests, and disability were considered. This research supplements general mentoring research with specific attention to disability concerns. Mentors were matched with mentees who had a similar disability. Mentors could share experiences in their lives with their mentee which were unique to their disability and situation. Providing guidance about issues such as accommodations in the classroom, socialization with peers, personal care attendant management, responding to public stares and independent living are challenges which can be addressed by a person who can share these same experiences. The mentors in this study did assist with disability related concerns of the mentees. As Whelley stated in his article, mentees who are involved with people who have similar disabilities, expand their perception of career and educational possibilities (2003). Two mentors, both with college degrees and employed, reported that their mentees had continued to pursue higher education degrees. One mentee completed her degree and was working in her field of study and the other was still enrolled in elementary education. Association with a mentor who is employed offers mentees connections to possibilities in the workforce (Sword & Hill, 2003).

The mentors in this study were aware of training offered by PYD however four of the five rarely attended with their mentees. The one mentor who had attended trainings and events, learned about youth in transition and other disability needs at a PYD workshop. They all had established relationships to the organization and the people who worked for PYD. Perhaps to better understand the lack of utilization of training and supports could be explained by the individual connection to the organization. One mentor was a staff member of the program, therefore facilitated and attended events as part of her job. A second mentor joined the staff after participating in a mentoring relationship. A third mentor was currently seeking a new job and

mentioned that she would like to work for the program. Another mentor was a youth participant prior to becoming a mentor. Only one mentor mentioned on-going support. She stated that she received occasional calls from a PYD staff member to inquire about goals in the relationship. More research about the needs of mentors would be valuable in understanding the types of training and support activities required to support the mentoring relationship.

Activities and frequency of contact varied with all of the mentors. Mentors encouraged their mentees to suggest activities, however most often the mentor initiated the planning and communication to facilitate a meeting. They met at sports events, restaurants, shopping centers, theatre performances and each other's homes. McLearn et al., reported that mentors provide social, cultural, social and entertainment opportunities to their mentees that would not have normally been an option (1998). Conversely, mentors reported participating in activities that they would have not pursued if not involved in this relationship. For example, one mentee expressed an interest in art. This prompted them both to take a class in ceramics. The mentors also attended activities, such as baseball games and swimming lessons, where the mentee was a participant. When speaking about the accomplishments of their mentees, the mentors' voice inflection noted pride and affection.

In order for any relationship to continue, each person must derive some personal gain, often referred to as WII-FM (what's in it for me). The goals in a mentoring relationship are contingent upon the individuals' personal objectives and the type of relationship developed. For mentees, the benefits are often academic achievement, less likely to use drugs or alcohol, and better attitudes (Tierney, Grossman, & Resch, 1995). For mentees with disabilities in this study, their mentors report progress towards independent living and advocacy, completion of high school and higher education, and employment.

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I wanted to know more about the benefits to mentors as a result of this study and found that the evidence to describe mentors benefits was much more difficult to obtain. The mentors in this study were humbled to participate and redirected responses back to the mentees accomplishments instead of their own successes. The benefits I perceived through interviews with these mentors were pride, feelings of accomplishment, patience, and satisfaction in helping a younger person. Sword and Hill report increased self-esteem, creations of networks of volunteers, insight into childhood adolescence, and sense of effective ness and acquiring new skills or knowledge (2005).

Four of the mentors expressed challenges with their mentee's teenage years. Struggles with social networks, independence and school are normal transitions for this age group, thus the term, transition-age youth. As the youth described experiences or behaviors, mentors were challenged to respond in a supportive manner. One mentor expressed her discomfort with this time period of the mentee because it generated unhappy memories of her own youth.

Minor challenges coordinating activities with their mentees were also described. The ability to connect despite geographic proximity and access to transportation should be a consideration for sustaining the relationship. Overall, the mentors' perseverance was important to maintaining the relationship.

<div align="center">Unexpected Discoveries</div>

Partners for Youth with Disabilities (PYD) was selected a partner in this research in part due to their innovative Partners Online (POL) Web Portal for mentors and mentees. Today's generation of youth has become accustomed to computers, instant messaging, blogs and social communities on the internet. The internet removes geographical boundaries and time limitations which often prohibit face to face interaction. I anticipated that usage of the POL community would be a valuable component of the mentoring experience. PYD staff and representatives

from other organizations applaud the impact that this web portal provides. It was surprising to me that only one mentor utilized the POL community and did not do so regularly. E-mail was occasionally used between two mentor participants and mentees. One participant, who was non-verbal, did not communicate with his mentees through POL or email however he requested our interview be conducted through instant messaging.

All five mentors had been involved with PYD for more than five years. The duration of their mentoring relationships ranged from three to twelve years. This far exceeded the nine month national average of mentoring relationships (National Mentoring Partnership, n.d. b). The same study reported only 38% of mentoring relationships continued beyond one year (National Mentoring Partnership, n.d. b). Long term relationships are considered "highly effective" is assisting with education and employment (Whelley, Radtke, Burgstahler & Christ, 2003).

The mentors in this study assisted their mentees with learning to manage and communicate with their PCA's as part of their transition to independent living arrangements. The topic of Personal Care Attendants (PCA) is one that mentors involved in that situation will need to address with their mentees. Some individuals need assistance when family members are not home or if they live independently. People hired to provide this assistance are referred to as Personal Care Attendants. The salaries of PCA's may be reimbursed or paid by service agencies much as other benefits are determined. The needs of an individual with disabilities are evaluated by assessing their abilities in Activities of Daily Living (ADL). The scope of the limitations is used as a measure for services and benefits.

> "About 9 million people of all ages have disabilities so severe that they require personal assistance to carry out everyday activities. About 80 percent of the people who take on the role of primary helper are relatives, and nearly half of these primary helpers live with the person with a disability." (United States Department of Commerce, 1997, p.1)

Personal Care Attendants (PCA) are hired by the individual, family members or through social service providers to provide assistance. The individual and/or the family member are the employer of the PCA. Therefore, becoming a manager of a PCA is a business skill for discussion.

A consideration for becoming a mentor expressed by two mentors was their decision not to be a parent. All five mentors were not parents when they became mentors. One became a parent after mentoring for a few years.

Implications

Recruitment of mentors is the backbone of the success. Program administrators need to identify and expand the network of potential mentors through existing staff and participants in the program, partner with similar service organizations and offer opportunities for collaboration to build awareness of the need for volunteers. Maintaining contact with mentees as they transition to adulthood would provide a valuable resource for mentor recruitment.

The mentor-mentee match criteria should consider geographic location, access to transportation, schedules, accommodations, and a discussion of how limitations due to disability can be shared between participants.

Training and support of mentors provides a foundation for developing successful mentoring relationships. Mentoring program staff should be aware of the needs of the mentors and offer training opportunities to address such issues as age related challenges, disclosure, socialization, transition, academic support, PCA management and planning. Program staff should ask specific questions about the relationship, such as, "what are the current challenges you face" and "is there anything which limits your ability to coordinate activities with mentees" and "what can staff do to assist you?"

Mentors' success stories provide a valuable input for funding requests, inspiration to other mentors, and recognition of their efforts. People's lives are changed as a result of the relationship they develop through their lives. These stories contribute to outcomes which cannot be measured by numbers or charts.

Youth are the first priority of mentoring programs. Youth with disabilities want equal opportunity to participate in academics, communities, and in the workforce. Their personal objectives can be achieved with appropriate supports enabling them to achieve their full potential.

<div align="center">Need for Additional Research</div>

Emerging technologies remove geographic barriers and physical limitations. Exploration of new technologies opens additional opportunities for participation. Further research about the potential limitations which prevented access or usage of the online community could be explored.

Mentors in this study talked about encouraging independence. Descriptions about how they encouraged independence though conversation and activities would provide a lens to the unique challenges faced by mentors and mentees with disabilities.

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APPENDIX A
GUIDING QUESTIONS

Tell me about how you became involved as a mentor.

Who did you talk to when deciding whether or not to participate?

What were your expectations?

What characteristics do you have in common with the youth protégé?

How do you feel adults and youth should be matched for long-term relationships?

What support and preparation did you need before beginning as a mentor?

What activities did you participate with your youth participants?

How much time per month do you spend mentoring?

Do you email, phone and/or have face-to face meetings with youth?

Were accommodations needed to facilitate this relationship?

How did you arrange for these accommodations?

Did you talk about disability management, disclosure?

What was the most rewarding about being a mentor?

What were the challenges?

What would you say to someone considering volunteering to participate as a mentor?

Would you volunteer again?

Is there anything else you would like to tell me about your mentoring experience?

E- ANNOUNCEMENT

Mentors, Let's Talk!

Share your experience as a mentor and become an important voice to others learning about

mentoring youth with disabilities.

Contact me via email or phone to schedule a telephone conversation (approximately 30 minutes)

before July 30, 2006.

Participation is voluntary and your responses will remain confidential.   Your input will be

included in a graduate research project.

Thank You,

APPENDIX C

INTERVIEW SCHEDULING FORM

Contact Information	Interview Information	Follow-up
Name: Todd Phone: Email:	Date: 9/6/06 Time: 7:45 pm Accommodations: Telephone Interview	Talked at the National Conference in Boston
Name: Gary Phone: Email:	Date: 9/7/06 Time: 7:00 pm Accommodations: Instant Message interview	
Name: Lucy Phone: Email:	Date: 9/13/06 Time: 2:00 pm Accommodations: None Face-to- Face Interview, Boston	
Name: Jean Phone: Email:	Date: 10/9/06 Time: 9:00 am Accommodations: None Telephone Interview	
Name: Sandra Phone: Email:	Date: 10/21/06 Time: 2:00 pm Accommodations: Unable to access email – please contact by phone	

VITA

Kimberly Lynn Bailey Seeger was born in Pittsburgh, Pennsylvania, to parents Edward and Ruth Bailey. She graduated from Upper St. Clair High School in 1981. Kimberly earned her Bachelor of Science Degree with a major in human resource management and a minor in management information systems from Indiana University of Pennsylvania in 1984. In May, 2007, she will graduate from Louisiana State University with a Masters of Science Degree from the department of Human Resource Education and Workforce Development.

After flying the "friendly skies" for a few years, she met and married Brett Seeger, an air traffic controller. They have three children and currently reside in Prairieville, Louisiana.

In 1990, Kimberly was hired as a technical trainer for ExecuTrain, thus launching her professional career in adult professional development. Teaching for University of New Orleans, Tulane Computer Training Center, and Louisiana State University Continuing Education allowed her the opportunity to develop a diverse understanding of private and public organizations. Her portfolio of course offerings has expanded beyond computer software applications to include leadership development, inclusion in the workplace and customer service. In 2006, Kimberly added working with Louisiana Business Leadership Network to her consulting schedule. She facilitates communication between state and community agencies and develops opportunities for employers' to develop their capacity to hire people with disabilities.

Kimberly has served on the Board of Association of Rehabilitation Programs in Computer Technology, Oak Grove Parent Teacher Organization and Manchac Plantation Homeowner's Association. In 2006 – 2007, she serves as Vice President of Programming for American Society of Training and Development in Baton Rouge.