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COMPARISON OF CLINICIAN-DIRECTED AND STUDENT-SELF-DIRECTED PHYSICAL THERAPY INTERVENTIONS FOR YOUTH WITH SEVERE AND MULTIPLE DEVELOPMENTAL DISABILITIES

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COMPARISON OF CLINICIAN-DIRECTED AND STUDENT-SELF-DIRECTED PHYSICAL THERAPY INTERVENTIONS FOR YOUTH WITH SEVERE AND MULTIPLE DEVELOPMENTAL DISABILITIES

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DEDICATION

Dedicated to my parents, John and Theresa Sylvester, in loving memory. You always encouraged me to pursue education and to make the world a better place.

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ABSTRACT

I investigated two physical therapy intervention approaches, one clinician-directed (CD) and one participant self-directed (SD) for helping five young adults with severe and multiple developmental disabilities (SMDD) gain, maintain, and generalize mobility skills while using facets of the S*elf-determined Learning Model of Instruction (SDLMI)* in the process. The dependent variables in this small-n study included: (a) number of mobility steps accomplished, (b) frequency and type of supports required, (c) number of self-initiated supports requested by the participants, (d) percent self-evaluation match with therapist, (e) number of adjustment topics offered, and (f) number of mobility steps maintained in the familiar setting and generalized to a new applied setting.

All participants gained mobility skills steps regardless of the interventions applied, but the SD intervention proved somewhat more effective than the CD intervention. Participants maintained their mobility skills in their familiar setting, and generalized them in a less familiar applied setting. Results showed that participants learned and applied facets of the SDLMI more during generalization and maintenance, but less during the SD and CD sessions. Participants preferred the SD sessions because they could choose activities and control the course of the session, and they learned to relate the interventions to their mobility goal. Relative costs of the SD and CD sessions were comparable suggesting that implementing the *SDLMI* into PT sessions is beneficial for promoting self-determination and motor skill development for youth with severe and multiple developmental disabilities.

CHAPTER ONE

Introduction

"I don't want to go to therapy any more - I just want to go home and play, like my friends. I've been doing this ALL—MY—LIFE, and going to therapy doesn't make me feel like a regular person" (Snow, 2006, p. 16). This quote from a young boy with cerebral palsy demonstrates the general definitional quandary of the word disability, and it portends life challenges for this youth with severe and multiple developmental disabilities (SMDD) as he grows up and engenders supports that enable him to participate fully as an adult in his community. Physical therapy (PT) is a valuable service, an intervention that helps to ameliorate impairments for many children with disabilities. For the boy above, going to PT is also a reminder that having cerebral palsy (CP) makes him different from other children. He believes that ‘regular kids’ do not routinely go to therapy, nor does he believe that PT helps him to become a ‘regular kid.’ Norman Kunc, an adult and well known self-advocate with CP, remembers PT as an important contributor to seeing himself as ‘abnormal,’ and retains emotional scars from his childhood therapy experiences (Giangreco, 1996).

Who are Students with Severe and Multiple Developmental Disabilities?

Describing and working with students like the boy above is a bit like looking through a kaleidoscope. Initially, one sees interesting patterns; but introducing small perturbations produces repeated, and interesting, changes in the patterns. Figuring out how to move the kaleidoscope just the right way to produce the patterns you most desire is fun, but also frustrating. After a while, we learn how to move the kaleidoscope just enough to produce a consistent and preferred pattern, a still-challenging, but achievable task.

Participants in my study have severe and multiple developmental disabilities (SMDD), and demonstrate diverse skills, strengths, limits, and support needs. The following description acknowledges the impact of multiple-system impairments on a person and his family, the severity of associated health conditions, and his community participation. Individuals with SMDD experience deficits before or around the time of birth and they have two or more disabilities occurring simultaneously. The mobility, learning, physical, communication, and self-care supports required to achieve community living, employment, and self-sufficiency are extensive, pervasive, and often include assistive technology and PT related services.

Snyder and Mitchell (2006) defined disability as a body deficit or incapacity, and as a condition comprising a combination of factors: biological, cultural, experiential, environmental, and social. People classified with SMDD may have movement, communication, cognitive, sensory, and behavioral deficits, in addition to a host of medical complications, including cerebral palsy (NICHCY, 2004). Youth and adults with SMDD often require extensive support with multiple major life activities in order to participate in community settings, or to have the quality of life enjoyed by people who have fewer or no impairments. SMDD subsumes an amalgam of specific medical diagnoses and requires professional disciplines and support agencies working together to negate impairment or to help youth achieve alternative function, regardless of the etiology of the presenting impairments.

The SMDD definition above encompasses facets of definitions forwarded by researchers and a host of educational and social service organizations. Physical therapists work through these agencies to help negate impairments, improve functional capability, and overall quality of life for individuals with SMDD (Jette, 1993, 2005). While IDEA eligibility requirements for special education and related services insist that a student demonstrate characteristics from at least one of 13 disability categories, it is not unusual for students with SMDD to have multiple conditions. Estimates suggest that students with SMDD make up anywhere from 0.1 to 1 percent of the school-aged population of students with disabilities (Kim & Arnold, 2006). Albeit small, this diverse group of students represents huge challenges for teachers and related services providers in their efforts to help students learn and function effectively while they are in school, and to prepare them for postsecondary life.

Day-to-Day Challenges Faced by Students with SMDD

Service providers, teachers, and maybe some parents commonly believe that people with SMDD cannot take part in controlling their own lives because the decisions involved are too complex (Agran & Wehmeyer, 2000; Ward, 2006; Wehmeyer, 1998). Clear descriptions of students with severe and multiple developmental disabilities help providers to understand the day-to-day challenges that these students and their families face. A more complete and mutual understanding of students' strengths and limits enables providers to help students and families identify outcomes and determine and implement effective instructional strategies and supports, all within the context of the students' multiple system-constraints.

Related services providers, including physical therapists, must understand these students, and their various support agencies, to help negate their impairments, improve their functional capability, and their overall quality of life (Jette, 1993; 2005). Unfortunately, as the student with SMDD approaches graduation, PT interventions typically dwindle in frequency (David, 2005; Getzel & deFur, 1997; Inge, 1995), yet the number of skills required by the student with SMDD to function successfully in their postsecondary world outpaces their remaining time in public school (Shepherd & Inge, 1999).

Contemporary Views of Self-determination and Physical Therapy

Self-determination. Legislative attention and a growing number of research studies suggest that improving students' self-determination skills will enhance academic, employment, and quality of life outcomes for students with disabilities (Martin, Mithaug, Cox, Peterson, Van Dycke, & Cash, 2003; Wehmeyer, Garner, Yeager, Lawrence, & Davis, 2006; Wehmeyer, Palmer, Soukup, Garner, & Lawrence, 2007; Wehmeyer & Schwartz, 1997). Educational best practices now incorporate self-determination skills for transition-aged youths (Field & Hoffman, 2002; Test et al. 2004). Becoming self-determined involves interconnected elements that individuals learn across time, and for people with disabilities, requires specific interventions to increase skills (Carter, Lane, Pierson, & Glaeser, 2006; Mithaug, Mithaug, Agran, Martin, & Wehmeyer, 2003).

Teachers generally recognize the value and importance of teaching self-determination skills to help students with disabilities learn if they are going to achieve success both in school and after exiting high school (Agran & Wehmeyer, 2000). Yet, many special educators and related services providers still direct the educational programs and decision-making process for these students. Students have little control over what they learn, how to learn, and how to demonstrate what they have learned in meaningful ways (Sands &Wehmeyer, 1996).

For children with disabilities, developing self-determination facilitates achieving adult outcomes (Bremer, Kachgal, & Schoeller, 2003), and should be promoted at home, in school, in the community, and during physical therapy sessions. Critical elements of self-determination include opportunities for exercising personal choice, personal control of activities, and relevance of activities and choices to personal goals. Mithaug et al. (2003) suggest that the more that choice, control, and relevant goals exist between people with disabilities and those that teach or care for them, increased engagement and learning will occur.

Self-determination models. Originating with the *Adaptability Instruction Model* (Mithaug, Martin, & Agran, 1987), a number of self-determination models emerged enabling providers to teach and promote self-determination skills to people with SMDD (Field & Hoffman, 1997; Sowers & Powers, 1995; Wehmeyer, 1999; Wehmeyer, 2001). Later, Mithaug et al. (1987) built on the Adaptability Model and produced the *Self-determination Learning Theory.* The *Self-determination Learning Theory* is a multi-focal process whereby opportunities, engagement, and adjustment all factor into successful learning; it embodies self- and ecological influences on a person's ability to become self-determined.

The *Self-determined Learning Model of Instruction (SDLMI),* developed as an ecologically based instruction process, encourages students to recognize their abilities as well as support needs, to advocate for their own desires, and to self-regulate problem solving strategies, in order to achieve desired ends (Wehmeyer, 1999; Wehmeyer, Agran, Hughes, Martin, Mithaug, & Palmer, 2007; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). The *SDLMI* is implemented in three phases: setting a goal, taking action on the goal, and adjusting the plan to reach the goal. The *SDLMI* presumes that students with disabilities are the prime catalysts, and recognize that self-determination and independent performance are not synonymous (Wehmeyer et al. 2000). Research evidence supports successful implementation of the *SDLMI,* or its select components, with individuals who have developmental disabilities and receive interventions from a variety of professional disciplines (Kleinert, Gonzalez, Schuster, & Huebner, 2007; Wehmeyer 1999; Wehmeyer & Palmer, 2003; Wehmeyer et al., 2000; Wehmeyer et al., 2006), except physical therapy. To date, the literature reports no research investigating the impact of the *SDLMI* or its components within PT interventions and settings. The *SDLMI* is the foundation for the student-directed PT intervention condition under investigation in this study.

Physical therapy

Children with significant physical and cognitive impairments receive physical therapy (PT) throughout most of their public school lives. PT is one of a number of related services that are strongly implicated within IDEA (2004) to support postsecondary outcome achievement for youth with disabilities. Given the increased emphasis on improving access to the general education curriculum in integrated settings and the targeted postsecondary transition focus, related services like PT are expected to reflect the supports that students may need in order to benefit from transition services (David, 2005; Shepherd & Inge, 1999). Given improved technology and medical advances, children with developmental disabilities live well into adulthood; but they may lose functional mobility earlier due to secondary impairments (Connolly, 2005). Physical therapists need to understand and address these lifespan perspectives by applying evidence-based interventions that are focused on improving function for children adolescents, and adults with developmental disabilities (Campbell, 1997; Harris, 2005; Horsman, Suto, Dudgeon, & Harris, 2010).

The Value of Merging Self-determination and Physical Therapy

Graduates of physical therapy professional preparation programs still provide interventions that do not mesh with the postsecondary outcomes and needs identified by youth with SMDD and their families (Harris, 2005; Shepherd & Inge, 1999; Sylvester, 2006). The above definition implies that physical therapists typically determine goals and focus treatments on negating physical impairments and improving the quality of movement for children and adults with disabilities (McJansen, Ketelaar, & Vermeer, 2003; Shepherd & Inge, 1999; Sylvester, 2006). Treatment signifies that there is a cure; physical therapy is perceived as a treatment; therefore, efforts are toward a cure. Unfortunately, SMDD has no cure, so, physical therapy treatment implies a medical orientation to intervention, rather than acceptance of a human condition. When interventions are focused externally on trying to fix impairments of a child, without a common vision for the child's future, the intervention may hinder the child's development toward self-determination.

Related services literature seldom references self-determination (Klienert, 2005), even though IDEA (2004) requires related services to maximize learning for students with significant physical and cognitive impairments attending public school. IDEA also requires special education and related services to document the effectiveness of their intervention strategies to enable children with disabilities to benefit from special education. This includes provision of related services to enable transition-age youth to achieve post-high school adult employment, further education, and adult living outcomes. Studies in the field typically investigate the effectiveness of treatment techniques and protocols for children with disabilities relative to negating impairments, but do not look at long-term outcomes for participants. Related services providers rarely prioritize self-determination among their treatment strategies for a variety of reasons.

Powers et al. (2005) suggest that stigma, fear, and lack of interest are barriers preventing the advancement of self-determination for this population. Providers rarely address self-determination because other issues like education, high stakes testing, and health take precedence. In general, people with SMDD do not exhibit self-determination because they cannot communicate their preferences, and they have little exposure to the idea that they can impact their own lives in the first place (Powers et al., 2005).

Study justification. Growing research evidence suggests that people with disabilities achieve their chosen outcomes more readily when self-determination practices are promoted, taught, and used in relevant family, educational, vocational, and clinical settings. There is no research evidence to support clinician-directed PT interventions to help youth with SMDD gain functional mobility skills in relevant, non-clinical environments. This dearth of evidence raises important concerns about the effectiveness of clinician-directed PT interventions.

While emerging literature reveals some potential solutions for infusing self-determination into related services, even these are not without constraints and influence of traditional, more restrictive thinking. Consider again the opening scenario: "I don't want to go to therapy any more—I just want to go home and play, like my friends. I've been doing this ALL—MY—LIFE, and going to therapy doesn't make me feel like a regular person" (Snow, 2006, p. 16). This plea, by a young boy with cerebral palsy to his mom as he goes to physical therapy one day after school, portrays how this intervention is another reminder that he is not normal, and not like other children. His poignant statement shows the depth of his desire to just be a kid, and a budding, yet strong self-determination. This boy is trying to take control of his life by choosing to *not* participate in therapy. Does he value physical therapy for achieving the things he wants to do? Many other young children, now adults, with disabilities, echo his sentiments and indeed wish they had voiced them when they were younger (Sylvester, 2006).

As PT trends inch toward patient-directed interventions, therapist-driven approaches still abound in spite of the inconclusive results of long-term therapist-driven practice (Campbell, 1997; Harris, 2005; Wottrich, Stenstrom, Engardt, Tham, & von Koch, 2004). Nevertheless, physical therapists have unique skills that can support and help people with disabilities overcome barriers and learn alternative ways of achieving preferred goals (Flexer, Baer, Luft, & Simmons, 2001; McEwen, 1998; Wehmeyer, 1992).

This study is the first to merge self-determination intervention strategies into the PT arena, thereby extending the research base in both areas. It explores whether utilizing an established self-determination model, the *Self-determined Model of Instruction,* during PT interventions promoted functional mobility skill acquisition across applied settings for students with SMDD.

Investigative Approach

My investigative approach melded transformative, constructivist, and post-positivist research paradigms (Mertens, 2005). The fundamental principles of the *SDLMI* provided the transformative perspective given its unique application with people who have SMDD and participate in physical therapy. The constructivist paradigm helped to determine meaningful mobility skills with study participants. My research design choice recognized a post-positivist urge to analyze the immediate, lasting, and generalized benefits of two different intervention approaches within a discipline that strives to demonstrate its effectiveness for a still marginalized group of youth. With these paradigms in mind, I present the general purpose and specific research questions for this study.

Purpose

This study extended the self-determination research into the related services arena and explored whether utilizing an established self-determination model during PT interventions promoted functional mobility skill acquisition in students who have severe and multiple developmental disabilities. I wanted to determine how well students with severe and multiple developmental disabilities who receive self-determined PT interventions gained functional mobility skills and demonstrated use of self-determination skills from the *Self-determination Learning Model of Instruction* in the process. Irrespective of intervention conditions, I also investigated whether or not learned mobility skills were maintained and generalized to new environments. To these ends, the following specific research questions were addressed.

Research Questions

1. Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions achieve a higher percentage of functional mobility steps compared to when they receive clinician-directed physical therapy interventions?
2. Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions require fewer and less intrusive prompts to complete their functional mobility task compared to when they participate in clinician-directed interventions?
3. Do individuals with severe and multiple developmental disabilities and their caregivers participating in self-directed physical therapy interventions more often identify supports to accomplish their functional mobility task compared to when they participate in clinician-directed physical therapy interventions?
4. Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions demonstrate a higher percentage match with therapist and caregiver self-evaluation responses about their mobility skill progress compared to when they participate in clinician-directed physical therapy interventions?

5. Do individuals with severe and multiple developmental disabilities and their caregivers participating in self-directed physical therapy interventions suggest more adjustments to achieve targeted mobility skills compared to when they participate in clinician-directed physical therapy interventions?
6. Do individuals with severe and multiple developmental disabilities complete the same, higher, or a lower percentage of functional mobility steps in a new applied setting of their choice compared to when they are in a familiar setting?

CHAPTER TWO

Literature Review

Graduation from high school is a major stop on the transition itinerary for all youth; but is it their final destination before falling into a stagnant black hole, or is it a springboard to further education, employment, and a preferred quality of adult living? Students with severe and multiple developmental disabilities (SMDD) and their families make this trip too, but their journeys are laden with detours and stops that either block a preferred destination or smooth the road.

This literature review begins by situating youth with SMDD within relevant disablement models, and it frames the SMDD descriptor using medically and socially constructed labels that define and engender supports for them, including physical therapy (PT). Second, postsecondary transition outcomes for youth with SMDD are revealed along with presentation of contemporary evidence-based practices that can enhance students' involvement in their own transition planning process. Self-determination concepts, theoretical frameworks, and interventions are described relative to youth with SMDD, thus acknowledging the integral linking of self-determined and successful transition planning practices. Specifically, research evidence surrounding the overall effectiveness of the *Self-determined Learning Theory (SDLT)* and the *Self-determined Learning Model of Instruction (SDLMI)* for youth with varying disabilities within vocational, educational, and community living settings is presented. Third, I focus on literature that investigates the effectiveness of self-determination components and the *SDLMI* as applied with youth who have SMDD, and within related services, scant as it is. Fourth, physical therapy is defined within contemporary transition planning and self-determination preferred practices. Last, the summary merges self-determination and physical therapy best practices to enhance physical therapy and postsecondary outcomes for youth with SMDD, setting the stage for this investigation.

Severe and Multiple Developmental Disabilities Theoretical Framework

To define and describe youth with SMDD requires knowledge about medical, social, philosophical, legislative, and educational issues that simultaneously serve to marginalize and support people with disabilities. Defining disability has significant implications for the way we associate with, educate, and provide support for children and adults who have disabilities (Edwards, 2005). Youth with SMDD are described by their varied clinical presentations, or body system impairments, that start early in life, often at or before birth. They are later described according to criteria set by various agencies and classification systems that support them at home, school, and in the community. Indeed, the general definition applied to disability forms the basis for political, legislative, and programmatic activities that either include or exclude people based on their disability category at all points along the lifespan (Edwards, 2005). This section begins with relevant disablement models that are based in clinical and social frameworks, as well as international disablement models, and then select categorical definitions of pertinent disabilities that make up the SMDD complex are presented. The summary definition of SMDD ending this section comes full circle with the description forwarded in Chapter one.

Relevant Disablement Models

Contemporary disablement models that describe and classify children and adults with disabilities infuse moral, medical, rehabilitative, social, and cultural characteristics (Kaplan, 2000; Whiteneck, 2006). Kaplan described a connection between morality and disability; that is, disability is the result of sin, or some other moral turpitude. Snyder and Mitchell (2006) described the common association of a *disabled body* with disenfranchisement from the late 18th century that is still with us today. Snyder and Mitchell located disability entrenched in bodily-based incapacities that shaped medical, rehabilitation, aesthetic, cultural, and civil rights agendas. Devalued body conditions were connected to decreased social value (Snyder & Mitchell, 2006). Though not as prevalent, remnants of these eugenics practices and beliefs are evident throughout the history of disability.

Medical model. Physical therapists are familiar with the medical model; it defined disability in terms of illness and infirmity, where a person required significant care, usually outside of mainstream society (Kaplan, 2000). There was no expectation for the person with disability to contribute to their community. When special education was established, the medical model defined eligibility for special education services by virtue of the assignment of 13 diagnostic categories and remains so today (Triano, 2000; Simeonsson, 2005). Unfortunately, a system of biologically based medical deficits suggests deficits in social worth, often resulting in the maintenance of an oppressed state for people with disabilities (Clark & Lillie, 2000; Snyder & Mitchell, 2006).

Rehabilitative model. Kaplan's (2000) rehabilitative model presumed that the person with disability could and should be cured. As an offshoot of the medical model, the rehabilitation model promoted medical professional involvement in trying to fix impairments, and restore function. Section 504 of the Rehabilitation Act of 1973 defined a person with a disability as having “one or more physical or mental impairments that substantially limit one or more major life activities, has a record of such an impairment, or is regarded by others as having such an impairment” (20 U. S. C. 794 § (1) (j); (2) (i - iii). This law also covered individuals who were treated *as if* the impairment substantially limited major life activities, even if the impairment did not.

Disability rights model. The disability rights and independent living movements promoted disability as a social issue, from the perspective of the person with a disability living in the community. Disability was described as a natural human occurrence – a part of a person that does not require pity, cure, or treatment, but does presume access to and participation in society at large. The Americans with Disabilities Act, a byproduct of this social and environmental impact on perceptions of disability (Kaplan, 2000), promoted inclusion of people with disabilities by prohibiting discrimination on the basis of disability in employment, public state or local governments, public accommodations and telecommunications (Snow, 2006).

Disablement in PT. Table 2.1 demonstrates the major shifts in international disability conceptualization that occurred over the last generation. Disablement refers to the “various impact(s) of chronic and acute conditions on the functioning of specific body systems, on basic human performance, and on people’s functioning in necessary, usual, expected, and personally desired roles in society” (Verbrugge & Jette, 1994, p. 3). Physical therapists try to impact all of these areas through their interventions. Yet, achieving universal disablement terminology in medicine, medical research, and rehabilitation services provision, including physical therapy, is a recent professional focus (Stucki, 2005; Jette, 2006). Emerging from a study commissioned by the Social Security Administration, Nagi's (1964) conceptual framework focused on the interrelationship between pathology, impairment, functional limitation and disability, forming the basis for determining rehabilitation potential and achievement. In 1991, the Institute of Medicine (IOM) accepted and promoted Nagi's revision of his disablement model to reflect the impact of social and environmental processes in medicine and rehabilitation (Masala & Petretto, 2010). The IOM later elaborated on Nagi's model by considering two critical pieces to the disablement puzzle: secondary conditions and quality of life (Jette, 2006).

Derived from Nagi's model around the same time, the National Center for Medical Rehabilitation Research (NCMRR) model investigated how individuals adapted to their functional limitations at home, at work, and in their communities. The NCMRR described and dynamically linked pathophysiology, impairment, functional limitations, disability and social factors in the effort to improve the quality of epistemological and scientific rehabilitation (U.S. Department of Health and Human Services, 1993; Masala & Petretto, 2010).

Released in 2001, the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF) language unifies communication across medical and rehabilitation providers, encourages interdisciplinary research, and better informs health policy and management (Jette, 2006; Stucki, 2005; Stucki, Ewart, & Cieza, 2003; WHO, 2001; Whiteneck, 2006). The biopsychosocial framework of the ICF extends our habilitation and rehabilitation efforts beyond disease processes and impairments to facilitating improved quality of life with a disability (Jette, 2006).

Implications for physical therapists. The *Guide for Physical Therapist Practice* (*Guide*) still references Nagi's model for framing disablement in terms of pathology, impairment, functional limitation, and disability, although it incorporates broad interpretations of other models (American Physical Therapy Association, 2003). The *Guide* is now under revision to ensure language and conceptual consistency using the ICF for physical therapists. It promotes universal, standardized disablement language and an intervention framework that focuses less on mortality and disease process, and more on how people with disabilities live with their conditions (Jette, 2006). Figure 2 depicts the ICF model relative to physical therapist practice.

Table 2.1

Concepts and Terminology Used by Models of Disability

Model, Year	Origin	Organ Level	Person Level	Societal Level	Other Domains
Nagi, 1976	Pathology	Impairment	Functional limitations	Disability	
WHO, 1980	Disease	Impairment	Disability	Handicap	
IOM, 1991	Pathology	Impairment	Functional limitations	Disability	
NCMRR, 1992	Patho-Physiology	Impairment	Functional limitations	Disability	Societal limitations
IOM, 1997	Pathology	Impairment	Functional limitations	Disability	Environmental factors quality of life
WHO, 2001 (ICF)	Health Condition	Body structure and function	Activity	Participation	Environmental factors, personal factors

Note. From "Workshop on Disability in America," by M. J. Field, A. M. Jette, and L. Martin, 2006, *Future of Disability in America,* p. 54. Copyright 2006 by the Institute of Medicine of the National Academies. Reprinted with permission (Appendix A).

Derivation of the SMDD Definition

Snyder and Mitchell (2006) defined disability not only as a body deficit or incapacity, but also as a condition comprising a combination of factors: biological, cultural, experiential, environmental, and social. People classified with SMDD may have movement, communication, cognitive, sensory, and behavioral deficits, in addition to a host of medical complications, including cerebral palsy (NICHCY, 2002). Youth and adults with SMDD often require extensive support with multiple major life activities in order to participate in community settings, or to have the quality of life enjoyed by people who have fewer or no impairments. SMDD subsumes an amalgam of specific medical diagnoses, professional disciplines, and support agencies working together to negate impairment or to help youth achieve alternative function, regardless of the etiology of the presenting impairment. The next sections describe four of the most common diagnostic categories typically presented in the SMDD complex.

Intellectual disability. Intellectual disability is the current term used to describe individuals who were formerly diagnosed with mental retardation (AAIDD, 2008; Lucasson, et al. 2002). It is an important diagnosis to consider given that many youth with SMDD also have cognitive impairments. The definition of intellectual disability proffered by the American Association on Intellectual and Developmental Disabilities (AAIDD) is the same as that promulgated for mental retardation by the American Association on Mental Retardation (AAMR, 2002; AAIDD, 2008; Lucasson, et al. 2002). Intellectual impairments originated before age 18, and are characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed by conceptual, social, and practical adaptive skills (AAIDD, 2008). Devlieger's (1999) semiotic distinction between abilities and access for people with impairments aligns with five essential assumptions forwarded by the AAIDD: (a) consider limitations in present intellectual and adaptive behavior functioning within the context the person's age, peers, and culture; (b) assess cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioral factors; (c) recognize that limitations often coexist with strengths within an individual; (d) accurate description of limitations helps to develop a plan for needed supports; and (e) providing appropriate personalized supports over a sustained period of time can improve functioning of the person with intellectual disability. Unlike developmental disability and cerebral palsy, intellectual disability distinctly presumes cognitive impairments, with or without the presence of other impairments.

Developmental disability. The Developmental Disabilities Bill of Rights Act of 2000 included the essence of the AAIDD definition as follows:

> Developmental disability means a severe, chronic disability of an individual five years of age or older that: (a) is attributable to a mental or physical impairment or combination of mental and physical impairments, (b) is manifested before the individual attains age 22, (c) is likely to continue indefinitely, (d) results in substantial functional limitations in three or more of the following areas of major life activity (self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and

> economic self-sufficiency), (e) reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, supports, or other assistance that is of lifelong or extended duration, and (f) is individually planned and coordinated (Pub. L. No. 106-402, § 102, 114 Stat.1684).

While cognitive impairments are the hallmark of the definition of intellectual disability, they may or may not be part of the developmental disability scenario.

Cerebral palsy. Even though cerebral palsy (CP) is a common, well-recognized and generally understood neuromotor condition of youth and adults receiving physical therapy, its definition continues to challenge physicians and researchers, as noted by the numerous attempts to redefine it over the years. Its definition reflects a variety of factors associated with understanding developmental neurobiology, changing functional status and changes in service delivery to children with disabilities (Bax, Goldstein, Rosenbaum, Leviton, & Paneth, 2005). The current proposed definition of CP is “a group of disorders of the development of movement and posture causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of CP are often [but not always] accompanied by disturbances of sensation, cognition, communication, perception, and/or behavior, and/or by a seizure disorder” (Bax, et al., 2005, p. 572). Like the definition of developmental disability, CP is characterized by the early inception of a variety of motor, sensory, communicative, and possibly (but not certainly) cognitive deficits.

Special health care needs. Special health care needs is an umbrella term often used to describe youth with multiple disabilities (Bryan, Stiles, Burstein, Ergul, & Chao, 2007). It can include one of about 200 chronic conditions affecting children and may include a myriad of physical problems like cerebral palsy, spina bifida, asthma, or diabetes, cognitive deficits like Down syndrome, developmental delays, and behavioral or emotional conditions (Newacheck & Stoddard, 1994), or a combination of these. Like children with intellectual disability, developmental disability, and CP, children with special health care needs are also heterogeneous in the types and severity of physical, health, cognitive, and communicative limitations they present. Again, cognitive impairments may or may not factor into the special health needs diagnosis. Newacheck and Stoddard indicate that transition planning for this group is often not a priority given the significance of their health issues.

Severe disabilities. People described by any of the above disability definitions may be classified on a continuum of severity that might include mild, moderate, severe, or profound. This classification is meaningless independent of other descriptors, but often relates to how society perceives the individual (Triano, 2000). A person can have severe cognitive or intellectual impairments (with or without physical impairments), severe physical impairments (with or without intellectual impairments), or severe communication impairments sans either intellectual or physical impairments. TASH, a long-standing disability advocacy organization, described these individuals with significant disabilities and support needs as people who are

> most at risk for being excluded from society; perceived by traditional service

> systems as most challenging; most likely to have their rights abridged; most likely to be at risk for living, working, playing, and learning in segregated environments; least likely to have the tools and opportunities necessary to advocate on their behalf; and are most likely to need ongoing, individualized supports to participate in inclusive communities and enjoy a quality of life similar to that available to all people (TASH, 2011).

Summary of Disability Models and SMDD Definition

When considering attitudes toward and interventions on behalf of people with disabilities, it is critical to understand that attitudes do not develop in a vacuum. These self and societal attitudes comprise complex and dynamic social, political, economic, and technological emphases at particular points in time (Wappett, 2002), and figure prominently in how we define and determine eligibility for services for youth and adults with SMDD.

In the end, no single definition accurately depicts individuals with multiple-system impairments. The simplest definitional solution lies in Tasse’s (2002) rationale for the original AAMR definition of mental retardation. Regardless of the person’s diagnosis, understanding their support needs is more useful than emphasizing deficits and functional skill levels. Knowing that a disability happened at or around the time of birth explains the developmental aspect of the definition. But, arranging useful supports is the critical intervention that enables an individual to achieve his chosen outcomes (AAIDD, 2008).

Turnbull, Turnbull, and Wehmeyer’s (2007) simple criteria can be reliably observed in people with severe and multiple developmental disabilities: (a) two or more disabilities typically occur simultaneously, and (b) the supports required are usually extensive or pervasive.

Students with SMDD in this study. People with SMDD in my study may encompass descriptions from some or all of the above disability categories. They all have severe impairments requiring physical, cognitive, communicative, or other daily care supports. For this study, youth and adults with SMDD experienced deficits before or around the time of birth; they have two or more disabilities occurring simultaneously; the mobility, learning, physical, communication, and self-care supports they require to achieve community living, employment, and self-sufficiency are extensive and pervasive.

Students with SMDD require systematic instruction and support in many areas in order to achieve the quality of life they choose. Supporting self-determined learning processes may help students with SMDD achieve meaningful outcomes beyond impairment-level improvement. Self-determination is both a valued transition outcome and process used by students to achieve their transition and postsecondary outcomes (Agran, Snow, & Swaner, 1999). The next section explores evidence-based transition practices that promote achievement of postsecondary goals and transition outcomes for youth with SMDD.

Postsecondary Transition for Youth with SMDD

The last 25 years of transition education research lends value and credence to a process that helps students succeed in life after high school (Alwell & Cobb, 2006; Halpern, 1990; Hasazi, Furney, & Destefano, 1999; Johnson, 2004; Johnson & Rusch, 1993). This section defines and describes postsecondary transition for youth with SMDD. It investigates transition outcomes expressed by students with SMDD before they graduate from high school, and explores postsecondary employment, educational, and adult living outcomes they actually achieve. A discussion surrounding postsecondary health care transition is provided given the association between good health and one's ability to work, attend college, and live independently. I explore contemporary transition practices using *The Taxonomy for Transition Programming* (Kohler, 1996) as a categorical outline before leaving this section.

Transition Defined

Blum, Hirsch, Kastner, Quint, and Sandler (2002) defined transition as "a dynamic, lifelong process that seeks to meet individuals' needs as they move from childhood to adulthood" (p.1304). During the postsecondary transition process, students with disabilities and their families gradually adopt new roles and modify existing roles (King, Baldwin, Currie, & Evans, 2005). The Career Development and Transition Division of the Council for Exceptional Children defined transition as

> Change in status from behaving primarily as a student to assuming emergent adult roles in the community. These roles include employment, participating in postsecondary education, maintaining a home, becoming appropriately involved in the community, and experiencing satisfactory personal and social relationships. The process of enhancing transition involves the participation and coordination of school programs, adult agency services, and natural supports within the community. The foundations for transition should be laid during the elementary and middle school years, guided by the broad concept

> of career development. Transition planning should begin no later than age 14 (now 16), and students should be encouraged, to the full extent of their capabilities, to assume a maximum amount of responsibility for such planning (Halpern, 1994, p. 117).

The general mission and purpose of special education according to IDEA (2004) builds upon Halpern's (1994) view: "to ensure that all children with disabilities have available to them a free and appropriate public education that emphasizes special education and *related services* designed to meet their unique needs and prepare them for *further education, employment, and independent living*" (p. 1255). While all of special education's work is geared toward preparing students for postsecondary life, transition services also provide the coordinated activities that should facilitate progression from high school to adulthood.

Transition Outcomes for Students with SMDD

Over the last decade or so, improvements in transition services have resulted in more youth with disabilities graduating from high school and moving into satisfying adult lives. Yet, postsecondary expectations and transition planning for students with more significant disabilities lags behind and is somewhat more challenging to discern (Bryan et al. 2007; Cameto, Levine, & Wagner, 2004; Gallivan-Fenlon, 1994; Getzel & deFur, 1997; Liebert, Lutsky, & Gottlieb, 1990; Stewart, Law, Rosenbaum, & Willms, 2001; Young et al. 2006). Today, most students with SMDD do not, nor are they expected to go to college or become employed after leaving high school, and less than 10% work competitively in an integrated setting (U.S Department of Education, 2004; Wills & Leucking, 2003). Of those employed, most work at stereotypical jobs, and many work for sub-minimum wages in a special minimum wage program authorized by the Fair Labor Standard Act (Cameto, et al., 2004; Inge & Moon, 2006). About 95% of the adults working under this program still work in extended employment, formerly known as sheltered employment; and indeed, most IEP team members continue to expect this outcome for students with more significant disabilities (Gallivan-Fenlon, 1994; Inge & Moon, 2006).

The National Longitudinal Transition Study (NLTS) provided over a decade of data surrounding transition outcomes for youth with SMDD in the United States and abroad in each of the 12 special education disability categories (Newman, Wagner Cameto, Knokey, & Shaver, 2010; Newman, Wagner, Cameto, & Knokey, 2009; Cameto, et al. 2004). Through two large investigations the NLTS gathered data surrounding postsecondary transition goals stated by students prior to graduation as well as actual post-high school employment, education, and adult living outcomes achieved (Newman et al., 2010; Newman et al., 2009; Cameto et al. 2004, Wagner, Newman, Cameto, Levine, & Garza, 2006). A recent report compared postsecondary outcomes achieved for a subset of students with disabilities participating in the NLTS in 1990 and the second NLTS in 2005.

In spite of well-intentioned legislation and a number of proven interventions that are known to positively impact educational, employment, and adult living outcomes for youth with disabilities, post-school outcomes remain disappointing (Wills & Leucking, 2003). Do students with SMDD identify postsecondary employment, education and adult living goals while they are still in high school?

How do youth with severe and multiple disabilities, and those with incumbent special health care needs, fare in terms of postsecondary outcomes achieved? Multidisciplinary research informing the postsecondary outcomes literature base for youth with SMDD surfaced, but these studies were sometimes difficult to decipher. Data were difficult to disaggregate by severity and multiplicity of impairments to match the participants with SMDD in my study.

Though experimentally non-rigorous, a recent mixed-methods Canadian study provided a comprehensive picture of educational, employment, adult living, and health status outcomes for youth who typified students with the most pervasive and intensive support needs (Young et al., 2006). Out of their sample of 100 adults and 190 youth who had cerebral palsy, spina bifida, and traumatic brain injuries, Young et al. found that 95% of youth and 61% of the adults lived with parents, 55% of the adults were employed compared to 23% of the youth, and 43% of the adults enjoyed very good health compared to 60% of the youth.

Though a decade of NLTS data revealed some positive trends for young adults with disabilities, postsecondary employment, education, and adult living outcomes remained less than optimistic for students who have severe and multiple disabilities, with comparatively little change noted for these particular student cohorts from 1990 to 2005 (Newman, Wagner Cameto, Knokey, & Shaver, 2010). Interpreting both the NLTS and NLTS2 data requires caution given that almost two-thirds of both samples included youth with learning disabilities. Disability categorization in the respective student cohorts did not necessarily reflect the actual severity of the disability, leaving the potential for substantial functional variation between participants. The NLTS described and compared postsecondary outcomes that students representing the 12 federal special education disability categories identified and achieved. Students with disabilities who were in seventh grade or higher in December 2000, and sometimes, their guardians, were interviewed by phone or mail survey regarding the graduate's postsecondary outcome-achievement since exiting high school. Therefore, NLTS data for youth who have multiple disabilities, the category most like SMDD (Newman et al., 2010; Newman et al., 2009; Wagner et al., 2006; Cameto et al. 2004), compared to data for youth who have the sole impairments of learning disability, mental retardation, and emotional disturbances will be described.

Postsecondary Transition Goals Identified While Still in School

Employment. NLTS2 data revealed that only 27% of youth with multiple disabilities expressed a goal to attain competitive work compared to 57% of students with learning disabilities, 58% of students with emotional disturbances, and 44% of students with mental retardation. Over 66% of youth with multiple disabilities identified supported or sheltered work for sub-minimum wages, compared to 2.5%, 11.3%, and 54% for youth with learning disabilities, emotional disturbances, and mental retardation, respectively (Cameto et al., 2004).

Education. While in high school, 30% of youth expressed a postsecondary education goal to attend either a two or four-year college, or a vocational training program. In comparison, nearly 98% of students with learning disabilities, 36% of students with mental retardation, and 93% of students with emotional disturbances identified a postsecondary educational goal (Cameto et al., 2004).

Adult living. Thirty-five percent of students with multiple disabilities expressed the desire to live independently, compared to almost 50% of students with learning disabilities, 51.6% of students with mental retardation, and 53.3 % of students with emotional disturbances, respectively. More students with multiple disabilities identified adult living goals to 'maximize functional independence' or to 'enhance social and interpersonal relationships' compared to their peers in the other categories (Cameto et al., 2004).

Summary of postsecondary goals identified while in high school.

The inequality between my SMDD definition and the NLTS2 multiple disabilities category makes it difficult to make global assumptions for either group for employment, education, or adult living. Considering that by the definition offered in Chapter one, students with SMDD will likely present more system impairments and require more supports to achieve postsecondary outcomes. Therefore, it is realistic to suspect that the percent of goals students identified in high school could actually be lower than those reported.

Achieved Postsecondary Employment, Education, and Adult Living Outcomes

Overall, NLST2 data revealed that youth with intellectual and multiple disabilities were least likely to be involved in employment, postsecondary education, or job training four years after completing high school (Newman et al., 2009; Cameto et al., 2004). These youth had fewer social interactions, were least engaged in volunteer service, extra curricular classes, or community groups, and were less financially independent compared to youth in other disability categories. Other investigations corroborate these findings.

Achieved employment. Liebert et al. (1990) investigated the postsecondary experiences of 106 youth and adults with severe physical disabilities. Of these, 23% had neurological deficits; 15% had cerebral palsy; and orthopedic impairments that included spina bifida, birth defects, or accidents accounted for 54%. Participants' IQ scores ranged from 91 to 105. While 62% of the participants in Liebert et al.'s study were employed either full or part-time in competitive jobs, 12% were unemployed and seeking work. About 25% were not seeking work due to health and other unspecified reasons. Over half of the participants used personal networks via family and friends to find jobs, instead of job placement agencies. Respondents who had received vocational rehabilitation services were more likely to be employed and received attendant care or other services from that agency. Most of the participants indicated that their continued employment resulted from their own determination to work, which was supported by their families' expectation for their sons and daughters to work and support themselves. Contrary to studies from the United States (Hasazi, Furney, & Destefano, 1999; Benz, Yovanoff, & Doren, 1997; Blackorby & Wagner, 1996), high school paid work experience was not associated with better employment status or higher salary. Liebert et al. named transportation, age, contact with the Office of Vocational Rehabilitation (OVR), and job referrals as the four best predictors of employment after high school. Education level was the only factor that discriminated job skill level. College graduates had more skilled jobs than non-graduates, and individuals working for higher pay had higher job satisfaction. Neither severity of disability or medical condition related to job skill or satisfaction (Liebert et al., 1990).

Results from a comprehensive Canadian outcomes survey of youth with cerebral palsy, spina bifida, and acquired brain injury revealed similar employment outcomes (Young et al., 2006). Young and colleagues clarified their participants' severity of disability using the Gross Motor Function Classification System (GMFCS) developed by Palisano et al. (1997) and Palisano, Rosenbaum, Bartlett, and Livingston (2007) by considering gait and communication difficulties, all methodological details considered in my proposed methodology. Adults with cerebral palsy were less likely to be employed and were not looking for work, although 75% of the youth did not answer the employment survey questions. The latter finding could indicate either the perceived irrelevance of work, or the sensitivity and difficulty surrounding finding meaningful employment (Young et al., 2006).

Wills and Leucking (2003) reported that employment and economic outcomes for youth with disabilities remained poor, and that the employment outcomes for youth with significant disabilities were even worse. The U. S. Department of Education (2004) reported that one out of 10 youth with severe and multiple disabilities work in integrated settings, five out of 10 endured extensive waits for postsecondary adult employment support services, and most of the youth earned less than $2.40 per hour in sheltered employment settings.

In a survey of 55 youth with disabilities and special health care needs, Bryan et al. (2007) found that 20% of respondents had either minimum wage-paying jobs, or volunteered for no pay. While at least 66% of the youth identified employment goals when asked, many participants stated non-specific goals like getting rich, working with children, or just getting a job (Bryan et al., 2007). Of the youth who stated specific employment goals such as becoming a lawyer or teacher, Bryan et al. found these youth unable to specify how they would achieve their career goals.

Newman et al., (2009) found that compared to their peers without disabilities (66%), 57% of respondents with disabilities were employed for pay outside the home at the time of the survey interview. At least 72% of youth with disabilities had worked at some point since completing high school, and about 15% of youth with disabilities who worked for pay just after high school were not working at the time of the wave 3 interview survey, indicating the employment flux apparent for youth with disabilities. Four years after high school, youth with orthopedic impairments, mental retardation, or multiple disabilities remained least likely to be currently working, or working at all since high school compared to youth in all other disability categories (Newman et al., 2009). For example, only about 65% of youth with mental retardation and multiple disabilities reported engagement in school, work, or preparation for work compared to youth with other health impairments (92%), learning disabilities (89%), hearing (86%), or visual impairments (88%), respectively. In all employment-related comparisons, youth with mental retardation and orthopedic impairments worked significantly less (52% and 40%) compared to youth with learning disabilities, speech/language impairments, and other health impairments (73 percent to 80 percent, respectively, $p < .001$). Youth with emotional disturbances were more likely to have worked since high school compared to youth with orthopedic impairments (63 percent vs. 40 percent, $p < .01$).

NLTS2 data suggested that students with SMDD still did not work for pay at levels enjoyed by their peers with singular impairments. Compared to students with mental retardation (49%), fewer students with multiple disabilities were employed full-time, or more than 35 hours per week (29%). Students with multiple disabilities reported more part-time employment, less than 35 hours per week, at 71.5% compared to 51.2% of youth with mental retardation (Cameto et al., 2004). These results were even less encouraging considering that some of the employment data in categories like mental retardation may have been inflated. NLTS2 researchers did not delineate specific competitive employment criteria. Paid employment included school, supported, or sheltered employment where participants earned sub-minimum wages (Cameto et al., 2004).

Compared to earlier NLTS data, Newman et al. (2010) found no differences in employment status (job duration, hours worked per week, job type, average wages, or health insurance benefits) for students with disabilities across the board. However, students' rates of concurrent engagement in employment and postsecondary education in 2005 was significantly greater compared to 1990 (21% vs. 9%). Students with multiple disabilities reported a higher rate of community engagement in 2005 (86%) compared to 45% in 1990; however, the data does not differentiate between adult day programs or other community activities.

Achieved postsecondary education. An early study by Love and Malian (1997) reported that about 16% of youth with disabilities and health care issues had access to postsecondary education compared to 56% of the general population. In a similar investigation surrounding postsecondary education participation of young adults with severe physical disabilities, Liebert et al. (1990) found that youth attended higher education and had either earned or expected to earn degrees. Nevertheless, most of the participants reported difficulty adjusting to college, and they felt academically unprepared for college. Recently, Young et al. (2006) reported similar results for adults with spina bifida. Students in the Young et al. study finished high school or higher education; however, they did not achieve their expected educational standards or typical diploma, making postsecondary education data difficult to disaggregate.

Consistent with NLTS2-Wave 2 data (Wagner et al., 2006), Newman et al., (2009) reported nearly half of the youth with disabilities in all disability categories represented in the NLTS2-Wave 3 data to be engaged in some form of postsecondary education, compared to youth with mental retardation multiple disabilities (27%). About 35% of youth with multiple disabilities, compared to 27% of youth with mental retardation attended any postsecondary institution at all. Nearly 18% of students with multiple disabilities attended a 2-year community college, compared to 20% of their peers with mental retardation, demonstrating a slight decrease compared to Wave 2 findings. Slightly improved over Wave 2 data, 16% of Wave 3 students with multiple disabilities attended a vocational or technical school, compared to 21% of students with mental retardation, and 19% of students with orthopedic impairments. Again demonstrating slight (but not significantly) improved findings over Wave 2, nearly 10.5 percent of students with multiple disabilities in Wave 3 attended a 4-year college, comparable to the 4.6% of students with mental retardation and nearly 7 percent of youth with traumatic brain injury (Newman et al., 2009). It is notable that students with mental retardation and multiple disabilities also were enrolled in postsecondary education at less intense levels compared to all other students with disabilities.

The recent and slightly improved postsecondary education participation data is encouraging because the educational experiences reported were confined to distinct programs, including 2 or 4-year college or vocational/technical education programs. In contrast, students in the Wagner et al. earlier report attended a variety of postsecondary educational programs (2- or 4-year college, career or technical school, or any customized job-training that was not provided by a family member). It is conceivable that some of the earlier reported postsecondary education occurred in sheltered vocational training programs, again causing statistical inflation. While these vocational training premises did occur in the 'community', the experiences typically remained segregated. Recent NLTS2 data considered sheltered work and training as part of the community engagement, to be discussed under the following adult living section.

In recent comparative NLTS data Newman et al. (2010) found that students with disabilities generally enrolled in postsecondary education at a higher rate in 2005 (46%) compared to 1990 (19%). Specifically, students with hearing impairments, mental retardation, learning disabilities, and emotional disturbances showed the greatest increase in postsecondary education enrollment. Yet, students with multiple disabilities or other health impairments showed no significant changes in adult living status between 1990 and 2005.

Achieved adult living. Wagner et al. (2006) reported that most students with multiple disabilities in the NLTS2 study (73%) wanted to live with a parent, compared to 49% of students with mental retardation. Nearly 27% of students with multiple disabilities wanted to live elsewhere, compared to 44% of their peers with mental retardation. More recently, Newman, Wagner, Cameto, and Knokey (2009) reported youth with mental retardation and multiple disabilities to be less financially independent and less engaged in their communities compared to other youth with disabilities, and typical high school graduates. Most recent NLTS data reveal no significant changes in residential or financial independence for this group of youth between 1990 and 2005. However, youth with disabilities in general acquired voter registrations, savings accounts, and drivers' licenses at a higher rate in 2005 compared to 1990 (Newman et al., 2010).

Canadian findings from Young et al. (2006) revealed that 95% of youth and 61% of adults with CP, spina bifida, or brain injury lived with their parents. Four percent of youth and 10% of adults with CP lived in group-homes. Although most of the youth in Young's study reportedly made successful health care transitions, it is likely that adults with more severe disabilities remained at home with parents because they needed care.

Most of the graduates with severe disabilities surveyed by Liebert et al. (1990) also remained single and lived at home with parents. Fifty-six percent of the participants needed assistance in some daily living activity, i.e., dressing and homemaking. Considering the participants' day-to-day support needs, it was curious to note that not more of them had accessed the OVR for assistance.

Summary of achieved postsecondary outcomes. Legislation like *No Child Left Behind* and the *Individuals with Disabilities Education Act* contributed to today's results- and outcome-oriented legislative climate and possibly promoted increased achievement of postsecondary education, compared to vocational goals. Yet, the type of transition planning, levels of support, and postsecondary agency contacts should be aligned with post-school service needs identified in the student's IEP, all of which should reflect the student's post-school goals. Just as Gallivan-Fenlon (1994) found, youth with disabilities were not remaining competitively employed, even if they were gainfully employed just after graduation. The needs and related services identified for students with SMDD continue to reflect post-school goals for obtaining supported or sheltered employment, maximizing functional independence, or improving social and interpersonal skills, compared to goals targeted toward postsecondary education. Youth who demonstrate greater severity or multiplicity of impairments generally require more physical supports. Higher support needs likely reflect the need for adults with SMDD to live with their parents or seek paid assistance through a group-home living situation, just to ensure adequate care. These findings are significant for youth who require the most intensive supports to thrive in a community environment, and are consistent with more recent data (Sylvester, 2006).

Summary of Educational, Employment, and Adult Living Outcomes for Youth with SMDD

Remembering the definitional dilemma described in section one, the special education professional literature provided most of the transition outcome research surrounding one facet of the SMDD continuum. A few research teams studied transition to adulthood issues for youth with specific physical disabilities (Cameto et al., 2004; Liebert et al., 1990; Newman et al., 2009; Newman et al., 2010; Stewart et al., 2001; Wagner et al., 2004; Young et al., 2006). A host of studies from special education or vocational rehabilitation literature considered youth and adults with severe or multiple disabilities (Gallivan-Fenlon, 1994; Getzel & deFur, 1997; Reid, Parsons, & Green, 1998; West, 1995). Overall, youth with severe and multiple disabilities remain less likely to be competitively employed, enrolled in postsecondary education, or residentially or financially independent.

Special Health Care Transitions, Related Services, and Quality of Life Outcomes

The *Olmstead* Supreme Court decision in 1999 urged federal, state, and local governments to develop increased opportunities for people with disabilities by making community-based services more accessible and cost effective. This decision impacted individuals with the most significant disabilities and health care concerns by ensuring availability of reliable non-institutional community living and health care options (Johnson, 2004).

Health care transitions. Health care transitions are separate, yet related concerns implicated in each secondary transition evidence-based practice. In the last decade, isolated pockets of healthcare research emerged that examined transition to adulthood experiences of adolescents with special health needs. Surprisingly, nurses and some physicians recognized their unique position to enable adolescents to learn how to manage their specific disability-related health care issues in adult healthcare environments (Blomquist, Brown, Peersen, & Presler, 1998; Bryan et. al., 2007; Geenen, Powers, & Sells, 2003; Stewart et al., 2001). These studies focused on health care assessments and interventions that intersected with transition planning activities for youth in this low incidence population.

Results of a National Survey of Children with Special Health Care Needs (U.S. Department of Health and Human Services, 2008) conducted by the Health Research Services Administration (HRSA) revealed numerous transition barriers for youth with disabilities who also had significant health care concerns. Youth had (a) no experience managing their own health care, making medical appointments, or discussing their medical condition, (b) barriers in seeking education and employment, (c) barriers to becoming independent to a degree that was considered usual for youth without disabilities, (d) families that were unaware of programs and resources, or how to access them, (e) pediatric and health care professionals that did not communicate or collaborate to achieve successful transition of youth to adult care, and (f) no planning to facilitate healthcare transitions.

Using a multiple environmental and adult issues survey, Bryan and colleagues (2007) examined the transition to adult life experiences of 55 youth with special health care needs (SHCN) who had completed a youth leadership program. Researchers wanted to know what and how transition services were implemented to enable students to make successful transitions to adult life in terms of their own health care, postsecondary education, work, and ability to assume responsibility for their daily routines. Most of the participants in the Bryan et al. (2007) study indicated that they had good or excellent health, yet, 27% of the participants said they had been treated in the emergency room and/or been hospitalized at least once over the last year. Half of the participants took medications, though of this group, about 24% forget to take the medicine, and half of the young adults exercised on a regular basis. Half had medical insurance, usually through a parent's job, but a few had their own employer health insurance or received Medicaid.

While the findings in the Bryan et al. (2007) study were generally positive, most of the participants did not have transition plans or remember having a transition plan that addressed adult health care management. Bryan et al. raised a concern regarding youth who benefit from a parent's health insurance now but are in jeopardy of losing this benefit when the youth reaches the age of majority. Recommendations included making greater efforts to ensure that youth with special health care needs participate in transition planning activities that target health care from early school years (Bryan et al., 2007).

Geenen et al. (2003) investigated families' and providers' perspectives on the role of health care providers in transition planning for youth with disabilities and special health care needs (SHCN). They reviewed 731 parent and 141 provider surveys targeting youth between 13 and 21 years old with a variety of disability diagnoses. Parents classified the severity of their children's condition as mild (23%), moderate (42%), severe (27%), and very severe (8%). Disability categories represented included developmental disability (22%), physical disability (17%), learning disability (15%), emotional disability (10%), health impairment (6%), and multiple disabilities (18%). Seventy-eight percent of the health care providers for the adolescents in this study were pediatricians. Fewer than 25% of the providers' had adolescent patients, and fewer than 25% of patients under 21years of age had a disability or SHCN. The family and provider questionnaire listed 13 different transition activities that health care providers might engage to help youth prepare for adult life. Parents used the following rating criteria: (a) how important the item is for their child in general, (b) how much their primary care provider helped in this area, and (c) the extent to which they felt it was their primary care provider's job to help in this area. They modified the survey for the healthcare providers to provide a ranking of their own involvement and perceived responsibility to assist youth and families with transition activities. Geenen's team conducted analyses of variance (ANOVA) to see if parent ratings of the importance of transition activities varied by disability of the child; ANOVAs also helped discover variation between perceived level of provider involvement and provider responsibility. Responses varied by disability category (Geenen et al., 2003).

Six of the 13 survey items on Geenen et al.'s 2003 survey achieved a mean rating of 4.0 out of 5.0. The highest ranked items included: (a) caring for the child's general health and primary disability, (b) coordinating child's health with other providers, (c) securing health insurance and finding an adult health care provider, (d) teaching the child to manage his or her own health, and (e) working with the school to coordinate care. Parents and providers had divergent thoughts about the way providers were and should be intervening in transition activities. Interestingly, health providers reported having greater responsibility to assist with 11 out of the 13 transition activities. Parents and providers generally agreed that between 17 and 18 years of age, adolescents should be transitioned from pediatric to adult care. Providers disagreed with parents regarding the age when adolescents should assume management of their own health and begin spending time in medical appointments alone with the provider. Providers suggested having these discussions two or three years earlier (Geenen et al., 2003).

Important barriers to providers' involvement in transition planning activities for youth with significant disability and health conditions included time restrictions (63%), need for more training on transition issues (43%), financial reimbursement (37%), and the need for more information from parents (22%). About 11% of providers indicated other barriers that limited their involvement with this group of youth—feeling uncomfortable talking about adolescent issues surrounding sex, drugs, alcohol; feeling that it was more cost effective for other professionals to handle these issues; and difficulty identifying and accessing resources (Geenen et al. 2003).

Despite several study limitations including inability to match parent and provider surveys, response bias, and self-report accuracy, Geenen et al. (2003) identified important issues surrounding parental and provider collaboration regarding transition planning for youth with SMDD. Parents and providers did not agree on the importance of certain transition topics, nor did they agree on how much the provider should be involved. Youth with developmental disabilities were not perceived by parents to benefit from provider involvement in health management; youth may be excluded unnecessarily from such discussions. At least two individuals from a recent study (Sylvester, 2006) say that their healthcare providers do not see the relevance of discussing adult health issues with them. Geenen et al. provided insight into how medical and related services providers unintentionally exacerbate marginalization of youth and adults with SMDD.

Connecting Related Services and Physical Therapy to Student Outcomes and Quality of Life

In 2006, an entire special issue of *Physical & Occupational Therapy in Pediatrics* included five studies investigating transition issues and practices for youth with SMDD who received therapy interventions in Canada (Evans, McDougall, & Baldwin, 2006; Gall, Kingsnorth, & Healy, 2006; Stewart, Stavness, King, Antle, & Law, 2006; Wynn, Stewart, Law, Burke-Gaffney, & Moning, 2006; Young et al., 2006). While occupational and physical therapists conducted most of these studies, findings were globally descriptive about transition outcomes and support management for youth with significant disabilities. None distinctly investigated physical or occupational therapy impact on postsecondary outcomes.

Physical therapists work across diagnoses, ages, and functional capabilities of youth with SMDD. A multitude of agencies employ physical therapists to help negate impairments, improve functional capabilities, and improve overall quality of life for youth with SMDD (Jette, 1993). Research linked self-determination to improved quality of life for people with SMDD (Biersdorff, 2001; Schalock et al., 2005; Turnbull, Turnbull, Wehmeyer, & Park, 2003; Wehmeyer, 2005; Wehmeyer & Schalock, 2001; Wehmeyer & Schwartz, 1997). Physical therapists spend a lot of time rehabilitating adults with acquired disabilities, habilitating children with developmental disabilities, and trying to improve functional abilities for all. Most therapists agree that working to improve functional capacities in people with chronic disability will ultimately improve the person's quality of life (Jette, 1993, 1994; Jette & Bradley, 2000). Yet, our efforts remain focused on modifying deficits and impairments; functional outcomes are still tangentially associated with evaluating physical therapy interventions.

Quality of life. Quality of life is a major component of health care policy research. In 1990, the Agency for Health Care Policy and Research (AHCPR) advanced a research agenda to develop and disseminate scientific information about the effects of health care services and procedures on individuals' survival, health status, functional capacity, and quality of life. One of the largest non-physician groups of health care providers, physical therapists, was conspicuously absent from this rising tide of outcomes research (Jette, 1993). Canadian and Australian research groups investigated how mismatched health care and supportive services impacted quality of life for youth with SMDD.

Canadian research. In their survey of Canadian families who had children with cerebral palsy, Darrah, Magil-Evans, and Adkins (2002) asked families to rate their satisfaction with services they had received across health, education, employment, community life, and transportation. Results suggested that service providers cared and supported individuals; but providers also contributed to families' frustration with the lack of forthcoming resources and information and the ongoing navigation of systems to acquire needed support. Darrah et al. (2002) concluded that service providers operated under the traditional medical model and continued to marginalize people with disabilities. Darrah et al. suggested that providers re-evaluate the impact of their services on children with CP and their families, particularly when families need resources, information, and help to enter and navigate support systems.

Maher, Olds, Williams, and Lane (2002) correlated physical impairment levels with quality of life measures for 118 youth with cerebral palsy ages 11 through 17, who had sufficient cognition to understand and answer the survey questions. Analysis of co-variance (ANCOVA) compared the effects of gender, Gross Motor Function Classification System (GMFCS) level, socioeconomic status, number of health issues, and assistance needed to respond on the Pediatric Quality of Life Inventory (PedsQL). PedsQL scores differed according to GMFCS levels, number of health issues, and whether parental assist was needed to complete the PedsQL test items. As in the previous study, Maher et al. (2002) found a direct relationship between physical function and quality of life for the 71 participants they surveyed, implying that service providers needed to examine the success of their program efforts.

Summary of health care, related services, and quality of life. It is apparent that health care and status, severity of impairment, type of services provided, and family supports figure prominently into quality of life for people with SMDD (Bryan et al., 2007; Darrah et al., 2002; Geenen, et al., 2003; Jette, 2003; Maher et al., 2002). Physical therapists work with youth and adults who have the most severe multiple disabilities. These youth have goals that they can express and pursue, with assistance from family or paid caregivers. With appropriate supports, they can set, plan, adjust their plans, and achieve their goals. Activities that are pursued within physical therapy settings should support student and family goals; but this is rarely so, as noted in the aforementioned survey studies from abroad (Practice Committee on the Pediatric Section of APTA, 2003).

Transition-Focused Practices

Students with SMDD are more likely to achieve positive postsecondary outcomes when transition planning efforts include students, family members, educators, related services providers, and other community members working together to provide students with a broad transition-education program (Kohler, 1996; 2008; Kohler & Field, 2003). Transition-focused education programs are effective for youth with disabilities when they are connected with relevant service and support systems as students learn. Transition-focused educational practices work with the expectation that all students can achieve valued quality of life outcomes related to community living, working, and education (Kohler, 2008; Kohler & Field, 2003).

Transition-focused Educational Practices for Youth with SMDD

Halpern (1990, 1994) forwarded the foundational intent of special education transition services so that students with disabilities can maximize their adjustments to postsecondary adult community life. Preferred transition practices should consider students' preferences, interests, strengths, and needs regarding their desired postsecondary outcomes for education, integrated employment, independent living, or community participation (Martin, Mithaug, Husch, Frazier, & Huber-Marshall, 2003). Students with SMDD have and can express distinct preferences (Lohrmann-O-Rourke & Browder, 1998) if appropriate assessments are used (Martin, Woods, Sylvester, & Gardner, 2005), and if appropriate technology is applied (Lancioni et al. 2006; Stock, Davies, Secor, & Wehmeyer, 2003). For students with significant support needs, the Council for Exceptional Children's Division on Career

Development and Transition (CEC-DCDT) provides guidance for transition practices: (a) student has a primary role in developing a transition plan, (b) employment is a postsecondary outcome for all students with disabilities, and (c) community supports must be available to allow the student fullest community participation (Getzel & deFur, 1997).

Many innovative and effective transition practices emerged from the increased legislative support surrounding outcome-oriented educational programs for students with disabilities. Halpern's 1994 conceptual model formed the basis of Kohler's *Taxonomy for Transition Programming,* the seminal transition-planning framework now modeled in transition education programs around the country (Kohler, 1996; 2008; Kohler & Field, 2003). Also adopted by the CEC-DCDT, Kohler's (1996) perspective situated transition planning within a broad context and targeted the need for outcome-oriented planning and individualization (Flexer & Baer, 2008).

Taxonomy for Transition Programming - Connecting Current Transition Practices

Kohler's *Taxonomy* promotes evidence-based practices that include (a) student-focused planning, (b) student development, (c) interagency collaboration, (d) family involvement, and (e) program structure. The *Taxonomy* provides concrete transition-focused educational practices that form the basis for the next section's description of current transition-focused interventions. Each section of the *Taxonomy* will be summarized and followed by relevant literature about transition practices that are matched to each *Taxonomy* section. Research reviews focused on students with

SMDD that were conducted in home and community settings were selected from those cited in NSTTAC's evidence-based practice project for each category. One Canadian study not included in the NSTTAC evidence-based practice project mirrored transition planning practices found in the U. S., and informed related services providers (Stewart, Law, Rosenbaum, & Willms, 2001).

Student-focused planning. Transition-focused practices in this section focus on IEP development, transition planning strategies, and student participation in transition planning activities. Student-focused planning is a critical transition practice that is emphasized in the literature (Benz, Lindstrom, & Yovanoff, 2000; Collet-Klingenberg, 1998; Katsiyannis, Zhang, Woodruff, & Dixon, 2005).

Using mixed experimental methods, Benz et al. (2000) investigated post-school employment outcomes for students with learning disabilities (LD) after the students participated in a student-focused transition-planning tool called Youth Transition Program (YTP). The authors studied YTP relative to achievement of a standard high school diploma, time involved in YTP as a predictor of high school graduation, paid work experiences, and number of transition goals completed. With a purposive sample of YTP participants, Benz et al. assessed students' progress at high school exit, at six months, and two-years post high school. As a transition-focused educational practice, YTP promoted successful postsecondary outcome achievement for students with LD. Benz et al. collected data regarding postsecondary and annual IEP goals using NSTTAC's Indicator 13 checklist and found that greater time spent with YTP, completion of more than four transition goals, and having two or more paid work experiences resulted in students earning a standard diploma. Furthermore, if students held paying jobs while they were participating in YTP, they were more likely to work or attend postsecondary education. Focus groups verified quantitative findings and helped researchers evaluate the YTP program effectiveness. The YTP program enabled students to progress and adapt their performance according to personally relevant goals. It is clear that providing opportunities for students to complete self-identified transition goals and career-related paid work promoted graduation from high school with a standard diploma, and postsecondary engagement in employment and education.

Using case study methods, Collet-Klingenberg (1998) summarized discrepancies found between transition best practices in the literature and actual transition practice. Specifically, she determined that student and parent involvement in the IEP process consisted of passive participation. Lack of information seemed more the norm than the exception for students and parents. Collet-Klingenberg's study did not focus solely on outcomes for youth with severe and multiple disabilities, yet it suggested inconsistencies between the IEP document and process that may apply to students with SMDD. The authors noted that the transition planning process appeared to be teacher-directed with resultant gaps in parent knowledge about the process. While teachers in Collet-Klingenberg's study observed an instructional emphasis on teaching self-determination skills and transition planning activities, neither IEP documentation, nor teacher communication revealed this focus.

The student-focused planning section of the *Taxonomy* advocated for parental and student involvement in the IEP meeting (Kohler, 1996). Yet, Collet-Klingenberg

(1998) found that transition IEP teams were minimally cohesive and demonstrated limited and ineffective use of the IEP. As a result, students' transition planning efforts were negatively impacted (Collet-Klingenberg, 1998).

In their review of data from the NLTS2, Katsiyannis, Zhang, Woodruff, and Dixon (2005) found that students with mental retardation (MR) were less involved in their transition planning meetings and discussions than either students with learning disabilities (LD) or emotional/behavioral disorders (E/BD). Fewer general educators participated in transition planning for students with MR, but more related services personnel participated, as did personnel from community agencies (Katsiyannis et al., 2005).

Compared to students with milder disabilities, Getzel and deFur (1997) found that students with more significant disabilities were less likely to attend their IEP meetings. While 15% of the students were involved in some IEP planning, they did not attend their meeting. Thirty percent of the students had no participation in the IEP process at all. Students who were within a year of high school graduation were less likely to be involved in their transition IEP meeting compared to students who had at least three years left before officially exiting high school. This finding is consistent with Shepherd and Inge's (1999) discussion of waning physical therapy services as students approached the end of secondary school. Over a third of Getzel and deFur's IEP team participants consisted of specialized teaching staff or related services providers, while parents and guardians maintained a strong and consistent IEP presence across grade levels.

NLTS2 data compiled by Cameto et al. (2004) demonstrated that youth with multiple disabilities, the closest category to SMDD, participated minimally in their transition planning activities and IEP meetings. About 20% of youth with multiple disabilities did not attend their IEP meetings. Forty-two percent were present but participated minimally, 36% participated moderately in meeting discussions, but only 2% led their transition planning process. Only students with autism attended fewer IEP meetings (23%) and participated less actively in meeting discussions (30%). Students with multiple disabilities led their planning meetings the least of students in all categories. These findings were consistent with those of Getzel and deFur (1997), who found that only a third of Virginia students were present at their transition IEP meetings, while 15% were involved in some of their own planning, but were not actually present at their IEP meeting.

Student development. This section of the *Taxonomy* includes instructional strategies and assessments to promote life skills, vocational education, structured work experience, and relevant support services. Algozzine, Browder, Karvonen, Test, and Wood (2001) completed an extensive literature review of 51 studies that investigated strategies to teach self-determination or any of its components for students with disabilities. Algozzine et al. (2001) noted that while all aspects of self-determination were represented in their sample of studies, most surrounded teaching choice making to students and adults with mental retardation and self-advocacy skills to students with learning disabilities. While self-determination interventions did make a difference for many students, only about 13% of the studies reviewed by Algozzine et al. actually investigated and reported outcomes related to school, employment, or leisure activities. Identifying intervention strategies that proved most effective was difficult because only 19% of the studies reviewed had collected procedural and reliability data surrounding the intervention. Most of the studies reviewed by Algozzine et al. promoted self-determination as important and useful for students with disabilities, but only 45% of the studies actually reported social validity data. Recommendations for future research included consistent attention to procedural reliability, social validity, and more expansive coverage of self-determination components that produce favorable outcomes beyond choice-making and self-advocacy for individuals across a wider range of disabilities, ages, and contexts (Algozzine et al., 2001).

Family involvement. Practices focused on family training, family involvement, and family empowerment highlight this section of the *Taxonomy,* and typically surrounded family involvement in the IEP. Stoner et al. (2005) provided parental perspectives about their interactions with education and other professionals in the lives of their children. Using qualitative methods, Stoner et al. revealed situations that caused trust levels to falter as children grew up, including (a) parents needed support during the initial diagnostic process, (b) parents needed training regarding their child’s disability, (c) parents needed support when their children transitioned from early intervention into special education, (d) parents needed support and advice about the IEP process in meaningful ways that reduced power struggles, and (e) parents needed ongoing communication in a variety of ways that valued their own expertise surrounding their children’s needs.

Gallivan-Fenlon (1994) conducted a unique qualitative investigation surrounding the transition planning process from the perspectives of students with significant impairments, their parents, teachers, and other service providers. Gallivan-Fenlon's focus group data with eleven 20 and 21 year-olds revealed the following concerns: (a) that transition practices lacked family participation, knowledge and collaboration among transition teams, (b) expectations and aspirations for adult life were low or non-existent, and (c) transition planning was not timely and initial transition outcomes were not identified.

Gallivan-Fenlon's (1994) findings concurred with those from an unpublished study where neither parents nor teachers were able to state future expectations for the adults with SMDD in their care (Sylvester, 2008). Adult supported-employment agency representatives stated on the IEP for one student with SMDD that community participation was unimportant, while other IEP team members voiced their expectation that the student would end up sitting at home (Sylvester, 2008). The futility of transition planning for this student was apparent in Sylvester's study when one student's mother admitted that neither she nor his teachers knew what the student could or wanted to do as an adult, knew what to do with him in school, or knew who else could be recruited to assist them in the planning and assessment process.

Interagency collaboration. This section focused transition education practices on developing collaborative agency frameworks and service delivery. Timing and coordination of resources was a consistent theme expressed in studies surrounding transition practices for youth with SMDD (Gallivan-Fenlon, 1994; Stewart et al., 2001; Johnson, Stodden, Emanuel, Luecking, & Mack, 2002). Across transition programs, families lacked knowledge of helpful resources, perceived transition team collaboration to be poor, and felt that transition planning happened too late in the student's public school life (Gallivan-Fenlon, 1994; Stewart et al., 2001). Families thought that professionals, i.e. teachers and transition coordinators, lacked sufficient knowledge and resources to help them through the transition process.

Gallivan-Fenlon (1994) found that transition coordinators either facilitated or obstructed successful student transition outcomes, i.e. if a teacher expected a student with SMDD to work in a sheltered environment, the IEP team focused on this outcome instead of more competitive employment. None of the professionals responsible for coordinating transition activities were willing to involve themselves in systems change efforts to promote new or different student transition options (Gallivan-Fenlon, 1994). Bryan et al. (2007) reported that school personnel lacked sufficient knowledge about transition planning and links to adult support services in the community. Conversely, the majority of the participants in the Katsiyannis et al. (2005) investigation believed that high school had provided them with necessary resources to meet students' postsecondary needs. However, parents in Katsiyannis et al.'s study expected and did not dispute supported and sheltered employment and adult day programs as the expected postsecondary outcomes for their students with mental retardation.

Program structure. Practices in this category included those that identify program philosophy, policy and evaluation, strategic planning, resource allocation, and human resource development. Stewart, Law, Rosenbaum, and Willms (2001) investigated the impact of related services on successful postsecondary transitions for students with SMDD. Stewart et al. (2001) interviewed 34 people with a variety of SMDD descriptors between 18 and 30 years of age about their perceptions on satisfaction with their level of community integration. Participants with SMDD in the Stewart et al. study revealed that they had not achieved a level of comfortable community integration and that the fit into the adult world was problematic. These young adults acknowledged increased presence within their communities as they graduated from secondary school, but they lacked meaningful participation. Participants acknowledged that they had changed considerably since secondary school, but the society into which they moved as adults still treated them as children. Parents stated that it felt like their children were dropped off a cliff into a hole and lost in a maze of services. While families realized the need to advocate for their adult children, they did not know how to access available services that could help their children achieve meaningful adult outcomes (Stewart et al., 2001).

Using a pre-post tests control group design, Izzo, Cartledge, Miller, Growick, and Rutkowski (2000) investigated the impact of extended transition services for young adults with disabilities surrounding employment rates, earnings, and benefits. Most of the high school graduates in the Izzo et al. (2000) study participated in a vocational training program for students with disabilities at a career and technical school and demonstrated a variety of impairments. Izzo et al.'s control group represented students who typically graduate and receive no adult services. The intervention group received services to match their vocational needs, including vocational assessment, agency contacts, IEP meetings, extended vocational training, employment counseling, interview training, job development, and job coaching. Data were collected via phone interviews with parents (Izzo et al., 2000).

Izzo et al. (2000) found that adults earned more in jobs after they completed the extended transition services compared to adults who had not participated. Youth who received extended transition services remained employed or sought additional training four to six years after finishing the program, and were more likely to be involved in social groups compared to control group participants. Izzo et al. did not find group differences for adults receiving health benefits and suggested that health coverage continued to be a disincentive for employment, or that limited health benefits received by the participants reflected the entry-level employment options they chose (Izzo et al., 2000).

Summary of transition-focused education practices. Students with disabilities viewed the transition-planning meeting as a place where professionals shared information and decided what happened next (Gallivan-Fenlon, 1994). This observation is consistent with findings surrounding IEP involvement for students with milder learning disabilities (Martin, Van Dycke, Christensen, Greene, Gardner, & Lovett, 2006), and more recently with students who have SMDD (Sylvester, 2006; 2008). We now know that students' presence at their IEP meetings has a positive impact on IEP team members' perception and understanding of IEP meetings, as well as increased knowledge of the students' strengths, preferences, and needs (Martin, Huber-Marshall, & Sale, 2004). The question remains how meeting presence and active involvement at some level for students with severe and multiple disabilities impacts their transition-focused educational planning efforts.

Families in the U. S. and Canada continued to feel at odds with their children's transition planning process in terms of system supports and navigation, garnering needed resources, communication with relevant secondary and postsecondary service providers, and ultimate postsecondary outcomes achieved (Darrah et al., 2002; Gallivan-Fenlon, 1994; Getzel & deFur, 1997; Katsiyannis et al., 2005; Liebert et al., 1990; Stewart et al., 2001; Stoner et. al, 2005). Students and families had difficulty setting expectations and postsecondary goals for students with SMDD, which made transition-planning efforts extremely challenging and often resulted in default referral and admittance to sheltered employment or adult care facilities. Families had insufficient and untimely resource coordination to enable their children to identify and pursue postsecondary goals, even if they were identified (Johnson, Stodden, Emanuel, Leucking, & Mack, 2002; Gallivan-Fenlon, 1994; Stewart et al., 2001). In general, families thought that professionals lacked sufficient knowledge and resources to help them through the transition process.

Interagency collaboration and systems change efforts formed the basis of program structural concerns and were apparent within education. In addition to expanding individualized transition services for students with disabilities during high school, Izzo et al. (2000) recommended that students with significant support needs continue with transition services beyond graduation from high school until their employment situation stabilized. Programs should provide employment counseling, job development, and adult services coordination to ensure that students are not dropped into a postsecondary black hole.

As more students with the most significant disabilities and health issues grew up, the program infrastructure was challenged to ensure meaningful transition planning efforts, heightening the need to create more effective collaborative relationships at all levels. Ineffective health care transitions resulted in fewer postsecondary outcomes achieved by youth with SMDD, and was a concern voiced by many families that should be addressed in future research.

Service providers, teachers, and maybe some parents commonly believed that people with severe disabilities could not participate in controlling their own lives because the decisions involved were too complex (Agran & Wehmeyer, 2000; Ward, 2006; Wehmeyer, 1998). It is in this particular area that physical therapists can contribute much—helping students with SMDD utilize the supports they need to be in charge of their own lives. Yet, physical therapists remain tangentially involved in transition planning for students with SMDD. It seems inconceivable that physical therapists are not more actively intervening with transition-aged youth. In fact, at the first National Secondary Transition and Technical Assistance Center (NSTTAC) Institute in May 2007, there were exactly two physical therapists represented out of about 400 participants comprising transition teams from 43 states and U.S. territories. These teams gathered to develop strategies to improve postsecondary transition outcomes for youth with disabilities in their respective states. How can physical therapists facilitate postsecondary outcome achievement for students with disabilities if they remain peripheral to the students' team functions?

Physical therapists can benefit from promising practices within education that are positively affecting outcome achievement for students with SMDD. Promoting and teaching proven student self-determined practices in the context of physical therapy settings may enable students with SMDD to accomplish therapeutic activities, match PT activities to preferred postsecondary goals in relevant environments, and manage the supports they will continue to need to enjoy the quality of life they choose.

Stewart et al. (2001) found that if interventions focused on helping students develop self-management and self-determination skills and included goal-directed services, parents perceived a greater impact on the outcomes achieved. Physical therapists need to understand what self-determination is about and how they can merge established self-determination practices into their intervention protocols before we can move beyond impairment-focused interventions. The next section describes self-determination and provides evidence supporting the use of self-determined practices and models in multiple professional arenas that serve youth with SMDD.

Self-Determination for Youth with SMDD

While the conceptual definition continues to evolve, to control and decide the course of our own lives is the crux of self-determination, and underlies our very existence. A mom of a young man with cerebral palsy believes that self-determination as "inalienable right of being fully human" (Snow, 2011), a notion that is fully supported in a position paper by Council for Exceptional Children's Division on Career Development and Transition (Field, Martin, Miller, Ward, & Wehmeyer, 1998a). Ward (as cited in Field, Hoffman, & Posch, 1997) provided an early description of self-determination as "the attitudes, which lead people to define goals for themselves and the ability to take the initiative to achieve those goals," (p. 286). Martin and Marshall offer that self-determined people:

> know how to choose – they know what they want and how to get it. From an awareness of personal needs, self-determined individuals choose goals, and then doggedly pursue them. This involves asserting an individuals presence, making his or her needs known, evaluating progress toward meeting goals, adjusting performance and creating unique approaches to solve problems (Martin & Marshall, 1995, p. 147).

Self-determined people know and express their own preferences, interests, strengths, skills, and limitations (Martin, Mithaug, Husch, Frazier, & Huber-Marshall, 2003). They engage in goal-directed, self-regulated, and autonomous behavior (Field, Martin, Miller, Ward, & Wehmeyer, 1998b). People with SMDD can demonstrate self-determined behavior too, but they often need support to do so (Agran & Wehmeyer, 2000; Sowers & Powers, 1995; Ward, 2005, 2006; Wehmeyer, 1998; Wehmeyer, 2001).

Self-determination Defined

Merriam-Webster's Collegiate Dictionary (2004, p. 1127) defines self-determination as free choice of one's own acts or states without external compulsion. Wehmeyer (2005) recently provided a revision of his well-known self-determination definition that embodies quality of life issues for people with severe disabilities: "Self-determined behavior refers to volitional actions that enable one to act as the primary causal agent in one's life and to maintain, or improve one's quality of life" (p. 117). Although Wehmeyer suggests that self-determination and control are not equable terms (control is not all that self-determination entails), his continued use of the term *causal agency* is somewhat contradictory, and his term *quality of life* may be incompatible with self-determination (Mithaug, 2005).

Mithaug (2005) responded to this definitional dilemma by providing a simpler definition of self-determination: “Self-determined behavior is provoked by choice making, which leads to desired ends in life.” However, it is clear that self-determination is not solely about making choices (Wehmeyer, 2005). Self-determination involves a self-regulated process of expressing preferences (choices) that results in a person’s ability to set goals, plan, self-evaluate, and self-adjust (Mithaug, 2005).

Self-determined people choose, set, and persistently pursue their own goals (Martin & Marshall, 1995, 1996; Martin, Oliphant, & Weisenstein, 1994). They self-evaluate outcomes and recognize options and alternatives from experience that can alter their next steps (Martin & Marshall, 1995, 1996; Martin, et al. 1994). Self-determined people are self-advocates, and articulate the supports they need to be successful, while often relying on a healthy interdependence with critical people in their lives (Bremer, Kachgal, & Schoeller, 2003; Martin & Marshall, 1995; Ward, 2005, 2006). Self-determination is an essential quality and critical component of a successful transition to adulthood for youth with SMDD (Bremer, et al. 2003; Thoma & Getzel, 2005).

Conceptual Framework for Self-Determination and Students with SMDD

The previous paragraphs demonstrate the multifaceted nature of self-determination depicting both the collective or political *rights* perspective and a *personal control* perspective evident in motivational psychology (Wehmeyer, 1998). Wehmeyer (2005) concluded that these are two distinct ways to interpret self-determination, and that applying the same meaning at both levels may be problematic. People with severe disabilities are often perceived as lacking the prerequisite skills to be in control of, or manage their lives. Yet, utilizing varying levels of support, people with severe disabilities can manage their own lives.

Self-determined people pursue their own interests persistently in settings that are personally meaningful. Self-determination begins with expressing real choices and it is supported by a combination of related components: goal setting, self-planning, self-evaluating, and self-adjusting (Mithaug, 2005). The availability of preferred choices makes it more likely that a person will pursue their interests that lead to achievement of their life goals. People with disabilities, including those with severe and developmental disabilities, must possess (or be taught or given) opportunities and supports to become self-determined (Mithaug, 2005). Disability related factors, including therapeutic interventions, could inadvertently suppress development of self-determination for some youth with severe physical or cognitive deficits.

The American Association on Intellectual and Developmental Disabilities' (formerly the American Association on Mental Retardation) recent definition of intellectual impairments recognized a paradigm shift from thinking in deficit-based terms to an assumption that a person with mental retardation needs supports in order to achieve chosen goals and a quality life. Tasse (2002) stated that refocusing assessment and interventions on the supports that a person with a disability requires in order to be a happy and full participant in life is more useful than focusing on IQ and other functional deficits.

Blending self-determination theoretical frameworks. The literature presented different, yet I believe, complementary perspectives of self-determination. One theory recognized a person's innate psychological needs relative to self-motivation that incorporated autonomy, competence, and relatedness (Deci & Ryan, 2000; Ryan & Deci, 2000). This theory suggested that social contexts could either enhance or thwart development of self-determination. A second theory assumed that individuals could develop self-determination skills, if provided the appropriate supports and strategies, in order to achieve meaningful outcomes. It presumed interaction with the environment through a process of self-regulated problem solving with the person setting goals, taking action, and adjusting or evaluating their goal attainment (Mithaug et al., 2003). Finally, each perspective plays a significant role in how physical therapists may or may not promote self-determination for children with disabilities.

Deci and Ryan (2000) considered a person's innate psychological needs as the basis for differentiating between the content of goals and outcomes, and the regulatory processes people use to pursue and attain preferred outcomes. Satisfaction of needs required different regulatory processes and goals. For children with disabilities and their families, the depth and breadth of social contexts became significant in how basic needs were met. Critical to this theory is Deci and Ryan's contention that social contexts and individual differences facilitated natural growth processes in terms of integrating intrinsically and extrinsically motivated behavior. Satisfaction of needs required different regulatory processes and goals. Intrinsic and extrinsic motivations that forestall autonomy, competence, and relatedness result in poorer motivation, performance, and well-being. When the psychological needs for competence, autonomy, and relatedness are met through relevant social contexts and experiences, Ryan and Deci (2000) contended that enhanced self-motivation and positive mental health could occur. However, when these psychological needs are not promoted, then self-motivation and well-being were thwarted. Children with disabilities have significant interaction with health care providers, therapists, and special education personnel. It is conceivable that these "atypical" social contexts, most of which are based in a medical model of intervention for children with disabilities and their families, may have a significant impact in how these children develop self-determination.

While recognizing innate individual needs, the *Self-determined Learning Theory* (Mithaug et al., 2003) extended self-determination development into functional ecological arenas and assumed that people, even people with significant disabilities, can act upon their innate psychological needs and show increased self-motivation if distinct teaching and learning strategies are provided. This theory imbedded perspectives that emphasized civil rights and self-advocacy for people with disabilities (Ward, 1996, 2005, 2006), as well as the notion that self-determination skills can and should be taught within distinct learning environments, like classrooms and vocational settings (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). Empirical evidence for the latter perspective surrounding strategies used by families and related service providers for youth with severe and multiple developmental disabilities is emerging (Erwin & Brown, 2003; Palmer & Wehmeyer, 2003).

Self-determined learning theory. The *Self-determined Learning Theory* (*SDLT*) is a multi-focal process whereby opportunities, engagement, and adjustment all factor into successful learning (Mithaug et al., 2003). It epitomizes the interplay of self- and ecological influences on a person becoming self-determined. The presence of gainful opportunities provokes engagement; engagement affects adjustments; and adjustments determine what one chooses to learn. In other words, people learn when they are provoked by an event that interrupts their goal pursuits; they engage the event by altering their expectations, choices, and actions to control the event; and then they adjust by altering their beliefs and patterns of responding to the event. Mithaug et al. delineated the causal links between each of the *SDLT* propositions as:

> (a) The closer to optimal the opportunity for experiencing gain, the more likely is the regulation of expectations, choices, and actions to produce gain.
> (b) The more often the regulation of expectations, choices, and actions to produce gain, the more likely it is that adjustments optimize as expectations, choices, actions, and results become adaptive, rational, efficient, and successful.
> (c) The closer to optimal the adjustment to an opportunity, the more persistent the engagement to produce gain, the greater is the feeling of control over gain production, and the closer to maximum is the learning from that adaptation.
> (d) Therefore, the closer to optimal the opportunities for experiencing gain, the more persistent is the engagement, the greater is the sense of control, and the closer to maximum is the learning (p. 14).

In short, the *SDLT* is a process whereby students (a) set their own goals based on their interests, preferences, and needs, (b) develop and implement action plans to achieve their goal, (c) evaluate their progress toward achieving their goals to regulate their learning, and then (d) revise their goals or plans as needed (Agran & Wehmeyer, 2000). People learn when they are provoked (*to act or not*) by an event that interrupts their goal pursuits; they engage the event *(or not)* by altering their expectations, choices, and actions to control the event; and then they adjust (*or not*) by altering their beliefs and patterns of responding to the event. The authors maintain that the *SDLT* process enables people to learn more when they experience initial free choice, compared to processes that force or deny choices. However, the process is not just about making choices. It is about knowing you can gain something from the choice. It is the ability to regulate choices, actions, and expectations to produce gain. It is the ability to optimally adjust to different choices and actions based on old and new experiences. Finally, it involves persistent engagement so that we feel control over making more gains, i.e., we learn (Mithaug et al., 2003).

Utility of the SDLT. The utility of the *SDLT* and its prescriptive elements were demonstrated and evaluated in educational and employment settings, but not in the related services arena. Mithaug and Mithaug (2003) used a multiple baseline across subjects with reversal to compare the effects of two choice conditions on student use of self-regulation during independent work for six young children with disabilities. Conditions included (a) baseline (student worked independently at desk), (b) teacher-directed instruction on the use of self-regulation (students wrote what they did and what they planned next on the card), and (c) student-directed instruction where the student wrote down what they planned, what they did when they finished working, and what they planned next. Children in the second and third group were also reinforced through verbal praise and a chance to choose an item from a prize box if their card responses matched (what child planned matched with what child actually did). While these children did not exemplify severe and multiple developmental disabilities, results still bore out this *SDLT* prescription: “To increase self-engagement and learning, give students a choice of their learning goals, a method for regulating their expectations, choices, actions and results to meet those goals, and reward them for meeting their goals” (Mithaug & Mithaug, 2003, p. 156).

Summary of self-determination theoretical frameworks. People with disabilities who are self-determined have intrinsic maturational tendencies and inherent needs that form the basis for self-motivation and integration of their personality within their disability context (Ryan & Deci, 2000). Our role as family members, teachers, and physical therapists is to recognize and enhance the conditions that promote this process. Therefore, the basic premise for this study relies on the recognition of competence, autonomy, and relatedness as innate psychological needs (Deci & Ryan, 2000; Ryan & Deci, 2000), combined with the notion that individuals with disabilities themselves can develop and use self-determination skills, if provided the necessary tools and support. Numerous prescription and verification research studies completed in educational and employment settings support the *SDLT* as a comprehensive theoretical framework applicable for students who have SMDD (Mithaug et al., 2003).

Self-determination Models of Intervention

Table 2.2 briefly reviews evolution of self-determination intervention models. The *Self-Determined Learning Model of Instruction* is the intervention focus for this study and is discussed in more detail below.

Table 2.2.

Self-Determination Models and Curricula -- Descriptions, Components, & Evidence

Model & Developers	Description and Self-Determination Components	Evidence of Effectiveness
Intrinsic Model (Deci & Ryan (as cited in Wehmeyer, 2001); Ryan & Deci, 2000).	Individuals have internal needs and behaviors that are intrinsically motivated. Natural capacity to make choices, solve problem, internal drive. Internal locus of control	(Deci & Ryan, 2000; Ryan & Deci, 2000)
Ecological Process Model Abery (as cited in Wehmeyer 2001).	Self-determination is an internally driven process, but one's interaction with environment is critical and ongoing. Choice making, problem solving self-regulation, assertiveness, and environment impacts capabilities, self-efficacy, locus of control (internal and external), self-assessment, and self-advocacy. Assessment and curricular material developed and tested with adolescents with mental retardation.	Abery & Stancliffe, (1996) evaluated with youth who had mental retardation. Improved choice-making, problem solving, self-regulation, and assertiveness.
Model for Self-Determination (Field & Hoffman, 1994)	Know and value self; plan, act, experience, and learn. Self-determination as part of adolescent development. Beginnings of ChoiceMaker.	(Field, Hoffman, & Posch, 1997; Field, Martin, Miller, Ward, & Wehmeyer, 1998a & b).
Mastery Motivation – TAKE CHARGE (Powers, et al., 1996)	Reduce learned helplessness and promotes self-efficacy. Mastery, motivation, and self-efficacy expectations. Competence, self-esteem, keeping internal locus of	(Powers, Turner, Matuszewski, Wilson, & Phillips, 1996; Sowers & Powers, 1995).

	control. TAKE CHARGE facilitated skills, mentors, provided peer and parental support. Used with students who have mental retardation and severe disabilities	
Adaptability Model (Mithaug, Martin, & Agran, 1987; Mithaug, Martin, Agran, and Rusch, 1988)	Four-step process to choose and obtain employment outcomes. Regulated problem-solving activities. Connected needs/wants/actions/results. Match opportunity with capacity. Decision-making, independent performance, self-evaluation, and adjustments.	Effective with student who had mild/severe intellectual impairments (Wehmeyer, Agran, & Hughes, 2000)
Self-determined Learning Model of Instruction (Mithaug, et al., 2003)	All of the above in Adaptability Model, plus persistent self-regulation and problem solving. Presumes students need to learn and can be taught how to advocate for their own needs and wants, take action to change circumstances to improve their situation. Three phases with questions in each phase that enable the student to (a) set a goal, (b) take action, and (c) self-evaluate and adjust.	Adaptations of the model in process or use with young children, adolescents, and adults, and within a variety of educational and vocational contexts. (Agran, 1997; Agran & Wehmeyer, 1999; Agran & Wehmeyer, 2000; Agran, Blanchard, Hughes, & Wehmeyer, 2002; Martin & Marshall, 1996; Mithaug, 1996; Mithaug, 1998; Palmer & Wehmeyer, 2003; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000).

Note: Contributing information and noted citations from "Self-Determination and Mental Retardation," by M. L. Wehmeyer, 2001, *International Review of Research in Mental Retardation, 24*, p. 23-47. Copyright 2001 by the Academic Press.

Mithaug (2005) imbued self-determination with self-regulated problem solving skills that are free of external influence. Inherent in this new thinking was the ability to set expectations that reflected capacity and opportunity. Mithaug melded the personal (individual) and social (political ideal or legal rights) components of self-determination discussed earlier (Wehmeyer, 1999), and the original Adaptability Instructional Model (Mithaug, Martin, & Agran, 1987) to form the foundation of the *Self-determined Learning Theory* and the *Self-determined Learning Model of*

Instruction (Mithaug et al. 2003). The *Self-determined Learning Model of Instruction (SDLMI)* is the basis for the intervention proposed in my study; therefore, it warrants further description with discussion of relevant research to support its use.

Self-determined Learning Model of Instruction

The *Self-determined Learning Model of Instruction (SDLMI)* is an ecologically based instructional process, not a curriculum per se, that has its roots in the *Adaptability Instruction Model* developed in the late 1980's by Mithaug, Martin, and Agran (1987). The *SDLMI* promotes student-directed learning and self-regulated problem solving processes that require no prerequisite skills from the students in order to benefit from the process. Implementation of the *SDLMI* occurs in three phases: (a) students set goals, (b) take action on the goal, and (c) adjust their plan to reach their goal. Implicit in the *SDLMI* process is the student's ability (with supports) to self-advocate and self-regulate problem solving strategies to achieve desired ends. Developers of the *SDLMI* presumed that students drive the process; but they also recognized that self-determination and independent performance are not synonymous as students pursue their goals (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). The *SDLMI's* utility was field tested with school-aged young children (K-5), adolescents with milder disabilities, and recently adapted for use with college students with disabilities. These studies are described next.

SDLMI with K-5 students. Palmer and Wehmeyer (2003) investigated the utility of the *SDLMI* to enable 14 teachers to promote self-determined behavior in 50 elementary school-aged students. Participating students were gifted (n = 2), had learning disabilities (n = 21), mental retardation (n = 6) or speech impairments (n =

5), or had not yet been identified with a disability label (n = 16). Researchers provided training for the participating teachers on how to implement the *SDLMI*, and how to measure goal attainment using the Goal Attainment Scale (G.A.S.). Teachers implemented the three phases of the *SDLMI* model as in the previous adolescent-focused study, and used the G.A.S. process similarly to measure goals attained and efficacy of the *SDLMI.* Students and teachers identified academic, behavioral, or social goals appropriate for the students' grade level. Researchers calculated mean G.A.S. scores for teachers and students, and utilized paired-sample *t* test to compare differences between teacher and student scores. Chi-square was used to compare teacher rated scores by grade level, pre-, and post-instruction on the identified goals.

Results indicated average or slightly greater than average goal achievement than what teachers expected, and more students exceeded goal expectations than not. The *SDLMI* was found to be effective across goal areas. Teachers reported positive progress in academic or behavior areas for 42 of the 50 students as a result of the intervention, and they valued the process enough to continue using it in their classroom. This study supported use of the *SDLMI* with younger students who had a variety of milder disabilities. Teachers valued the model, which allowed them to support students as young as five years old to select goals, evaluate their own progress, and make changes to ensure goal attainment. The *SDLMI* provided teachers with valuable tools that support young children with disabilities to set their own goals, in becoming accountable for their own learning, and to evaluate the learning process. Adults achieve self-determination through years of guided practice and opportunities during childhood. The *SDLMI's* authors advocated a lifespan focus for developing these skills, which should begin early in life, continue through adolescence, and into adulthood. The next study examined the *SDLMI* used with adolescents in an educational setting.

SDLMI with adolescents. High school teachers and students with disabilities field tested the *SDLMI* to evaluate its efficacy as a strategy for teaching students transition-related goals, and to study the degree to which *SDLMI* benefited students in terms of their goal oriented outcomes and self-determination (Wehmeyer et al., 2000). Students in this study represented a variety of disability categories: mental retardation (n = 13), learning disabilities (n = 2), learning disability and cerebral palsy (n = 1), multiple disabilities (n = 5). The latter category comprised students who had mental retardation in addition to at least one of the following disabilities: blindness, cerebral palsy, orthopedic impairments, or diabetes. Teachers referred student participants based on their perceived need for the student to become more self-determined.

Wehmeyer et al. (2000) provided training for the 21 teachers and their 40 student participants that covered self-determination, student-directed learning, and the *SDLMI*. Dependent measures included employment, adult living, and community-social skills. Students selected their goals with help from their teachers, and the Goal Attainment Scale (G.A.S.) measured progress on goal-achievement. Other dependent variables included global self-determination, student perceptions of control in their lives, and student goal-orientation.

Wehmeyer et al. (2000) found a distinct increase in target behaviors after *SDLMI* training compared to baseline performance, and an overall maintenance of the target behaviors in the post-training phase. Overall, students exceeded teachers' expectations for achieving their goals. The mean score on the G.A.S. was 60, indicating that students generally exceeded teachers' expectations for achievement of their goals (mean *t*-scores of 50 were acceptable).

Wehmeyer et al. found that teachers were better able to assist students with disabilities to self-regulate learning and improve self-determination using the *SDLMI* instructional process. The majority of the students made progress on their goals, and most of the students' goals were achieved at a level expected by their teachers. The authors conclude that the *SDLMI's* flexibility in terms of accommodative process and supports made it appropriate for students with a wide range of ages and disabilities, and who participate in a wide range of educational content areas.

SDLMI with college students. Finn, Getzel and McManus (2008) developed and implemented a series of training modules that incorporate facets of the *SDLMI* to enable college students with disabilities at Virginia Commonwealth University to meet the demands of postsecondary education. This training program was piloted over two semesters with 15 students representing the following disability categories: orthopedic, other health impaired, deafness, specific learning disability, and emotional disturbance. Over half of the students (n = 9) were classified as other health impaired. As in the previous two studies, these college students were taught the three-step *SDLMI* process for problem solving: set a goal, take action, and adjust the goal and plan; but within module content that helped them cope with college life and learning. Focus groups were conducted with the students that enabled the researchers to develop these content areas that included (a) understanding disability and its impact on learning, (b) disclosing disability to gain needed accommodations, and (c) developing organizational skills for college.

VCU students participated in eight 90-minute sessions over the course of two semesters, in an undetermined comfortable setting. Results from student self-assessments revealed improved confidence in talking with professors to gain the necessary accommodations to successfully complete classes. Nearly half of the participants gained a greater understanding and acceptance of their disability and were able to seek out necessary resources and support to help them achieve their academic goals. Finally, student's goal-setting behavior improved as they divided large goals into more manageable tasks. Students persistently worked on their plans, used their strengths, recognized and managed their needs, and adjusted their plans accordingly.

The *SDLMI* showed utility in the college setting for these students because freshmen and returning sophomore students with disabilities clarified new challenges that could have become barriers. New and returning students with disabilities were ill equipped to handle the stress of college. Findings suggested that students with disabilities needed training focused on developing self-determination skills for these students prior to high school graduation. Yet the authors suggested that even if students graduated from high school with self-determination skills and strategies, the new college environment prompted students to seek new information and strategies that can help them stay prepared and capable of completing their college years successfully.

Summary of SDLMI Use and Efficacy Studies

Self-determination involves a self-regulated process of expressing preferences (choices) that result in a person's ability to set goals, plan, self-evaluate, and self-adjust (Mithaug, 2005). Research evidence supported using the *SDLMI* with young children, adolescents, and college students with disabilities to evaluate their own learning progress and make changes in their plan toward goal achievement (Fin, Getzel, & McManus, 2008; Palmer & Wehmeyer, 2003; Wehmeyer et al. 2000). Evidence from two of the studies above (Palmer & Wehmeyer, 2003; Wehmeyer et al., 2000) portended future investigative efforts surrounding use of the *SDLMI* in elementary and secondary-level IEP meetings. Infusing the *SDLMI* into daily school lessons and activities was suggested as a valuable way to promote self-determined learning for students with disabilities, rather than conducting separate classes. The IEP meeting, a consistent venue for teaching and promoting the *SDLMI* process for students with disabilities, offered repeated opportunities for practicing self-determination skills as students evaluate and monitor their progress. It is apparent that college students with disabilities benefited from targeted instruction using the *SDLMI,* whether or not their secondary transition planning offered targeted self-determination programming. The question remains, can teaching self-determination skills and strategies to youth and adults with more severe disabilities, like the participants with SMDD in this proposed study, have the same benefits? What does self-determination intervention look like for individuals with more severe disabilities? The research literature is just beginning to tell.

Self-determination Training for People with SMDD

Most of the current literature to date surrounded efficacy of teaching self-determination components and models like the *SDLMI* to children, adolescents, and adults with mild or moderate, more singular disabilities. Wood, Fowler, Uphold, and Test (2005) completed an ambitious and comprehensive review of literature investigating the efficacy of teaching component self-determination skills separately or through models like the *SDLMI* to individuals with severe disabilities. They identified 21 articles that investigated a variety of self-determination component skills using primarily single-subject experimental designs. Wood et al. included studies that described participants with severe disabilities according to the definition developed by the Association for Persons with Severe Handicaps.

Wood et al. identified choice making as the most common self-determination component measured as a dependent variable, and all studies that explored choice making used single subject designs. A few of the Wood et al. studies measured self-management and problem solving as separate dependent variables specifically surrounding management of educational materials; self-management was also explored as an independent variable in five studies. Five of the Wood et al. studies reviewed measured multiple components of self-determination simultaneously.

Self-Directed IEP. Martin, Huber Marshall, Maxson, and Jerman (1996) developed the *Self-Directed IEP* curriculum to provide students the opportunity to learn and practice leading their IEP meeting, stating their interests, skills, and limits, and discussing options during the IEP meeting. Following a model–lead–test format, this multi-media package presents 11 steps to help students lead their IEP meeting.

This curriculum was moderately effective for increasing student involvement and conversation during the IEP for students with learning disabilities (Martin et al., 2006).

Summary of self-determination research review. Though Wood et al. (2005) examined only a few intervention studies; their findings suggested that a greater variety of teaching strategies were being implemented to teach self-determination to people with severe disabilities. This limited research demonstrated that students and adults with severe intellectual disabilities could be taught and learned self-determination skills; yet, component skills like self-awareness, goal setting, self-advocacy, and self-efficacy needed further investigation (Wood et al., 2005). Only one study in the Wood et al. cohort investigated a published intervention curriculum or model, like the *SDLMI*. Based on current knowledge in the field, Mason, Field, and Sawilowsky (2004) asserted that teachers should rely on research-validated methods, rather than less formal and systematic instruction. Wood et al.'s findings likely demonstrated the lack of published instructional models and programs geared toward the unique needs of people with SMDD.

Related services providers like physical therapists often work with youth and adults who have the most severe disabilities. These youth have goals that they, with help from caring support people, can express and pursue, if they are taught and encouraged to use self-determination skills. Yet, the literature reported growing concerns that self-determination concepts did not apply to individuals with SMDD (Wehmeyer, 1998; 2005). In a national survey of teachers' understanding and use of self-determination to enhance student learning, teachers agreed that self-determination was a valuable instructional area, except for students with the most severe disabilities. Teachers reported that students with more severe disabilities needed instruction in other areas more urgently than self-determination (Wehmeyer, et al., 2000).

The developmental history of self-determination interventions reinforced the importance of self-efficacious behaviors through informed choice-making, setting goals, making plans, evaluating progress, making adjustments or regulating one’s behavior based on self-evaluation results. Mentoring and peer support were unique features of the *Take Charge* model. Each model presumed that students with disabilities could and did learn from their experiences, but only the *SDLMI* merged these features with supports from family members and peers. The *SDLMI* represented the most comprehensive model for teaching self-determination skills to youth with SMDD across a variety of disabilities and settings. The *SDLMI* has undergone significant research scrutiny with individuals who represented a multiplicity of impairments across numerous applied settings.

Studies Linking Self-determination to Related Services

Related Services

The Individuals with Disabilities Education Act (2004) defines related services as programs that enhance a student's ability to function in the educational environment. IDEA 2004 states that transition services can be special instruction and/or *related services*, if those *related services* are designed to help students with disabilities benefit from special education (Johnson, 2004). Related services should be integrated with and related to the students’ educational programs and needs

(NICHCY, 1998). Related services must assist students to benefit from all educational programs, including programs emphasizing transition to postsecondary life.

Related services providers in the United States rarely engaged in research surrounding self-determination (Klienert, Gonzalez, Schuster, & Huebner, 2007; Wood, Fowler, Uphold, & Test, 2005). Usually, studies in the field reported effectiveness of treatment techniques and protocols for children with disabilities that negated impairments. A few studies within related services and physical therapy investigated self-determination elements within their intervention programs (King et al., 2002; Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Wottrich, Stenstrom, Engardt, Tham, & von Koch, 2004). One study from speech and language pathology investigated the impact of a clinician-directed and a student-directed approach to teaching syntax skills to children with developmental disabilities (Klienert et. al, 2007). Canada presented a related service delivery model that promoted and used self-determination elements within occupational and physical therapy interventions (King et al., 2002). A unique investigation from the Netherlands surfaced recently that considered self-determination and its component elements within two different physical therapy treatment approaches in a pediatric setting (Ketelaar et al., 2001), while another study compared function- and impairment-focused intervention paradigms in an adult rehabilitation context (Wottrich et al., 2004).

Speech and language pathology. Kleinert, Gonzalez, Schuster, and Huebner (2007) investigated the efficiency of syntax target acquisition by students with developmental disabilities involved in a speech and language clinical setting. Investigators compared syntax target acquisition by students with developmental disabilities involved in a traditional clinician-directed teaching paradigm compared to a student-self-determined teaching paradigm. Using an adapted alternating treatment design, Kleinert et al. found that both treatment paradigms were effective in teaching syntax targets for students; but the clinician-directed session was slightly more efficient. However, students in the self-determined teaching sessions better evaluated their progress, compared to students in the clinician-directed regime.

Kleinert et al. (2007) wanted to know if infusing the *SDLMI* component elements into the communication intervention impacted acquisition of speech targets, without interfering with on-going speech and language programming. However, this study pointed out the difficulty and need to clearly define the intervention conditions as well as to ensure skill equivalency. Other study limitations for Klienert et al. concerned the cognitive requirements of the self-evaluation tool and therapist as researcher bias. Both of these latter issues are issues that will be challenging to address in my study.

Life needs model. Canadian physical and occupational therapists forwarded programmatic and descriptive research evidence to support a focal change from treating children's impairments to helping them develop self-actualization, well being, and happiness–all components of the self-determination models discussed earlier. The Life Needs Model provided pediatric services that emphasized child and family strengths and capacities as well as needs (King et al., 2002). The model demonstrated a shift in related services provision toward a more holistic and broad-based system reflected in the World Health Organization schema (WHO, 2001), including (a) a developmental model that reflected service groupings based on children's ages while acknowledging and incorporating transition points in the developmental processes, (b) a social-ecological model that matched child development to pertinent child contexts or settings, (c) a comprehensive community-based model that acknowledged the required community services needed by individuals in the community, and (d) a transdisciplinary model that provided a common goal implementation process based on concepts and perspectives gleaned from the rehabilitation sciences (King et al., 2002).

This pediatric service model valued self-determination and cited existing self-determination models and research (Field & Hoffman, 1997, 2002; Mithaug et al., 2003; Wehmeyer, 1994, 2001). Ironically, the Life Needs Model was developed within the context of 19 segregated children's rehabilitation centers in the Ontario Association of Children's Rehabilitation Services for the purpose of enhancing community partnerships and integrated services (King et al., 2002). The overarching goal of the model promoted community inclusion and increased satisfaction with community participation and quality of life for children and adolescents with disabilities. The Life Needs Model presumed a common language and framework for articulating therapy goals and services, which the authors claimed enabled teams to collaborate in goal-directed ways to determine clinical service priorities for children with disabilities (King et al., 2002). While the Life Needs Model as conceptualized by King et al. is theoretically appealing, research surrounding its implementation and effectiveness has yet to emerge.

Physical Therapy

Physical therapists exert substantial influence on patients during therapy sessions to maximize recovery of lost function if the disability is acquired later in life (Wottrich et al., 2004), or to promote initial skill acquisition in children who never acquired functional mobility due to early onset of impairment.

The definition of physical therapy (PT) as a related service under the Individuals with Disabilities Education Act (IDEA) has not changed since the law's original enactment in 1977 (20 U. S. C. Section 1401). A most oblique and antiquated description of PT encompasses "services provided by a qualified physical therapist" and a related service to be provided "as may be required to assist a handicapped child to benefit from special education" (20 IDEA Sec. 300.24 (b) (8); McEwen, 2000, p. 11). PT addresses posture, muscle strength, mobility, and organization of movement in educational environments for students with cognitive and physical impairments (20 U.S.C. Section 1401, 2004). Wottrich, Stenstrom, Engardt, Tham, and von Koch (2004) viewed PT as a common rehabilitative intervention for people with either acquired or developmental impairments, aiming to maximize a person's ability to become independent and achieve their chosen quality of life after injury or a developmental impairment occurs.

PT evolution. Emerging from the medical model described in Chapter one, early training guides for school-based physical and occupational therapists clearly recommended that therapists work with children to enable them to perform in educational environments (Giangreco, Edelman, & Dennis, 1991; McEwen, 2000; McEwen & Sheldon, 1995). Without specific language and emphasis on promoting secondary transition and postsecondary outcomes, physical therapists were compelled to work with students only in the school building, rarely considering community-based contexts.

McEwen and Sheldon (1995) described the evolution of pediatric physical therapy from medical to educational as PTs began to align their services with mandates of the 1990 IDEA reauthorization. Special education in the 1990's provided for increased parental influence, and greater efforts toward achievement of relevant and meaningful student goals. Children and families began to identify intervention goals that were meaningful to them and therapy approaches needed to help youth and families accomplish those goals. Over 10 years ago, McEwen and Sheldon suggested that therapy services needed to be responsive to child and family needs, and that the effectiveness of the interventions needed to be measured by the accomplishment of functional goals set by the child and family (not isolated medically-based goals). The transition-focused mandates of the IDEA 1997 and 2004 only strengthened this approach to service delivery for students with disabilities throughout high school.

Emerging research documented the generalized results of PT interventions in pediatric or adult settings (Campbell, 1997; Ketelaar et al. 2001; King, McDougall, Palisano, Gritzan, & Tucker, 1999; Sekerak, Kirkpatrick, Nelson, & Propes, 2003; Wottrich et al. 2004), but lacked evidence supporting self-determined approaches that promoted achievement of post-high school adult employment, further education, and adult living goals.

Pediatric outcomes in PT. Ketelaar et al. (2001) presented a unique experimental research report that informed physical therapists in the Netherlands about ways to promote self-determination for students with disabilities and their families; it encouraged therapists to consider progress on variables beyond impairments when assessing treatment outcomes. Ketelaar's research team thoroughly examined literature investigating common neurophysiological therapy approaches, as well as recent studies that looked at function-based approaches. Their review supported the lack of functional maintenance and generalization of motor skills for children with disabilities.

Using an experimental pre-post design, Ketelaar and colleagues (2001) evaluated whether the motor abilities of 28 children with cerebral palsy (CP) receiving function-based physical therapy intervention improved more than the motor abilities of a group of 27 children with CP in a comparison group, where therapy focused on normalizing quality of movement, a more typical form of intervention. The researchers hypothesized that children receiving the function-based therapy would show greater improvement than children in the comparison group receiving the more typical intervention. All children were evaluated using the Dutch version of the Gross Motor Function Measure (GMFM) and the Pediatric Developmental Inventory (PEDI) prior to beginning the study and at six, 12, and 18 months following the pre-test. Variables were assessed for therapist effects using a repeated-measures analysis of variance, because some of the therapists participated in the study with more than one child.

Findings revealed no difference in basic gross motor abilities between groups, although Ketelaar et al. (2001) did note a maturational effect at work in all domains of the GMFM and the PEDI for both groups. There were no significant therapist effects found for variables on either instrument. There were no interaction effects noted between age, group, or time, although younger children improved more than older children. However, in terms of functional skill acquisition, a larger main effect for the functional mobility occurred. That is, children in the functional intervention group demonstrated greater capability and performance of self-care and mobility skills, compared to the comparison group who experienced typical handling intervention. Post-intervention survey responses by therapists regarding overall program benefits revealed that therapists in the functional therapy group changed the way they wrote and discussed their goals (functional versus impairment-level goals) compared to the referent group. Therapists indicated that their goals were more function-based; however, therapists took longer to come up with the functional goals in the beginning of the program. Parents reported that they and their children practiced functional skills more often, and practiced goal-related tasks in functional situations. The Ketelaar et al. sample was small and represented children with milder forms of CP; however, findings supported self- and family-determined therapy interventions.

In a Canadian evaluation of school-based therapy services including occupational, physical, and speech therapy, King et al. (1999) investigated goal attainment as a process for documenting therapeutic change. King et al. conceded that therapy services are costly, but that available evidence did not necessarily support the interventions. King et al. noted statistically and clinically significant improvement in children’s functional status and goal attainment for all three related services, and the changes were maintained months later. In particular, PT interventions led to mobility gains. The authors suggested that collaborative goal setting and planning processes used in the study were valuable, and that a mix of intervention approaches including direct intervention, consultative services, and monitoring all helped children achieve functional goals.

Adult outcomes in PT. Using qualitative methods, another team of researchers investigated characteristics of physical therapy sessions from the perspectives of the patient and therapist. Therapy recipients were adults recovering from a stroke; however, the study is timely given the self-determination themes identified during the interventions (Wottrich et al. 2004). Wottrich's team conducted individual interviews and observed physical therapy sessions. After separately interviewing the patients and the therapists, the following six characteristics of therapy sessions emerged: (a) setting and attaining goals, (b) focusing on motor activity, (c) finding the optimal training strategy, (d) facilitating active patient involvement, (e) making use of environmental factors, and (f) adjusting to the structural reorganization of the rehabilitation service.

Setting and attaining goals received simultaneously similar and discordant opinions. Patients said it was important to express their goals, but it was hard for them to determine progress on goals. The authors remarked that goal setting in the clinical environment is incompatible with patient goals relative to home and community environments, an apparent practical and philosophical disconnect. Wottrich et al. (2004) asserted that physical therapists must listen to their patients and pursue patient-relevant goals. Furthermore, Wottrich et al. suggested that PT progress could be determined by improvement on patient-stated goals and that therapists should develop a conscious strategy to enable patients to share power and responsibility for their rehabilitation.

Wottrich et al. (2004) never once used the term self-determination; yet, self-determination elements were quite evident in their studies. I contend that the *SDLMI* can be that conscious strategy for physical therapists to use to improve not only patient satisfaction, but also therapeutic outcomes in clinical, school, or other community settings.

Linking Proven Self-determination Elements and Physical Therapy

As previously stated, the self-determination literature is replete with evidence identifying factors at work in classrooms. The above studies contain references to setting meaningful goals, evaluating progress, and making adjustments in the PT program to improve outcomes. Youth with SMDD can choose, set goals, plan, evaluate, and adjust their plans with appropriate supports to achieve their postsecondary transition goals. Activities that are pursued within physical therapy settings should support student and family goals through student-self-determined interventions.

The following studies examined elements of self-determination that were used as support strategies in classroom settings. While clarifying outcome variables, these studies informed my methods for implementing self-determination strategies within physical therapy interventions. Specific self-determination elements gleaned from the literature and investigated in my proposed study are outlined below.

Autonomy and choice. Stefanou, Perencevish, DiCintio, and Turner (2004) investigated autonomy as a part of self-determination, and strategies that teachers used to support its development in typically developing children. Through literature review, coupled with classroom teacher observations, Stefanou et al. (2004) investigated autonomy and differences in the ways that teachers can promote autonomy in the classroom. They sought to break down the larger concepts (e.g., self-determination, motivation, and autonomy) into facets that obviously included choice and control, and attempted to put forth a hierarchy of support strategies for teachers to use to maximize student autonomy. Stefanou et al.'s work points out the need for very clear operational definitions of autonomy (e.g., organizational, procedural, and cognitive autonomy in this case), rather than maintaining global definitions of self-determination. While Stefanou and associates discussed self-determination and autonomy according to Deci and Ryan's (2000) thinking, they attempted to move beyond this foundational basis for self-determination by discussing ways to support autonomy. In the end, their discussion of autonomy as primarily an issue of choice that needs to be supported is only part of the issue that they intended to elucidate, just like choice is only one aspect of self-determination.

This study is timely and relevant. Many of the citations used by the authors meshed with the *Self-determined Learning Theory* (Mithaug et al. 2003). Unfortunately, the qualitative methods used by Stefanou et al. (2004) resulted in a one-sided (teachers), and rather ambivalent and confusing discussion of autonomy as a part of self-determination; therefore, methods suggested by the authors to support autonomy in classrooms by teachers remain suspect. While I agree that a discussion of the three types of autonomy supports was valuable to consider in the mix of self-determination, autonomy alone comprises other constructs, i.e. control, choice, and intrinsic/extrinsic motivation. I believe that a clearer definition of student autonomy as an element of self-determination is useful, as would a more distinct method for measuring autonomy. This paper, as a descriptive piece, is thought provoking and pertinent to the self-determination literature. Its findings, however, do not advance the self-determination body of knowledge beyond descriptive considerations at this point, given its unfocused methodology.

Choosing and setting goals. Setting goals is a significant part of rehabilitation for children with disabilities and their families, and families agreed that goals should be specific, measurable, activity-related, realistic, and time specific (Siegert & Taylor, 2004). Siegert and Taylor's research revealed that therapists wrote impairment-based goals, thus negating opportunities to promote self-determination via mutual goal setting with children and families. Therapists could promote better outcomes for patients if autonomy, competence, and interpersonal relatedness were embedded in the process of goal setting, as promoted by Ryan and Deci (2000). Siegert and Taylor's self-determination model recognized that intrinsic motivators are more powerful than extrinsic motivators, likely because they provided relevance to something the patient wanted to do.

Siegert and Taylor's study implies that extrinsic therapy goals, like impairment-based goals, served to disrupt behavior that is intrinsically motivated. They also suggested that negotiating shared goals between patients and their rehabilitation team could be more effective than the more typical process of passive goal setting in these clinical environments. Siegert and Taylor progressed our understanding of self-determination beyond the process of recognizing innate psychological needs into the realm of understanding the impact of social contexts on these needs. The *Self-determined Learning Theory and Model of Instruction* may provide useful strategies for individuals with disabilities, and those who support them, to recognize and develop autonomy, competence, and relatedness within their own lives.

Goal setting, self-evaluation, and self-advocacy. In a related study that examined the importance of self-determination for postsecondary students, Thoma and Getzel (2005) used focus groups to clarify self-determination skills and supports that were needed for success, as well as those skills needed for self-advocacy. Thoma and Getzel chose students who had self-disclosed their disability in order to ensure that the participants had experienced some level of self-determination. The authors posed targeted questions to focus-group participants that helped identify important self-determination skills needed for success in post-high school educational settings. These skills included problem solving, understanding the disability, goal setting, and self-management, and are all part of the *Self-determined Learning Theory* (*SDLT*) discussed earlier. Participants in this study learned these self-determination skills in a variety of ways including trial and error, parental input, and by interacting with other people with similar disabilities.

Recognizing support needs as part of self-advocacy. Youth with severe and multiple developmental disabilities and their caregivers often recognize that that functional mobility skills may not be independently achieved; but, these individuals can often direct the supports they require to achieve a mobility goal. Physical therapists typically evaluate their patient's progress toward therapist-identified goals, and make changes in the PT program according to their own progress evaluations, with little input from the patient. Patients rarely get the chance to evaluate their progress, or make changes in their PT programs to match their own goals. Recent evidence suggested that interventions might not generalize to settings outside of the clinic. Sylvester's (2006) discussions with two adults who have CP and received childhood therapist-directed interventions had no idea why they received it. They were unable to express their preferences or choices about participating in PT exercises; they did not understand the relevance of PT exercises to goals they and their parents wanted to pursue at home and in school. Yet, these individuals never self-advocated to challenge the PT plan.

The *Supports Intensity Scale (SIS)* described in Chapter three not only provided a clearer description of an individual with SMDD, it also acknowledged recent changes in the way providers perceive and intervene with people who have SMDD. The *SIS* shifted providers' focus from deficits to self-determined inclusive practices that improve overall quality of life.

Thompson et al. (2002) developed the scale in order to help individuals with SMDD determine the supports they need in order to participate and assume valid roles in their communities and achieve greater satisfaction and fulfillment. The *SIS* defined supports as resources and strategies that promote the welfare and interests of people with disabilities to enhance personal independence, and greater participation in an interdependent society, with fuller community inclusion. Use of the *SIS* is spreading around the country in programs charged with developing and funding supports for individuals who have SMDD; however, no research investigating its utility with this population exists.

Summary of PT and Self-Determination Component Links

Investigating how teachers can encourage decision-making processes by typical middle school-students, Stefanou, Perencevish, DiCintio, and Turner (2004) conceptualized self-determination, motivation, and autonomy into facets that included choice and control, as well as competence and relatedness. Interestingly, relatedness assumed that student choice making is a familiar experience resulting in behavioral actions that are meaningful. Stefanou et al. suggested that if teachers provide cognitive autonomy supports to their students with disabilities, more complete learning results. The interplay between self-determination, choice, control, and autonomy supports discussed by Stefanou et al. appeared relevant for physical therapists to consider when determining the effectiveness of their interventions, and matches theories of motor learning held by many therapists today.

Specific, measurable, applied, activity-related, realistic, and time specific goal setting appeared to play a significant role in improving the habilitation of children and adults with disabilities and their families in the above studies. Researchers suggested that shared goals between patients and their rehabilitation team could be more effective than the more typical passive goal-setting process. To maximize opportunities to promote self-determination, physical therapists need to include children and families in the decision-making process, and focus on applied goals to be pursued in current and future settings. This means that therapists need to minimize writing and pursuing impairment based goals (Ketelaar et al., 2001; King et al., 1999; Siegert & Taylor, 2004; Wottrich et al., 2004).

Thoma and Getzel's (2005) investigative strategies informed my proposal by hinting at the elements that should be part of the student-self-determined intervention. The authors provided clarification of the self-determination factors I will examine in my single-subject investigation. Finally, Thoma and Getzel reinforced the notion that self-determination skill development should start very early in childhood. Given that most children begin physical therapy intervention early in life, and some continue therapy well into adulthood, these findings have considerable merit within the physical therapy arena.

Kleinert et al. (2007) modeled the investigative process I propose in this study. They were sensitive to the student value in using the *SDLMI* within speech and language pathology interventions. They also suggested that the minimal time investment to enable a student to consistently self-evaluate his progress might outweigh the slight delay in skill acquisition, compared to students who do not have the opportunity to self-determine (Klienert et al., 2007).

In consultation with significant others, self-determined people set their own goals, express choices and decisions, recognize options and alternatives, solve their problems based on experiences, self-advocate, articulate the support they need to be successful, and evaluate outcomes (Martin & Marshall, 1996). Mithaug (2005) asserted that self-determined people pursue their own interests in settings that are personally meaningful. Self-determination begins with self-regulated choice making and it is supported by a combination of related components: goal setting, self-planning, self-evaluating, and self-adjusting. Mithaug believed people with disabilities, including those with severe and multiple developmental disabilities must have opportunities and supports to become self-determined.

Unpublished pilot studies connecting self-determination and PT intervention. Keeping Mithaug's principles in mind and in anticipation of this dissertation, I conducted three distinct, but related pilot studies to investigate 1) the presence and use of self-determination elements within PT settings, 2) recognition of self-determination elements by therapy recipients and their families, and 3) the relevance of PT interventions to post-secondary transition planning (Sylvester, 2006; 2007; 2009). The first qualitative study showed that opportunities to promote self-determination elements like choice, control, and goal relevance are possible, but missing from PT interventions. Adults with cerebral palsy retrospectively recognized opportunities for exercising self-determination in their childhood PT sessions, but they felt those opportunities were thwarted rather than promoted by the therapists (Sylvester, 2006). Therapy recipients and their caregivers in a second study (Sylvester, 2007) were asked to identify whether or not self-determination elements were present during their PT sessions, compared to PT interventions lacking these elements. Participants in this single-subject study received alternating treatments. One treatment promoted opportunities for making choices, controlling the flow of activities, and relating their activities to personal goals; the other treatment offered no choice, control, or goal related opportunities. Participants consistently recognized and preferred the PT sessions that offered choice, control, and goal-relevance. Qualitative findings in the third study revealed disconnected PT interventions and transition planning for youth with severe and multiple developmental disabilities.

Using the National Secondary Transition and Technical Assistance (NSTTAC) Indicator 13, I found that the postsecondary goals written on the participants' IEP rarely matched the goals they stated during our interviews. In fact, some of the participants had no postsecondary goals written on the transition IEP pages. Finally, PT frequency for youth with disability as they approached high school completion decreased and was irrelevant to their stated postsecondary goals (Sylvester, 2009).

Summary of Literature Review

Students with SMDD in this study are characterized by a myriad of medical, educational, social, and support agency's definitions and descriptions as reported in the literature. These individuals remain marginalized as they grow into adulthood, often by virtue of the supportive systems surrounding them. Intervention approaches continued to follow impairment-based protocols, although disablement models are moving the medical and rehabilitation services beyond impairments to improving quality of life for people with SMDD (Jette, 2005).

Students with SMDD demonstrated the poorest ability to set and achieve postsecondary employment, education, or adult living outcomes. Disaggregating data from the NLTS2 proved challenging when determining post-school outcomes for such a small segment of students with disabilities; nevertheless, students with SMDD fared worst across all postsecondary categories. Kohler's (1996) *Taxonomy for Transition Programming* provided the framework for discussing current transition practices for these youth. Transition practices that promoted student IEP involvement and leadership resulted in better postsecondary outcomes. Coordinated transition programs that extended supports beyond high school graduation resulted in better employment outcomes in terms of wages earned and job stability. One study provided contrary evidence regarding the relationship between paid work experiences and postsecondary employment outcomes, but significance of disability and support needs likely factored into the results. The combination of severe impairments and health care concerns resulted in poorer outcomes if families did not engender the necessary supports.

Youth with SMDD were rarely involved in their transition IEP meetings, yet the research evidence showed that when students with mild and moderate disabilities were taught how to lead and become more involved in their IEP meetings, they and their team members understood what happened at the meeting, all team members perceived the meeting more positively, and the meeting remained student-focused (Martin et al., 2006). Person-centered planning programs like the *Self-Directed IEP* should be implemented with youth who have SMDD.

The effectiveness of targeted self-determination training and focused educational practices was evident in the literature. While my study investigates the effect of the *Self-determined Learning Model of Instruction (SDLMI)*, most of the studies reviewed investigated the effectiveness of isolated self-determination elements, such as choice making and self-advocacy skills. Very few studies investigated the impact of teaching self-determined approaches to students or adults with SMDD, and even fewer studies investigated self-determination relative to outcomes achieved through related services. Exceptions included Klienert et al. (2007), who investigated use of the *SDLMI* for students learning syntax strategies during speech pathology interventions, and the researcher's three unpublished pilot studies (Sylvester, 2006 2009, 2010).

Students and adults with severe intellectual disabilities were taught and learned choice making and self-management skills; but once learned, did these skills generalize to new situations and settings? Taking Wood et al. (2005) to task, my study provides an opportunity to investigate the *SDLMI* in new settings with different related services providers and with individuals who have SMDD. What is the impact of a PT intervention that supports the participant's ability to express choices, set goals, self-evaluate, and self-adjust as they pursue relevant mobility skills in familiar and new applied settings? This investigation aims to extend the *SDLMI* research parameters to include postsecondary transition-aged youth who have SMDD and who receive PT intervention.

Chapter Two Summary

In 1999, The Association for Persons with Severe Handicaps (TASH) forwarded a resolution regarding the use of related services providers like physical therapists. This resolution recognized the important and valuable contributions that we make as we assist people with disabilities to become fully included in their communities. TASH's recommendations outlined in Table 2.3 provide beacons that direct our services and help us to keep moving children and adults with SMDD toward full societal inclusion. Each item in the resolution features aspects discussed in this literature review and reinforces my need to conduct this study.

Table 2.3.

TASH Resolution on Related Services

Effective service provision requires that related services personnel:
• Establish positive and respectful relationships with the person who has disabilities and with individuals who are significant in his/her life, working in a person-centered or family-centered manner such that self-determination is encouraged;
• Determine appropriate services and supports based on an understanding of the desires and needs of the person, and on assessment of participation in everyday activities and routines;
• Adhere to the guideline of “only as specialized as necessary” when determining needs for services, so redundant, unnecessary, and unwanted services and supports are not provided;
• Collaborate with others who facilitate inclusive education and living for the person with disabilities to determine supports, adaptations, and interventions that optimize meaningful participation in typical home, school, and community life, both immediately and in the future;
• Provide individualized services in real life settings and teach others to provide specific and individualized support and intervention strategies to enhance participation in everyday activities and routines; and
• Evaluate effectiveness of services and supports through feedback from the person with disabilities and significant individuals in his/her life, and through outcomes in real life settings.

Note: From “TASH Resolution on Related Services,” 1999. Copyright 1999 by TASH. Retrieved 3-12-11 from http://tash.org/advocacy-issues/inclusive-education

Promoting Evidenced-Based Practice

IDEA (2004) requires special education and related services to document the effectiveness of their intervention strategies to enable children with disabilities to benefit from special education. Little research was found that generalized results to physical therapy interventions into postsecondary employment, education, or adult living settings (Campbell, 1997; Ketelaar et al., 2001). Very often, physical therapists assume that patients can generalize and transfer what they learn and accomplish in the clinic to their home or community setting; but research evidence did not support this claim (Bax, 2001; Campbell, 1997; Dole, Arvidson, Byrne, Robbins, & Schasberger, 2003; Harris, 2005; Schmidt & Lee, 1999; Shumway-Cook, Woollacott, & Mullally, 2001). The degree to which acquired mobility skills generalize to another environmental setting is of interest to physical therapists (Campbell, 1997; Cooper, Heron, & Heward, 2007; Marley, Ezekiel, Lehto, Wishart, & Lee, 2000).

Physical therapists want to know if their interventions are beneficial and optimize learning of motor skills even after hands-on interventions cease, as in the maintenance phase of this study (Campbell, 1997; Shumway-Cook et al. 2001). More importantly, therapists want to know if the motor skills learned and practiced in a clinical setting are effectively performed in daily life functions in meaningful environments (Campbell, 1997; Marley et al. 2000). Single-subject studies like this one offer powerful methods for therapists to use to assess and improve the effectiveness of their interventions for their clients and families.

Physical therapy, like special education, is a field that is concerned with individual student's performance, active intervention to improve performance, and practical procedures that the student can use in other meaningful contexts (Horner et al., 2005). Harris (2005) viewed single-subject research as particularly relevant for use with individuals who have developmental disabilities given the heterogeneity of diagnostic categories represented; that is, finding sufficient numbers of similar participants is nearly impossible for large group studies. Horner et al. 2005 consider single-subject research as evidence-based when

> (a) the practice is operationally defined; (b) the context in which the practice is to be used is defined, (c) the practice is implemented with fidelity, (d)

> results from single-subject research document the practice to be functionally related to change in dependent measures, and (e) the experimental effects are replicated across a sufficient number of studies to allow confidence in the findings (p.175-176).

Harris (2005) urged physical therapists to be responsible for demonstrating treatment efficacy and sharing results with colleagues, whether interventions were successful or not, thus expanding the physical therapy knowledge base through carefully controlled investigations. Single-subject studies are well suited to provide simple, systematic, and efficacious determinations of intervention strategies in a variety of settings as proposed in this study. With these issues in mind, I re-introduce the purpose of this study found at the end of Chapter one.

This study will extend the self-determination research base into the related services arena and explore whether utilizing an established self-determination model during PT interventions will promote functional mobility skill acquisition in students who have SMDD. The primary focus of this study is to determine how well students with SMDD who receive self-determined PT interventions gain functional mobility skills, and generalize these learned skills to non-clinical environments that they choose, compared to when they receive clinician-directed PT interventions.

CHAPTER THREE

Methodology

Overview

Using a multiple probe with alternating conditions across participants design, this study compared two physical therapy intervention approaches, clinician-directed (CD) and participant self-directed (SD), for teaching five young adults with severe and multiple developmental disabilities (SMDD) gain mobility skills. This study also investigated how well the participants maintained learned mobility skills in a familiar applied setting without intervention, and generalized to a new applied setting. Finally, I investigated whether participants used more facets of the *Self-determined Learning Model of Instruction (SDLMI)* after participating in the SD condition compared to when they participated in the CD intervention. While primarily a single-subject study, participant interviews, document reviews, and field notes detailing observations and participant comments provided additional qualitative data to socially validate the intervention.

While participants knew and pursued their uniquely determined mobility skill in each CD and SD physical therapy session, the CD intervention required therapy recipients and caregivers to remain blind to the scope and sequence of daily intervention activities. CD interventions required the physical therapist to choose and direct the therapy activities in a predetermined sequence and the therapist conducted all exercises without openly discussing any adjustments or connections between the participant's actions, chosen mobility skill, or postsecondary events.

The SD condition incorporated the three phases of the *SDLMI* (Mithaug et al., 2003; Wehmeyer et al., 2006; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) that the student with SMDD pursued with supports from caregiver or assistive technology as needed. As in the CD condition, the SD intervention required the student with SMDD to know his or her mobility skill or goal. Contrary to the CD condition, participants in the SD condition chose intervention activities from an established menu and determined the activity implementation sequence. Participants took action and made a plan to solve the mobility problem, self-evaluated progress on their mobility skill, and then adjusted their goal or plan accordingly to promote successful achievement of the goal. Using standard verbal, augmented, or alternative communication modes during the SD condition, participants engaged in open discussion with a caregiver and the therapist about their postsecondary goal(s) that required achievement of their identified mobility skill.

Research Methods and Procedures

Participants

Youth with SMDD. Seven youth with SMDD aged 14 to 22 years who were involved in transition planning efforts were recruited and agreed to participate in this study. Four participants recently graduated high school in the last year, and three had yet to graduate. After securing appropriate consents (Appendix B), six of the seven participants were eligible to participate in the study. One youth exhibited only mild learning disability and slight mobility impairment; therefore, he did not meet the criteria for inclusion. Five of the remaining six participants went on to complete baseline and alternating interventions, but only four participants completed all study activities through the maintenance and generalization phases. One participant's worsening pre-existing condition and frequent durable medical equipment failures caused his inconsistent participation, resulting in his voluntarily withdrawal from the study altogether. Another participant had un-resolvable conflicts with her work schedule that forced her withdrawal from the study. Though she participated in a sufficient and comparable number of CD and SD interventions as the other active participants, she remained one mobility step shy of achieving her goal and had not entered generalization when she withdrew from the study. Given the participants' severity of disability, health-related concerns, and their varied supported living and working conditions, I expected sample attrition. Out of the six individuals who began the study, five participants completed sufficient intervention and/or generalization sessions that allowed for thorough data analysis. Therefore, results will be presented on all five participants.

The five remaining participants had SMDD and exhibited at least two concurrent impairments that occurred before or around the time of birth, and required extensive and pervasive supports to achieve their daily activities. All participants exhibited neurological impairments affecting mobility, speaking, and ability to accomplish typical daily tasks independently. Andy and Jess carried a formal diagnosis of CP with intellectual impairments; Toby had multiple developmental and intellectual impairments with associated communication and sensory impairments; Holly had spina bifida with associated sensory and cognitive impairments; and Carla had multiple developmental disabilities with concurrent communication and cognitive impairments. Holly, Andy, and Jess moved independently within their environments using power wheelchairs; Toby depended on others to push his wheelchair everywhere; and Carla walked independently, but demonstrated balance and motor skill deficits. All participants required family caregivers and/or paid support staff to manage daily living and work activities.

Table 3.1

Participant Demographics, Diagnosis, IQ, & Pre-Post Study Assessment / Descriptions

Name	Age	Male Female	Grade	Diagnosis /IQ	AIR–ED PT (%)		GMFCS Level	FIM Areas and Measures	SIS Percentile	IEP Goal Match
					Pre	Post				
Carla	18	Fem	Junior	MD; ID; Sensory; Comm; <70	45	78	I	7I – eating, lower body dressing, bowel and bladder management, transfers to all surfaces and walking; 6I - upper body dressing, stair climbing, and memory skills; 5D – grooming, bathing, comprehend and express ideas; 3D – toileting; 2D – social and problem solving skills	37th - requires significant supports in all areas, especially those dealing with safety, problem solving.	Yes
Toby	19	Male	HS Grad	MD; ID; Sensory; Comm; <70	22	75	V	1D – all areas except bladder/bowel management (6I); 5D – social; 4D auditory comprehension	45th – requires extensive physical supports in all areas	No
Holly	18	Fem	Junior	Spina Bifida; Sensory;ID; <70	50	75	IV	7I – Eating, grooming, dressing-upper body, bladder management/assistance or freq. of accidents, vocal or non-vocal expression, social interaction, and problem solving. 6I-modified for locomotion using a wheelchair; 5D – supervision for transfers (bed/wheelchair) and memory; 4D – minimal contact – does 75% or more for bowel management/freq of accidents; 3D – moderate assist (does 50-74%) for bathing and visual comprehension; 1D – total assist (does 25% or less) for dressing lower body, toileting, bowel management assist, toilet transfers and tub transfers; 0 for locomotion and stairs.	13th percentile indicating that her support needs are not very extensive overall, but reinforces her needs in areas of transfers, bathing, and some help with decision-making.	Partial – College vs. non-specific Training

Jess[a]	20	Fem	HS Grad	CP; ID; <69	65	85	IV	7I – complete independence for eating, dressing upper body; bladder and bowel management; wheelchair locomotion; auditory or visual comprehension; vocal or non-vocal expression; social interaction; problem solving; memory. 6I- modified independence with bladder management assist (pill); transfer to bed/chair/toilet. 5D-supervision for grooming. 4D-minim contact help/can complete 75% or more of bathing and toileting tasks. 1D –total assist (<25%) for lower body dressing and shower transfers. 0 -Jess doesn't do tub transfers, walk or use steps.	30th – demonstrates Jess's physical support needs in some areas (specifically dressing & bathing), though not extensive in all areas.	IEP document not available. By report, no match. Jess wanted and thought she was going to McCall's on a 1-2 month transition basis before moving into her own apt. Thought she was going to get a real job. Didn't happen. Stuck in ICF-MR for 2 years.
Andy	21	Male	Junior HS drop out	CP; ID; <70	75	85	IV	7I – Bladder/bowel manage; locomotion wheelchair; comprehension auditory/visual; social interaction; memory 6I-modified – Freq. of bladder accidents & problem solving; 5D – transfers-toilet; 3D – 50-74%assist for eating; 1D - <25% assist for grooming, bathing, dressing uppers and lowers, toileting, transfers bed/chair, and shower transfers. 0 – transfers tub, locomotion (walk) and locomotion (stairs)	30th percentile indicating significant physical support needs in a few domains like toileting, dressing, grooming, meals. Other areas like decision-making he requires less support.	No

Note. CP – cerebral palsy; ID = intellectual disability; comm. = communication deficits; MD = multiple disability; AIR = AIR Self-Determination Assessment (educator); GMFCS E & R = Gross Motor Function Classification System – Expanded and Revised (Appendix C); FIM = Functional Independence Measure: (Appendix C); SIS = Supports Intensity Scale: (Appendix C); IEP Goal Match = yes or no relative to goals voiced during interview compared with IEP stated goals.

Participants either previously or currently received physical therapy services in one or a combination of the following service delivery systems: school-based programs under one of the IDEA disability categories, Home and Community-Based Waiver under the Oklahoma Developmental Disabilities Services Division (DDSD), or private community-based physical therapy services. Jess and Toby, recent high school graduates, had no ongoing direct physical therapy services and no therapist on record. Carla and Holly were eligible for physical therapy under IDEA in their respective high schools, but therapy services were deemed unnecessary and not provided. Eligibility requirements for DDSD services required individuals to demonstrate IQ's at or below 70. Therefore, all participants exhibited intellectual impairments demonstrated by an IQ near 70, or slightly below. However, all met the inclusion criteria for sufficient intellectual ability to understand and respond to simple intervention directions and questions, using standard, augmented, or alternative communication methods. None of the participants previously or currently received physical therapy intervention from the researcher until the study's inception.

Caregivers. At least one caregiver per therapy recipient participated in each PT session. Caregivers were parents, sometimes paid support staff, and sometimes both. Participant and caregiver demographic information was gleaned from the initial survey and interview conducted prior to beginning the study in an effort to ensure adherence to established communication criteria.

Therapist. The researcher was a licensed physical therapist with nearly 24 years of experience working with children and adults with SMDD. Using the researcher as therapist introduced obvious experimenter bias during interventions, requiring strict attention to fidelity of intervention and inter-observer agreement on dependent measures. Therefore, participants in this study were not among the researcher's current cases.

Settings

Pre-study, initial baseline, alternating CD and SD interventions, and follow up phases happened in participant-chosen environments: one familiar (e.g. living room) and another less familiar setting (e.g. bedroom). Each participant and their caregivers worked one-on-one with the therapist in their homes, or another familiar applied setting for initial baseline, intervention, and maintenance conditions of the study.

Generalization probes occurred in a second, less familiar applied setting chosen by the participant, but one that also required use of the mobility skill. For example, Holly learned to independently transfer from her wheelchair to her bed, and back to her wheelchair. She wanted to learn to transfer to her bathtub at home. Holly's bedroom became the initial familiar setting for baseline and intervention phases because she was most familiar with this transfer. She was lifted directly into the tub by a caregiver and had not practiced a bathtub transfer. Holly's bathroom and tub became her preferred setting for generalization probes.

To facilitate learning and transference of a motor skill, it must be practiced with contextual interference, or within the context of other [relevant] tasks or environmental constraints (Davis & Broadhead, 2007; Schmidt & Lee, 1999). Thus, conducting all phases of the study in applied settings promoted real-world application in real-world settings.

Pre-intervention Activities

After gaining approval from the University of Oklahoma Institutional Review Board, I met with each participant to review the study protocol and activities, and gained appropriate signed consent and assent prior to beginning any study activities (Appendix A). Participants understood that study-related physical therapy services were free, and that they would receive a $10 gift card in compensation for each week that they participated in the study. Before engaging baseline and intervention conditions, I conducted the following pre-intervention activities.

Interviews. Guided by the interview questions in Appendix B, participants and their caregivers shared their respective visions and goals for adult living, working, or education. Using participants' IEP documents (when available), I matched their interview responses with specific goals, strengths, limits, and support needs to provide an ecological basis for physical therapy interventions. From this information, each participant determined one unique mobility skill. Identified mobility skills were comparable in difficulty level across participants in terms of number of steps or tasks to complete the mobility skill. Holly, Andy, and Toby chose a goal that involved moving from a wheelchair to another surface, and back to their wheelchair independently and safely; Carla chose to ride her adapted tricycle independently and safely; and Jess' goal combined moving into and out of her wheelchair with caring for a baby. In addition to their chosen mobility goal target for intervention, participants chose a second setting in which to perform their mobility goal skills once interventions ceased (generalization setting).

Participant-descriptive measures. I administered the following four pre-study measures to give a clearer description of each participant, not to assess pre- and post-intervention status (Appendix B). These measures included (a) the Gross Motor Function Classification System for Cerebral Palsy – E & R (Palisano, Rosenbaum, Bartlett, & Livingston, 2007), (b) the Functional Independence Measure (Balandin & Morgan, 1997), and (c) the Supports Intensity Scale (AAIDD, 2008). I assessed pre- and post-study self-determination for each participant using the American Institutes for Research (AIR) Self-Determination Scale (Wolman, Campeau, DuBois, Mithag, & Stolarski, 1994) for descriptive and pre- to post-intervention comparison. My perspective alone was used because neither participants nor caregivers' provided consistent or complete responses. Table 3.1 shows participant demographic and pre-post-assessment findings. A discussion of each pre-study assessment follows.

Gross motor function classification system - E & R. Expanded and revised (E & R) from the original Gross Motor Function Classification System (GMFCS) for cerebral palsy, the GMFCS – E & R is a five-level classification system based on self-initiated movement that emphasizes sitting, transfers, and mobility within meaningful daily life activities (Palisano et al., 2007). The GMFCS - E & R includes youth 12 to 18 years of age and conceptually aligns with the World Health Organization's International Classification of Function, Disability and Health (ICF), and considers the environmental and personal factors that impact youth's present abilities and limitations in gross motor function (Palisano et al., 2007). Appendix B delineates the mobility criteria for adolescents at each level of the GMFCS – E & R. The participants with SMDD in this study generally reflected levels IV and V, with no expectation of major change during the course of the study.

Rosenbaum, Palisano, Walter, Russell, Wood, and Galuppi (1996) established the content validity of the original GMFCS prior to development of the expanded and revised edition, reaching consensus in two Delphi surveys among 28 Canadian physical therapists, occupational therapists, and developmental pediatricians (Rosenbaum et al., 1996). Palisano, Rosenbaum, Bartlett, and Livingston (2007) investigated the expanded and revised version of the GMFCS using quantitative and qualitative methods and again incorporating nominal group techniques and Delphi survey consensus processes. Palisano et al. (2007) achieved consensus, defined as 80% agreement on description clarity, accuracy, and distinctions between the five GMGCS - ER levels among 30 health care professionals surveyed from across seven different countries. Palisano et al. determined that the GMFCS - ER content is valid and useful for clinical decision-making, communicating performance levels, use in clinical databases, and research surrounding youth up to 18 years of age.

Functional independence measure. The Functional Independence Measure (FIM®) assesses functional status and change over time in 18 items over six distinct domains: self-care, sphincter control, mobility, locomotion, communication, and social cognition (Balandin, Alexander, & Hoffman, 1997; Balandin & Morgan, 1997; Law, 1997). Each participant’s task performance is rated on a scale (see Appendix B) from 1 (fully dependent on others to complete the task) to 7 (independent).

The FIM® is a useful predictor of burden of care as measured by the amount of assistance time provided by another person in people with multiple sclerosis and predictor of disability in survivors of stroke (Oczkowski & Barreca, 1993). The FIM® is marginally responsive to change in clients with spinal cord injury from admission to discharge, and sensitive in describing disability levels for patients with multiple sclerosis, with item-specific Kappa scores ranging from .48 to.63 (Cole, Finch, Gowland, & Nayo, 1994; Law, 1997). Interclass correlation coefficients for inter-rater reliability both for the total FIM® scores and its distinct categories ranged from .88 to .96 (Law, 1997). Neither test-retest nor internal consistency reliability measures were reported in the literature. Although the FIM® is a clear and concise assessment with demonstrated utility in rehabilitation settings, it has rarely and only recently been used with individuals who have developmental disabilities, specifically, with children.

Wong et al. (2004) used the FIM® for Children (WeeFIM) to demonstrate correlation between functional mobility and language development in children with developmental delays. Later, Wong, Au-Yeung, and Law (2005) investigated risk factors associated with functional performance and found that despite impairments, children with cerebral palsy were able to achieve functional independence. Balandin, Alexander, & Hoffman (1997) utilized the FIM® to predict equipment needs and costs for adults with cerebral palsy and found that individuals with more severe disabilities required more support, resulting in higher equipment costs. In their quantitative analysis of the FIM®, Ottenbacher, Yungwen, Granger, and Fiedler (1996) found it to have acceptable reliability across settings, raters, and patients. In their 1996 study, Grimby et al. found the FIM® useful for assessing disability in adults with cerebral palsy and spina bifida. This singular study investigating the use of the FIM® with adults in community living settings found that it reliably matched performance with perceived difficulty of task (Grimby et al., 1996). Minimal change may be expected in participants' FIM® scores throughout the study.

Supports Intensity Scale. The Supports Intensity Scale (SIS) is an interview-based assessment tool designed to measure the level of practical supports needed by people with intellectual disabilities to live normal, independent, and quality lives in their communities (AAMR, 2002). The SIS measures an individual's support needs in three sections: (a) section one assesses 49 life activities grouped into six subscales that include home living, community living, life-long learning, employment, health and safety, and social activities; (b) section two measures supplemental protection and advocacy activities; (c) section three measures supports needed in 15 medical conditions and 13 problem behaviors often associated with intellectual disabilities (Appendix B). Support needs are assessed according to the frequency, daily support time, and type of support. Minimal change may be expected in participants' SIS scores throughout the study.

Developed over five years by experts from the American Association on Intellectual and Developmental Disability (AAIDD), formerly the American Association on Mental Retardation (AAMR), the SIS support indicators were established through an extensive literature review followed by a Q-sort by 50 professionals in the field of intellectual disabilities in order to establish content validity and item grouping. Internal consistency of the SIS was demonstrated at .90 and construct validity tests yielded coefficients ranging from .45 to .87 (Thompson et al., 2002). The SIS is empirically based and was field-tested with over 1700 people with intellectual disabilities, and has demonstrated utility in the determination of functional support needs for people with developmental disabilities. The SIS aligns conceptually with the current definition of intellectual disabilities forwarded by the AAIDD (AAMR, 2002), and with the description of participants in this.

Air Self-Determination Assessment

As stated earlier, the pre-study measures provided a more detailed description of each participant, and were not for pre-post intervention assessment. However, given the emphasis on self-determined intervention approaches used in the study, I did consider pre- and post-study data for the AIR (Appendix B) from my perspective only, surrounding work on the study-related mobility goal. Participant and caregiver responses were not consistently or reliably available. Reliability tests for the student-version of the AIR Self-Determination Scale included split-half test for internal consistency, alternative item correlation for item consistency, and a test-retest assessment of stability of the results across time. Alternative item correlations ranged from .91 to .98; odd and even-numbered items using split-half comparisons resulted in a .95 correlation; and test-retest reliability conducted over three months yielded a correlation of .74. Factor analysis of the scores on 30 items reflected and verified the conceptual structure of the AIR assessment surrounding the following constructs: *capacity-opportunity, home-school*, and *knowledge-perception*. Educators in California and New York involved in the field-testing of the AIR Self-determination Assessment found it to be reliable, valid, and useful with over 450 students between six and 25 years of age who reflected multiple diagnostic categories and cultural backgrounds.

Social Validity

Pre-intervention activities enhanced social validity of this study by reflecting the participant's specific mobility, self-care, or other functional activities that they want or need to achieve. Mobility skill examples include wheelchair mobility at home, in school, or in the community; transfers from wheelchairs to commode, bed, or other surfaces at home, school, community; toileting at home or in the community; bed mobility; using public transportation.

Once the overall mobility skill for each participant was identified, task analysis delineated the smaller functional steps to be trained during each condition. Specific mobility skill steps in the task analysis and criteria for achieving each step required modification during baseline due to unique and sometimes unanticipated individual or environmental constraints that either made the task easier or more difficult to accomplish. Therefore, the execution and assistance required for each participant's mobility skill steps were uniquely determined.

Ecological task analysis. An ecological task analysis (ETA) process helped identify the unique and specific mobility skill steps for each participant's mobility goal, which were verified by an outside observer prior to baseline performance. Basic tenets of ETA include (a) establishing task goals by structuring the physical and social environment; (b) allowing the participant to choose movement solutions; (c) manipulating performer, environmental, or task variables; and (d) providing instruction (Davis & Broadhead, 2007). According to the tenets of dynamic systems theory, ecological task analysis is a valid method for teaching movement skills.

Dynamic systems theory presumes that a person's motor development consists of multiple cooperative systems, including contextual factors that either support or limit real-world skill acquisition (Davis & Broadhead, 2007). The goal of physical therapy interventions is to enable the therapy recipient to learn and safely perform requisite mobility skills that match their required tasks in meaningful environments (Montgomery, 2005; Ketelaar et al., 2001)

The ETA approach combines traditional step, chain, and setting training, using varied time delay and pacing prompts to teach a chain of tasks comprising each mobility step (Bellamy, Horner, & Inman, 1979). A method historically used in special education and vocational training for individuals who have severe disabilities, step training allows the individual to gain new, or change behaviors, in measurable ways (Bellamy et al., 1979). ETA varies from this more traditional task analysis by including opportunities for participants to choose movement solutions, a behavior typically absent in CD interventions, but distinctly part of a SD approach. In this study, participant choice of movement solutions will occur in the SD interventions, but will be absent from the CD sessions.

Task achievement parameters. Table 3.2 describes an ecological task analysis of Andy's mobility skill that enabled him to get out of his wheelchair and onto his couch. In physical therapy vernacular, this mobility skill is called a wheelchair-to-couch transfer. Due to varying levels of skill difficulty, environmental constraints, and participant experience, intervention methods and amounts of assistance varied by participant and task (Davis & Broadhead, 2007). Therefore, each separate task in the participant's mobility skill set included a minimal assistance parameter as noted in Andy's example. From least to most assistance provided, the parameters were: (a) independent (I) execution presumed no physical, touch, verbal, or eye gaze assistance; (b) eye gaze assist consisted of a look (L) from the therapist to the participant, or to part of the task; (c) verbal (V) assist required the therapist to tell or otherwise verbally remind the participant about an aspect of the mobility task, without touching the participant; (d) touch (T) assist required the therapist to use of only one body part like a hand, arm, knee, or foot to help the participant achieve the task; (e) physical assist (P) required the therapist to use at least two body parts to help the participant achieve the task. I considered the task achieved if the participant accomplished it with the minimal level of assist assigned or with any combination of lesser assistance. Table 3.2 shows that Andy accomplished his wheelchair-to-couch transfer mobility skill with a maximum level of touch (T) assist on steps 6, 7, and 8. Andy needed only verbal (V) prompting on steps 4 and 5. Andy needed only a look (L) to remind him to lock his wheels on step 2. He accomplished steps 1, 3, and 9 independently (no assistance at all).

Table 3.2

Andy's Task Analysis of Mobility Skill with Minimal Assistance Parameters Wheelchair to Bed Transfer - Sample

Wheelchair to Couch Transfer	*Prompt Level*
1. Andy wheels himself close to the couch	I
2. Andy locks the wheels	L
3. Andy unlocks his pelvic belt	I
4. Andy shifts his body forward in his wheelchair	V
5. Andy pushes up from the wheelchair	V
6. Andy places his feet on the floor	T
7. Andy rotates closer to the couch	T
8. Andy pushes up again and shifts pelvis to the couch	T
9. Andy pushes up to secure stability on the couch	I
10. Andy accomplished the transfer in 5 minutes or less	Yes No

Note: I = independent, L = look, V = verbal, T = touch with 1 body part, P = physical help with two or more body parts. Yes = accomplished in five minutes or less, No = accomplished in > five minutes.

If a participant requested more help for a step in the mobility skill task analysis, the request was noted as a self-initiated support request, and the task assistance was recorded on the therapist's benchmark evaluation sheet as achieved or not using the established hierarchical assistance parameters. See Andy's sample benchmark evaluation sheet in Table 3.3.

Table 3.3

Therapist's Benchmarks for Andy's Wheelchair to Couch Transfer Mobility Skill

Wheelchair to Couch Transfer with Assist Benchmark	Achieved Yes / No	Assistance Level (Prompts) I L V T P	Self-initiated support requests (tally)
1. Andy wheels himself close to the couch. – I	No	V x 2	
2. Andy locks the wheels – L	Yes	I	
3. Andy unlocks his pelvic belt – I	Yes	I	
4. Andy shifts his body forward in his wheelchair – V	Yes	V x1	
5. Andy pushes up from the wheelchair – V	No	V x 2 T x 1	√ ("My foot slipped off. Put it back on the footplate.")
6. Andy places his feet on the floor – T	Yes	T x 1 V x 1	√ ("I need help to keep my feet down.")
7. Andy rotates closer to the couch – T, V	Yes	V x 1	√ ("Please take away the big pillows to give me room.")
8. Andy pushes up again and shifts pelvis to the couch – T	No	T x 1 V x 1 P x 1	
9. Andy pushes up to secure stability on the couch – I	No	V x 1 T x 1	
10. Andy accomplished the transfer in 5 minutes or less.	No		
% Mobility skills accomplished:	5/10 or 50% accomplished	I = 2 V = 9 T = 4 P = 1	Total # self-initiated support requests: 3

Note: I = independent, L = look, V = verbal, T = touch with 1 body part, P = physical help with two or more body parts. Yes = accomplished in five minutes or less, No = accomplished in > five minutes.

Research Design

I implemented a multiple probe with alternating interventions across applied settings and participants design to answer the research questions. Table 3.4 describes the settings, conditions, and anticipated number of therapy sessions for each condition. This multi-element design allowed me to demonstrate intervention-related changes for more than one person who needed to learn a new mobility skill. I expected that the severity of disability and functional mobility skill-levels of the participants to be similar, and that their respective mobility skills were new or challenging to perform. Each person's task contained a similar number of steps and each participant expressed the need to use this skill in a familiar and a new setting.

Utilization of the no-treatment baseline condition provided information about mobility skill performance before intervention started and changes that happened from pre-intervention to intervention (Richards, Taylor, Ramasamy, & Richards, 1999). The CD and SD interventions were alternately and quickly applied over relatively short periods of time and over the same number of sessions, reducing possible carryover treatment effects. A return to the no-treatment condition allowed assessment of mobility skill maintenance in the applied setting. Finally, a no-intervention assessment of mobility skills in a second less familiar applied setting helped determine if the learned skills generalized to a new setting.

Table 3.4

Study Phases, Conditions, Settings, and Anticipated Therapy Sessions

Phase	A	B	A	C
Condition	No treatment; baseline	Counterbalanced interventions (CD and SD)	No treatment; maintenance (time)	No treatment; Generalization (setting)
Setting	Home	Home	Home	New, less-familiar applied community setting
Therapy Sessions	At least five sessions or until performance stabilizes or worsen	At least 20 sessions, or until criterion for mobility skill achievement is met	At least five sessions or until performance stabilizes	At least five sessions or until performance stabilizes

Note. A = no treatment baseline, B = Counterbalanced interventions (CD = clinician directed and SD = student directed), A' = no treatment maintenance, C = no treatment generalization.

Several single-subject design authors advocated using a multiple-probe with alternating conditions design in clinical settings to determine the immediate and generalized effects of two or more interventions on target behavior (Cooper, Heron, & Heward, 2007; Kennedy, 2004; Richards et al., 1999). The multi-element design addressed multiple behaviors, settings, and individuals, a useful design feature for my study. It allowed fewer data collection points across multiple baselines and required fewer resources for data collection (Richards et al., 1999).

Alternating interventions offered a number of significant advantages in this clinical study. It did not require withdrawal of an intervention, thus eliminating ethical concerns often expressed by teachers or clinicians when an effective intervention is removed in order to demonstrate a functional relationship between the intervention and outcomes (Cooper et al., 2007; Richards et al., 1999). Alternating conditions was efficient and capable of producing quick intervention effects given the limited study time, while minimizing sequencing effects of the interventions. Experimental control was achieved when one condition resulted in changed behavior compared to the other intervention condition, regardless of the sequence of intervention application (Cooper et al., 2007; Richards et al., 1999). I minimized multiple conditions interference, a noted disadvantage of this design, by providing interventions that were considerably different from each other (Richards et al., 1999), and by applying distinct operational definitions of the intervention conditions and the dependent variables.

Conducting baseline, intervention regimes, and return to baseline across applied settings provided data regarding maintenance and transference of newly learned mobility skills in the absence of intervention. While stable baseline data was not required prior to introducing or following an intervention in this design, establishing a stable, no-treatment condition enhanced prediction, verification, and replication in this single subject study (Richards et al., 1999). If the participant improved mobility skills after baseline, and maintained those skills in the second baseline assessment after interventions, then maintenance of those skills over time was likely as a result of the intervention. Conduction of the no-treatment baseline measures in the final phase allowed me to know if the skills were transferrable to a less-familiar setting.

Counterbalanced interventions. In an effort to minimize sequencing effects of the interventions, I counterbalanced the scheduling of the CD and SD conditions by using a computer-assisted random number generation process. For example, on intervention day one, participants one and three got the CD intervention condition, followed by the SD intervention during their second treatment session. Participants two and four got the SD condition for their first treatment session, followed by the CD intervention in their second session. I reversed the order of intervention daily thereafter for each participant. Using the alternating treatment design presumed that the participants understood the differences between the two intervention conditions, each of which was clearly different from baseline. The number of intervention sessions (CD and SD) varied by participant, with some achieving their mobility goal in as few as six, or as many as ten sessions. Intervention sessions continued until ceiling criterion for mobility skill achievement was met, or until the participant requested to stop and move on to the next phase.

Dependent Measures

I evaluated global and step-by-step progress by counting tasks accomplished and documenting changes in assistance levels. Accurate assessment of the following dependent measures relied on clearly defined tasks in the participant's mobility skill set. Goal Attainment Scaling (G.A.S.) provided a more global measure of intervention-induced change for the participant at the end of each intervention.

I measured six dependent variables during no-treatment baseline, intervention, and follow-up conditions: (a) percent of mobility skill steps accomplished, (b) Goal Attainment Scale, (c) frequency and level of therapist-provided assistance prompts, (d) frequency of participant-initiated support requests, (e) percent match between participants', caregivers', and therapist's evaluations of mobility steps accomplished, and (f) frequency of adjustment topics suggested by the participant. Table 3.5 matches specific dependent measures and data analysis procedures with each research question. The following paragraphs summarize the research questions and their associated dependent measures and scoring methods.

Table 3.5

Research Questions, Dependent Measures, and Data Analysis

RESEARCH QUESTION	DEPENDENT MEASURE	DATA ANALYSIS
Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions achieve a higher percentage of functional mobility steps compared to when they receive clinician-directed physical therapy interventions?	Percent of mobility steps accomplished	Graph, visual analysis
Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions require fewer and less intrusive prompts to complete their functional mobility task, compared to when they participate in clinician-directed interventions?	Frequency and level of prompts	Frequency, t-test, qualitative data from interviews and discussions
Do individuals with severe and multiple developmental disabilities and their caregivers participating in self-directed physical therapy interventions more often identify supports to accomplish their functional mobility task compared to when they participate in clinician-directed physical therapy interventions?	Frequency of student-initiated support requests	Frequency, t-test, qualitative data from interviews and discussions
Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions demonstrate a higher percentage match with therapist and caregiver self-evaluation responses about their mobility skill progress compared to when they participate in clinician-directed physical therapy interventions?	Percent match between participant self-evaluation responses, therapist and caregiver evaluation responses.	Average % match; correlation, qualitative data from interviews and discussions
Do individuals with severe and multiple developmental disabilities and their caregivers participating in self-directed physical therapy interventions suggest more adjustments to achieve targeted mobility skills compared to when they participate in clinician-directed physical therapy interventions?	Frequency of adjustment topics suggested by the participant.	Frequency, t-test, qualitative data from interviews and discussions
Do individuals with severe and multiple developmental disabilities complete the same, higher, or a lower percentage of functional mobility steps in a familiar applied setting of their choice compared to when they are in a new preferred setting?	Percent of mobility steps accomplished	Graph, visual analysis

Percent of mobility skill steps accomplished. To answer research question one, “Do students with severe and multiple developmental disabilities participating in self-directed physical therapy interventions achieve a higher percentage of functional mobility steps compared to when they receive clinician-directed physical therapy interventions?" I scored each mobility task as achieved (yes) or not achieved (no). I counted each mobility skill as 'achieved' if it was accomplished within the assistance parameters originally set for each step in the participant's mobility skill task analysis as noted in Andy's example (Table 3.2). Then I counted the total number of mobility tasks achieved (yes) and divided by the total number of tasks in the mobility skill to determine the percentage of tasks accomplished. I considered Andy's chosen mobility skill as achieved, to transfer safely from his wheelchair to his couch independently, if he successfully completed the ten listed steps. For example, the therapist's benchmark evaluation data in Table 3.3 shows that Andy accomplished five out of 10 steps in this task chain, or 50% of his transfer mobility skills during this intervention session.

Goal attainment scaling (G.A.S.). Of clinical relevance to physical therapists is whether their clients can achieve identified mobility goals within a reasonable time frame (usually determined by insurance payers). G.A.S. provides a clinically useful way to measure important and person-centered client outcomes within the context of their real lives (Turner-Stokes, 2009; Turner-Stokes and Williams, 2010). Originally developed by Kiresuk and Sherman (1968), G.A.S. is a process familiar to rehabilitation service providers that facilitates increased multidisciplinary collaboration and enables practical comparisons of individuals' relative success in achieving goals that are individually determined and realistic to achieve within a given time (Bovend'Eerdt, Botell, & Wade, 2009; Czar, 1987;

Kiresuk, Smith, and Cardillo, (1994). Responsiveness of the G.A.S. is dependent on the therapist's and client's initial goal selection and goal attainment level determination that represents clinically important changes the client is capable of making (Palisano, Haley, and Brown, 1992; Turner-Stokes, 2009).

The success of G.A.S. lies in its structured four-step approach to specifying the goal: (a) defining the target goal; (b) weighting the goal in terms of importance and difficulty; (c) scaling (quantifying) the goal; and (d) evaluating goal achievement (Bovend'Eerdt et al., 2009). Each participant's precise and measureable goal is represented by the 0 point on the G.A.S.. A somewhat better than expected outcome is identified by +1, and a much better than expected outcome becomes the +2 point. Likewise, somewhat less than expected performance is graded -1, and much less than expected outcome becomes -2. For example, Table 3.6 is Holly's G.A.S. scoring rubric for achieving her wheelchair to bed transfer, evaluated at the end of each intervention.

Table 3.6

Holly's G.A.S. for Wheelchair to Bed to Wheelchair Transfer Scoring Rubric

Has goal been mutually negotiated between participant and therapist?	Yes____ No_____
Goal Attainment Levels	Goal: Transfer from WC to Bed to WC
Most unfavorable outcome thought likely (-2)	Holly requires 1 person lift to the bed from w/c, and back to w/c
Less than expected success achieved (-1)	Holly requires 1 person holding her legs to safely get into bed from w/c., and back to w/c from bed.
Expected level of success (0)	Holly requires only visual observation and verbal cues to safely transfer from w/c to bed, and back to w/c.
More than expected success (+1)	Holly gets into her bed from her w/c, and back to w/c with only visual observation.
Best anticipated success (+2)	Holly gets into her bed from her w/c, and back to w/c from bed independently and safely.

Frequency and level of prompts. In this study, prompt intrusiveness was measured on a continuum from least to most according to task achievement parameters discussed previously and delineated in Table 3.3. Counting the number and level of prompts an individual needs is a measure of independence as well as ability to remain focused on and attentive to the task; that is, fewer and less intrusive prompts reflected greater independence and greater attention to the wheelchair transfer task for Andy in Table 3.3. Nevertheless, I expected some participants to require some level of antecedent and/or pacing prompts in order to successfully and safely complete their mobility skill, especially if the skill was new and difficult. Andy's sample data (Table 3.3) showed that he needed nine verbal prompts or assist, four one-hand touch prompts, and one physical prompt, for a total of 14 prompts.

Frequency of self-initiated support requests. I expected that people with high support needs in multiple daily life activities such as toileting, dressing, eating, or transportation may not achieve activity-related mobility tasks independently (Turnbull, Turnbull, & Wehmeyer, 2007). However, many people with high support needs do achieve daily living and mobility goals by directing their own supports. In the effort to answer the third research question, "Do individuals with severe and multiple developmental disabilities and their caregivers participating in self-directed physical therapy interventions more often identify supports to accomplish their functional mobility task compared to when they participate in clinician-directed physical therapy interventions?" I counted how often participants requested or directed someone to help them achieve part or all of a mobility skill step. Participants requested supports either verbally or behaviorally. Note that these support requests are distinct from the therapist provided prompts or assistance. Sample data in Table 3.3 show that Andy asked for help to keep his feet stable on the footrest and floor, and he wanted pillows removed from his couch - a total of three self-initiated support requests.

Percentage match on evaluation responses. At the end of the baseline, intervention, maintenance, and generalization sessions, the participant, caregiver, and therapist evaluated the participant's performance on each task of the targeted mobility skill. Appendix E contains each participant's, and related caregiver's unique evaluation form. The terminology used in participants' respective self- and caregiver evaluations reflected their current knowledge about the mobility task and skills; that is, participants recognized and understood the skills they were evaluating. If the participant lacked sufficient vision or reading skill to respond independently on the self-evaluation, the caregiver or therapist read the questions to the participant using an interview format. Participants responded verbally while the caregiver documented his or her responses; or sometimes the participant responded using an augmentative or alternative communication system either verbally or in writing; or the participant wrote answers on the evaluation form itself.

Investigating how participants self-assessed their performance, compared to the caregivers' and therapist's evaluation, helped determine the accuracy of the participants' responses, and helped to gauge consistency of caregiver supports given their own understanding of the mobility skill performance. At issue here was whether or not a participant accurately determined if and how well he or she achieved the mobility skill set, and did the participant's self-evaluations match those of his or her caregivers and the therapist’s benchmark. Some participants responded positively to general mobility skill evaluation questions compared to specific tasks performed within the mobility skills. However, in order to achieve the entire mobility skill, each participant had to complete all ten discreet sub-tasks within the assistance parameters previously identified for their respective mobility goal (see Appendix C for each participant). Table 3.9 shows the match between my benchmark evaluation responses and Andy’s self- and caregiver evaluation responses.

Ensuring response reliability and validity. I expected participants to sufficiently understand the self-evaluation questions in order to answer reliably; however, unreliable ‘yes’ or ‘no’ responses occasionally occurred for different reasons. For example, Andy’s ‘yes’ answers might indicate a true evaluation of his performance; but answering ‘yes’ to all items could indicate his desire to finish and move on with activities, or an inability to understand the evaluation item. Pre-study determination of mobility skills, tasks, and support levels in commonly understood language helped reduce unreliable ‘yes’ responses. Routinely prefacing each evaluation question with: “Now Andy, listen carefully before you answer” also helped to ensure participants understood the question and gave reliable responses, as did re-phrasing with easier or different vocabulary. For example, rather than asking Andy “Did you unlock your pelvic belt independently?” I asked “Did you take off your seat belt by yourself?” Finally, asking the discreet task-specific evaluation items first (one through ten of Andy’s sample evaluation in Table 3.7), followed by the general mobility skill questions (one through five in of the evaluation) helped to ensure response reliability for the participants. Self-evaluation protocol and item modifications were uniquely determined for each participant as the need arose.

Table 3.7

Andy's Sample Self-Evaluation of Performance

General Mobility Skill Self-evaluation Questions	YES or NO
1. Did you achieve your whole transfer skill today (get on the couch from your wheelchair)?	Yes
2. Did you achieve some of your transfer skills today (get partway on the couch today from your wheelchair)?	Yes
3. Did the therapist help you with just a touch (just using one hand or foot)?	Yes
4. Did the therapist give you verbal help (just talk to you)?	Yes
5. Did the therapist give you physical help beyond a touch (have to use most of her body to support or help you)?	Yes
Discreet Mobility Skill Task-specific Self-evaluation Questions	YES or NO
1. Did you wheel yourself close to the couch independently (get over to the couch by yourself)?	Yes
2. Did you lock the wheels with no more than a look from the therapist for help (undo your brakes)?	Yes
3. Did you unlock your/his pelvic belt independently (take off your seatbelt by yourself)?	Yes
4. Did you shift your body forward in your wheelchair with no more than verbal assist from therapist (scoot your bottom forward in your chair)?	Yes
5. Did you place your feet on the floor with no more than one body part touch assist (did you get your feet down on the floor)?	Yes
6. Did you push up from the wheelchair with no more than verbal help?	No
7. Did you rotate closer to the couch with no more than one body part touch assist?	Yes
8. Did you push up again and shift your pelvis to the couch with no more than one body part touch assist (did you lift up and twist your bottom over)?	Yes
9. Did you push up to be safe on the couch independently (did you get your bottom all the way onto the couch)?	Yes
10. Did you complete the transfer before the five-minute timer went off?	Yes

Table 3.8

Andy's Sample Caregiver Evaluation of Performance

General Mobility Skill Self-evaluation Questions	YES or NO
1. Did he/she achieve the whole transfer skill today (get on the couch from his/her wheelchair)?	Yes
2. Did he/she achieve some of his/her transfer skills today (get partway on the couch today from his/her wheelchair)?	Yes
3. Did the therapist help him/her with just a touch (just using one hand or foot)?	Yes
4. Did the therapist give him/her verbal help (just talk to him/her)?	Yes
5. Did the therapist give him/her physical help beyond a touch (have to use most of her body to support or help him/her)?	Yes

Discreet Mobility Skill Task-specific Self-evaluation Question	YES or NO
1. Did he/she wheel him/herself close to the couch independently (get over to the couch by him/herself)?	Yes
2. Did he/she lock the wheels with no more than a look from the therapist for help (undo his/her brakes)?	Yes
3. Did he/she unlock his/her pelvic belt independently (take off his/her seatbelt by him/herself)?	Yes
4. Did he/she shift his/her body forward in his/her wheelchair with no more than verbal assist from therapist (scoot his/her bottom forward in his/her chair)?	Yes
5. Did he/she place his/her feet on the floor with no more than 1 body part touch assist (did he/she get his/her feet down on the floor)?	Yes
6. Did he/she push up from the wheelchair with no more than verbal help?	No
7. Did he/she rotate closer to the couch with no more than 1 body part touch assist?	Yes
8. Did he/she push up again and shift his/her pelvis to the couch with no more than one body part touch assist (did he/she lift up and twist his/her bottom over)?	Yes
9. Did he/she push up to be safe on the couch independently (did he/she get his/her bottom all the way onto the couch)?	Yes
10. Did he/she complete the transfer before the five-minute timer went off?	Yes

Evaluation response match. To determine the evaluation response match, I counted the number of matches on each item between participant, caregiver, and therapist, and then tallied a total percent match for all items combined (see Table 3.9). For example, Andy's response on unlocking his pelvic belt agreed with the therapist's 'yes' benchmark, but did not agree with his caregiver's 'no' response. Andy and his caregiver both matched the therapist's benchmark on 12 out of 15 (80%) possible items. In Andy's example, he matched his caregiver on 9 out of 15 items (60%). The average percent match on evaluation responses overall was 73.2%.

Table 3.9

Andy's Sample Evaluation Responses with Percent Match Data for Wheelchair-to-Couch Transfer Skill

Self-evaluation question	Participant (P)	Caregiver (C)	Therapist (T)	P/T Match? Yes/No	P/C Match? Yes/No	C/T Match? Yes/No	Avg. Percent Match
G1. Did participant achieve the whole transfer skill today?	Yes	Yes	Yes	Yes	Yes	Yes	100%
G2. Did he/she achieve some of his/her transfer skills today (get partway on the couch today from his/her wheelchair)?	Yes	Yes	Yes	Yes	Yes	Yes	100%
G3. Did the therapist provide a touch to help?	Yes	Yes	Yes	Yes	Yes	Yes	100%
G4. Did the therapist provide verbal help?	Yes	Yes	Yes	Yes	Yes	Yes	100%
G5. Did the therapist provide physical help beyond a touch?	No	Yes	No	Yes	No	No	33%
D1. Did participant wheel up close to the couch?	Yes	No	No	No	No	Yes	33%
D2. Did participant lock the wheels?	Yes	Yes	Yes	Yes	Yes	Yes	100%
D3. Did the participant unlock the pelvic belt?	Yes	No	Yes	Yes	No	No	33%
D4. Did participant shift his/her body forward in the wheelchair?	Yes	No	No	No	No	Yes	33%
D5. Did participant place his/her feet on the floor?	Yes	No	No	No	No	Yes	33%
D6. Did participant push up from the wheelchair?	No	Yes	No	Yes	No	No	33%
D7. Did participant rotate closer to the couch?	No	No	No	Yes	Yes	Yes	100%
D8. Did participant push up again and shift pelvis to the couch?	Yes	Yes	Yes	Yes	Yes	Yes	100%
D9. Did participant push up to be safe on the couch?	Yes	Yes	Yes	Yes	Yes	Yes	100%
D10. Did participant do the transfer in 5 minutes or less?	No	No	No	Yes	Yes	Yes	100%
Totals	11 yes, 4 no	9 yes, 6 no	8 yes, 7 no	12/80%	9/60%	12/80%	73.2%

Note: G = general skill; D = discreet skill; P = participant; C = caregiver; T = therapist

Type and frequency of adjustment topics. For purposes of this study, adjustment topics were defined as concrete suggestions made by the participant that reflected awareness of his or her self-evaluation performance on the mobility skill tasks, and that the participant can attempt to do or change in the next PT session. So, after completing the self-evaluation at the end of each therapy session, I asked a question: “Based on your performance today, what will you do differently in the next session?” Andy might answer this question by stating three distinct adjustment topics: (a) “I want to remove the pillows from the couch before I start the transfer;” (b) “I could undue my seat belt easier if I had a larger push button;” or (c) “I want to use my non-skid slippers to keep my feet from sliding off the footrests and staying still on the floor.” I recognized that the participant might not think of something initially, or might think of an adjustment later, but feel constrained to only answer once. Therefore, I gave another generic prompt such as, “anything else?” Adjustment topics typically arose from the participant’s self-evaluation and included such things as changes in PT activities, supports needed, or changes in the overall mobility goal. I simply counted the number and noted the type of adjustment topics suggested by the participant and recorded them in a format similar to Table 3.10.

Table 3.10

Sample Record - Frequency and Type of Adjustment Topics

Day 10 - Based on your performance today, what will you do differently during the next session?
1. Remove pillows from couch before starting the wheelchair-to-couch transfer. 2. Get a different seat belt with a larger push button so I can remove it more easily. 3. Put on my non-skid slippers so that my feet stay still on the footrests and the floor when I start to make the transfer. Total number of adjustment topics = 3

General Session Procedures

After gathering descriptive data, identifying the targeted mobility skills, and constructing the task analysis for each participant's mobility skill, I scheduled 90-minute one-to-one PT sessions two or three times weekly. I collected data on each dependent measure at least two times per session.

At the beginning of each 90-minute intervention session, I reviewed the participant's previously identified mobility goals and explained the intervention condition (no-treatment, CD or SD) to be used. A script for each condition ensured that accurate and consistent intervention descriptions were given to the participants. Sample scripts for each condition are provided in the explanations below.

Baseline Procedures

As previously stated, no-intervention baseline measures enhance experimental control by depicting natural performance levels, absent distinct interventions. Baseline sessions were also 90 minutes long and occurred in the participant's familiar environment. Participants had the opportunity to perform their chosen mobility skill over at least two and up to five trials without intervention during baseline. Baseline procedural steps are presented in Table 3.11.

Table 3.11

Baseline procedural steps

Step	Procedural Step
1	Review mobility skill and task analysis (previously decided) with participant and caregiver.
2	Describe measures that I will observe and write down during the therapy sessions.
3	I record dependent measures as in Table 3.3 (minimum of 2 times, up to 5 times).
4	Participant and caregivers complete self- and caregiver evaluations a minimum of 2 but up to 5 times during the session (see Appendix C and sample in Tables 3.7 and 3.8)
5	Participant suggests adjustments, or what he/she would do differently next time.

All subsequent baseline segments were conducted using identical procedural steps. At least five no-intervention baseline therapy trials were conducted in the participant’s identified applied location, before introducing either the CD or the SD intervention. Later, baseline measures were conducted again using the same protocol to assess maintenance of mobility skills in the same applied setting (A), and again in a new applied setting to assess generalization and skill transference (C). A sample baseline script is provided in Appendix D.

During the initial baseline phase, I noted any changes in the skill chain or tasks that removed unforeseen barriers to task accomplishment. For example, John’s feet slipped behind his footrest prior to shifting forward in his chair, causing him to lose his balance and nearly fall. So, an antecedent verbal cue was added at this step of the task analysis: “Andy, check your feet”, or a touch cue on his knees might also provide sufficient assistance to complete the step safely. Providing these simple, antecedent prompts resulted in safer and more successful achievement of Andy’s remaining tasks. The antecedent verbal and touch cues became permanently attached to this part of Andy’s wheelchair transfer skill chain and were considered as the minimum criteria for task achievement. Following Andy’s completion of the mobility skill tasks, the self- and caregiver evaluation process and suggestions for program adjustments commenced.

Except for a five-minute break between trials, baseline observations continued in the same way for the mobility skill until data was relatively stable, or until at least three stable baseline trials were completed. Some baseline sessions continued over the course of a few days, depending on the participant’s severity of impairment and physical condition on a given day. After completing initial baseline measures, I applied the CD or SD conditions over about 12 to 20 consecutive intervention trials, using the counterbalanced intervention schedule discussed previously.

Clinician-directed (CD) PT Intervention Procedures

I conducted the CD therapy intervention sessions using the same 90-minute segment scheduling protocol described during baseline procedures (see Table 3.11). I evaluated the participant's mobility skill performance a minimum of two times during the session (at the beginning and again after intervention).

Table 3.12

Clinician-directed intervention procedures

Step	Procedural Step
1	Therapist introduces the session as "Lorrie's PT session", where the therapist is in charge. She chooses and reviews mobility skill and task analysis (from one previously decided) with participant and caregiver.
2	Therapist evaluates participant's initial mobility skill performance.
3	Therapist takes the participant through all exercises and then asks participant to perform the mobility skill.
4	Therapist records mobility skill steps accomplished and other dependent measures as in Table 3.3.
5	Therapist, participant, and caregiver complete post-intervention evaluations (Appendix C and sample in Tables 3.7 and 3.8)
6	Participant suggests adjustments, or what he/she would do differently next time.

According to the CD intervention protocol, the therapist identified goals, provided equipment and materials, and sequenced the activities during the therapy session without the participant or caregiver's knowledge or input. The CD intervention was provided on an alternating basis with the SD intervention over a minimum of 20 sessions, until ceiling criteria was achieved, or until the participant refused to go further (See Appendix D for sample script).

Self-directed (SD) PT Intervention Procedures

The primary distinctions between the SD condition and the CD intervention was the participant's ability to choose or set their mobility goal, make a plan by determining related activities, and then adjust the plan according to their performance. Relevant questions and therapist objectives modeled the distinct phases of the *SDLMI* process to guide the PT session discussions as indicated in Table 3.13.

Table 3.13

SDLMI Phases, Questions, and Therapist Objectives

Phase 1: Set a Goal Problem for Student to Solve: What is my goal?			
Student / Family Question 1: What mobility skill do I want (John) to learn or to do?			
Therapist Objectives:	1. Enable participant/families to identify mobility strengths and needs.	2. Enable students to communicate preferences, interests, beliefs, values (relative to use of their mobility skills).	3. Teach participant to prioritize needs (physical, support)
Student / Family Question 2: How do I do the mobility goal now; what parts of the mobility skill do I need to work on?			
Therapist Objectives:	1. Enable participant to identify current status relative to mobility/therapy need	2. Assist participant/families to gather information about opportunities and barriers in their postsecondary environments relative to mobility skill needs.	
Student / Family Question 3: What must change for me to learn the mobility skills or tasks that I don't know now?			
Therapist Objectives:	1. Enable students/families to decide if PT interventions will be focused on physical capacity building, modifying the environment, or both	2. Support students/families to choose a need to address from prioritized list.	
Student / Family Question 4: What can I do to make my mobility goal happen?			
Therapist Objectives:	1.Teach students/families to state a goal and identify criteria for achieving the goal during PT intervention.		

Phase 2: Take Action Problem for Student (Family) to Solve: What is my plan?				
Student/family question 5: What can I do to learn what I don't know now about how my disability affects my movement?				
Therapist Objectives:	1. Enable student/family to self-evaluate current status and self-identified goals.			
Student/family Question 6: What could keep me from taking action?				
Therapist Objectives:	1. Enable student/family to determine plan of action to bridge gap between self-evaluated current status in PT, and self-identified mobility goal status			
Student/family Question 7: What can I do to remove barriers?				
Therapist Objectives:	1. Collaborate with student/family to identify most appropriate PT interventions.	2. Teach student/family needed student-directed learning strategies.	3. Support student/family to implement student-directed learning strategies	4. Provide mutually agreed upon therapist-directed interventions
Student/family Question 8: When will I take action?				
Therapist Objectives:	1. Enable student/family to determine schedule for PT action plan	2. Enable student/family to implement PT action plan	3. Enable student/family to self-monitor mobility skill progress	
Phase 3: Adjust Goal or Plan Problem for Student (Family) to Solve: What have I learned?				
Student/family Question 9: What actions have I taken?				
Therapist Objectives	1. Enable student/family to self-evaluate progress toward mobility goal achievement.			
Student/family Question 10: What barriers have been removed?				
Therapist Objective:	1. Collaborate with student/family to compare mobility skill progress with desired outcomes relevant to PT and postsecondary transition.			
Student/family Question 11: What has changed about what I don't know or can't do?				
Therapist Objectives:	1. Support student/family to reevaluate goal if progress is insufficient.	2. Assist student/family to decide if goal remains the same or changes.	3. Collaborate with participant to identify if PT action plan is adequate or inadequate given revised or retained goal.	4. Assist student/family to change PT action plan if necessary.
Student/family Question 12: Do I know what I want to know or do?				
Therapist Objectives:	1. Enable student to decide if progress is adequate, inadequate, or if mobility goal has been achieved.			

Note. From "Promoting Causal Agency. The Self-Determined Learning Model of Instruction," by M. L. Wehmeyer, S. B. Palmer, M. Agran, D. Mithaug, and J. E. Martin, 2000, *Exceptional Children, 66*, pp. 442-444. Copyright 2000 by the Council for Exceptional Children. Adapted with permission.

The procedural steps for the SD intervention condition are shown in Table 3.14. At the beginning of the SD intervention, I reviewed the mobility goal and associated skill steps that the participants chose, and discussed the relationship of this mobility goal to a postsecondary goal identified by the participants or caregivers using the *SDLMI* phase one guiding questions and therapist objectives (Table 3.13). I evaluated the participants' mobility skill performance before the SD intervention. Next, the participants made a plan by choosing the exercises or activities and their sequence during the session guided by the *SDLMI* phase two questions and objectives in Table 3.13. The participants sometimes asked questions, chose to stop participating, requested to change to a different activity, or modified the entire mobility skill, as allowed by the *SDLMI.*

Table 3.14

Participant-Self-Directed Intervention Procedures

Step	Procedural Step
1	Therapist introduced the session as "participant's PT session" and reviewed the participant's chosen mobility skill and tasks with participant and caregiver.
2	Participant chose related activities and exercises to work on during the session and therapist used guiding questions from the SDLMI phase one in Table 3.13.
3	Therapist and participant worked on participant-chosen activities, and then the participant performed the mobility skill and tasks. I used guiding questions from the SDLMI phase two (Table 3.13).
4	Therapist recorded dependent measures at the beginning and at the end of the intervention, and as often as participant performed the mobility skill, as in Table 3.3 and Appendix C.
5	Therapist used guiding questions from SDLMI phase three prior to participants completing self-evaluations. Participant and caregivers completed self- and caregiver evaluations after each performance of the mobility skill (Tables 3.7 and 3.8).
6	Participant suggested adjustments, or what he/she would do differently next time.

After completing the self-, caregiver-, and therapist evaluations of mobility skill steps accomplished, the therapist asked the participants to suggest program adjustments that could make achievement of the mobility skill tasks easier or more successful during the next therapy session. See a sample SD intervention script in Appendix D.

Counterbalanced interventions. Again, each dependent variable was measured and recorded as previously discussed for baseline and CD conditions and as demonstrated in Table 3.3. Only one SD intervention condition per day was presented. If the SD intervention was the first randomly assigned condition, then the next day’s intervention was the CD condition. This counterbalanced presentation of interventions continued over at least 12 but not more than 20 sessions, or until performance criteria were met, heralding a shift to maintenance phase, or participant requested to stop.

Maintenance Procedures

Maintenance probes on all dependent measures occurred in the same applied settings in which the initial baseline and intervention conditions were conducted. These no-treatment probes were conducted using the identical initial baseline protocol to determine how well the participants learned and maintained their skills over time during interventions and in the applied setting, without therapist intervention. The reader is referred to the baseline procedures and script previously discussed.

Generalization Procedures

After evaluating maintenance, a generalization phase commenced in an unfamiliar applied setting chosen by the participant. The participants had never performed the mobility skill in this unfamiliar setting, but indicated a desire and value for doing so in the future. I conducted this phase in same way as initial baseline, but in the new setting. I utilized the baseline procedures and scripts previously described in Appendix D in this phase.

Inter-observer Agreement

All sessions were videotaped for subsequent inter-observer analysis. Observers included a physical therapist, a student, and an adult with disabilities. Inter-observer agreement (IOA) provided confidence that the target motor skills and resultant task analyses were clearly defined and remained unambiguous throughout the course of the study. IOA also ensured consistent measurement and data collection procedures so that changes in behaviors could not be attributed to measurement errors (Cooper et al., 2007).

After initial training with videos, observers needed to achieve a minimum of 80% agreement on all dependent measures' scoring tools over three trials before observations within the actual experimental settings began. Once interventions began, each session was video recorded and periodic checks on sessions achieving less than 80% agreement were reviewed to discuss discrepancies. At least 20% of each participant's total number of baseline, intervention, and generalization sessions were observed and agreement calculated using total agreements/total agreements plus disagreements X 100. Table 3.15 shows the inter-rater reliability results across participants and conditions. Across all sessions, inter-observer reliability achieved 84%. Specific session agreement achieved 81% for baseline, 82% for CD sessions, 88% for SD sessions, and 85% for generalization sessions. Given the possibility of mere chance agreement between the participant, caregiver, and therapist, I attempted to calculate the more conservative Kappa statistic for inter-rater reliability; however, the sample size was insufficient for computing a valid reliability statistic.

Table 3.15

Inter-Observer Agreement

Date	Rx Session/Participant	% Agreement
9-29-09	CD / 07	70
8-7-09	CD / 01	70
9-18-09	CD / 07	80
12-30-09	CD / 02	90
9-8-09	CD / 03	90
11-10-09	CD / 02	90
9-25-09	SD / 07	100
9-4-09	SD / 03	100
8-10-09	SD / 03	80
8-13-09	SD / 01	100
8-4-09	SD / 01	100
10-2-09	SD / 07	90
11-6-09	SD / 02	80
11-16-09	SD / 02	50
10-10-09	BL / 03	100
8-23-09	BL / 02	90
8-31-09	BL / 02	80
9-8-09	BL / 07	90
9-8-09	BL / 07	80
7-17-09	BL / 01	70
7-17-09	BL / 01	60
9-28-09	GN / 01	60
9-9-09	GN / 01	70
10-10-09	GN / 03	80
11-3-09	GN / 03	90
11-3-09	GN / 07	80
10-13-09	GN / 03	100
3-23-10	GN / 02	100
3-24-10	GN / 02	100

Note: CD is clinician-determined session; SD is student-determined session; BL is baseline; GN is generalization

Discrepancies between observers generally surrounded grading "yes" to a skill without regard to level of assistance; most skills were written assuming independent achievement. Observer might have written "yes", but then noted that therapist gave a lot of physical assistance. The researcher then reviewed the criteria as they pertained to each participant, reminding the observer to read each skill step carefully.

Fidelity of Intervention

An intervention training video and observation data sheet similar to the sample in Table 3.16 was developed for the CD and SD conditions (Appendix E). At a minimum, an observer had to see and hear the statements from the *SDLMI* phases and the therapist's related questions as described in Table 3.13 and as associated with the SD intervention condition as described in Table 3.14. Using the training video described above as a pilot, an independent trained observer achieved at least 90% agreement over three trials, calculated using the same two methods described above for inter-observer agreement. If the independent observer did not achieve 90% agreement with the researcher, training continued until the observer reached the 90% criterion.

Fidelity agreement checks were conducted monthly throughout the study duration to ensure agreement at or near 80%. Table 3.17 shows instructional fidelity scores. Across all sessions, 89% of the intervention steps were accomplished with an overall inter-observer agreement of 99% on the steps accomplished or missed. For CD sessions, 84% of steps were accomplished with 98% inter-observer agreement on intervention steps missed or accomplished. For SD sessions, 83% of intervention steps were accomplished with 100% inter-observer agreement on steps accomplished or missed. In most cases, disagreements surrounded a misreading of the intervention marker, or not realizing the marker was actually accomplished, but out of sequence. Sometimes, fidelity items were not scored because the visual or auditory display was poor, or unavailable due to equipment failure. Nevertheless, a number of commonly missed steps were noted in both the CD and the SD conditions (Table 3.18), which likely resulted from carry-over, or auto-correlation between intervention conditions.

Table 3.16.

Condition-related – Fidelity of Intervention Data Sheet

Clinician Directed Intervention	yes	no	Student Directed Intervention	yes	no
Therapist states that this is the "student's name PT session".			Therapist states: "This is Lorrie's session". Therapist asks student which goal he wants to work on.		
Therapist reviews mobility skill goal			Therapist and student review mobility skill goal. (SDLMI phase 1 guiding question: What mobility skill do I want to learn?		
			Therapist asks student/caregiver what it will take for student to do the mobility skill, and what he thinks he can he do now. (SDLMI Phase One (Set a Goal): How do I do the mobility skill now, and what parts of the mobility skill do you need to work on? What can I do to make my mobility goal happen?		
No talking about goals or activities			Therapist asks student how the mobility skill relates to one of his postsecondary goals. Phase Two: Take Action) What's my plan? What can I do to learn what I don't know now about how my disability affects progress on my mobility goal?		
Therapist chooses the activities and sequence from an established menu and tells the student			Student chooses activities and sequence from an established menu and follows SDLMI Phase Two procedure: Make Plan) What's my plan to achieve my mobility goal? What can I do to make my mobility goal happen?		
Therapist begins exercises telling student what to do and how to move, or not talking at all for about 30 minutes.			Student and therapist work together on mobility skill performance, discussing the relevance of each task, for about 30 minutes.		
If student wants to stop, or change an activity, therapist continues on regardless.			If student wants to stop or change activity, session stops. We re-assess and then move on with appropriate changes. (SDLMI Phase Three: Adjust Goal or plan) if things need to change during the session. What do I need to do differently, remove barriers, etc.? What keeps me from successfully achieving my goal? When will I take action on my goal?		
Therapists answers questions with impairment-based answers.			Therapists answers questions regarding impairments, but also relate to postsecondary goals. SDLMI Phase Three: Adjust Goal or Plan. What will I do next? What did I learn today? When will I try again?		
Stop after 30 minutes of intervention and give general feedback, i.e., "Good job"; "We're through except for the survey.			Therapist and student stop after 30 minutes; discuss goal and progress according to SDLMI phases and questions.		
Therapist provides directions for student/caregivers evaluations and assists with reading or scribing the			Therapist provides directions for student/caregiver evaluations, and assists with reading or scribing the evaluation for the student (about 10 minutes). SDLMI Phase 3: What have I learned? Do I know		

evaluation for the student (about 10 minutes).	what I want to know or do next?
Therapist asks student and caregiver what they would do differently next time.	Therapist asks student and caregiver what they would do differently next time. Phase 3: Adjust Goal or Plan: What have I learned? What actions have I taken? What barriers were removed? What has changed about what I don't know or can't do?

Note: Actual questions and directives differed somewhat with actual participants.

Table 3.17

Fidelity of Intervention Scores

Rx Date	Observers	Session / Participant	% Observed Steps Accomplished – outside observer	% Agreement
8-11-09	SK + LS	CD (01)	80	80
8-11-09	SK + LS	SD (01)	93	100
8-13-09	MU + LS	SD (01)	50	100
8-14-09	MU + LS	CD (03)	100	100
8-24-09	MU + LS	SD (03)	79	100
8-31-09	MR + LS	CD (01)	100	100
9-2-09	MR + LS	CD (03)	90	100
9-4-09	MR + LS	SD (03)	79	100
9-18-09	MR + LS	CD (07)	100	100
10-2-09	MR + LS	SD (07)	100	100
10-8-09	MR + LS	CD (07)	100	100
10-13-09	MR + LS	SD (07)	86	100
10-14-09	MR + LS	CD (02)	90	100
11-16-09	MR + LS	SD (02)	93	100
12-23-09	MR + LS	SD (02)	86	100
12-30-09	MR + LS	CD (02)	100	100

Note: SK and MR are separate observers; LS is researcher; CD is clinician-directed; SD is student-directed.

Table 3.18

Commonly Missed Procedural Steps

Session / Step	Reason for step omission
SD / 4 – Description of dependent measures and recording process	Not done in later sessions, as participant usually understood the steps without direction as demonstrated by performance. Participant became familiar with the process and didn't need descriptions.
SD / 5 – Use guiding questions like "What mobility goal will you work on today"?	Researcher didn't always ask about the mobility goal. Participants 'learned' and knew their goal; they proceeded to work on their goal without researcher input. There was no need to repeat the goal.
SD / 6 – Participant performs chosen mobility goal before intervention commences (with little or no therapist direction unless safety is an issue.	Some direction was given, but unclear as to why in video.
SD / 7 – Adjustment steps questions – "How did that go for you? What parts do you need to work on (or what do you need to learn or do) in order to achieve your goal"?	It was not always clear on video if all of these questions were asked. Sometimes the therapist didn't ask, but participant stated answer anyway. No need to ask.
SD / 9 – [Phase 2, Take Action Question 5] Therapist converses with participant about the relevance of the exercise to the participant's chosen mobility and post-secondary goal, like "improving cycling increases fitness and stamina so I can hold a job".	This step was usually accomplished, but not in its order as in the SDLMI. Sometimes it was addressed at the end of the intervention.
SD / 13 – With therapist direction or support, participant & caregiver complete self- and caregiver post-intervention evaluation while therapist completes her evaluation.	Sometimes not accomplished (i.e., no direction given or needed after the first few sessions) because participants understood how to complete the post-intervention evaluations after having done them a few times already.
CD / 3 – Describe measures that I will observe and write down during therapy segments	Not done in later sessions, as participant usually understood the steps without direction as demonstrated by performance. Participant became familiar with the process and didn't need descriptions.
CD / 4 – Participant initially performs mobility goal without input from therapist	Difficult for observer to know when assistance was given for "safety" reasons only. Verbal discussion usually present. After a while, participants just proceeded to work on the goal without direction; they did not need the goal repeated.

CD / 6 – If participant objects to an activity or wants to stop, therapist continues on, cajoles participant to continue, and does not deviate from her plan.	Not observed, as this step became a non-issue. There were rarely objections.
CD / 10 – With therapist prompt, participant & caregiver suggest adjustments, or what he/she would do differently next time.	Prompt for what to do next time was not seen usually because the tape ended. Sometimes it was not asked.

Note: SD is student-directed; CD is clinician directed.

Carry-over or auto-correlation effects. Regardless of the randomized and counterbalanced assignment of conditions with participants I used in the attempt to distribute interactive effects across conditions, the missed steps noted in Table 3.18 show that I did not control for all interaction effects. In fact, visual analysis of data suggests that participants learned from previous sessions, regardless of the order in which the interventions were presented (Figure 4.0).

Social Validity

Youth with SMDD participating in physical therapy interventions want to improve their mobility, know how to manage needed supports, and achieve postsecondary goals that they identify. The mobility goals and associated tasks in this study are important to the participants and caregivers, and will be uniquely determined for each participant based on actual goals they want to accomplish in relevant settings. The dependent variables are socially important to the participants, that is, participants and their families want to know how they performed, and want to perform their newly-learned skills in new places. Implementing the student-self-determined PT intervention over extended time and across environments enhances social validity.

Three independent clinical and educational professionals reviewed the participant and caregiver interview questions in Appendix B1 as a measure of social validity to verify that these questions did help determine relevant motor skills and goals for the participants. All participants indicated the importance of their Individual Education Program (IEP), but agreed that there was inconsistent or irrelevant planning surrounding post-secondary adult life, and the relevance of physical therapy interventions.

Two independent expert physical therapists who were familiar with the motor skills and one special educator experienced in developing task analyses for people with developmental disabilities helped to establish face validity of the resultant motor skill task analyses and found these to be reasonable before the study began. Likewise, professionals who either created, published peer-reviewed articles, or taught classes surrounding the *Self-determined Learning Model of Instruction* and its associated self-determined tenets (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000) validated the CD and SD intervention conditions.

Data Analysis

Data were analyzed using a combination of visual graphic displays, statistical analyses, and qualitative data analysis. See Table 3.7 for dependent measures and their respective data analysis procedures.

Visual display. Functional relationships between the dependent measures and the interventions will be analyzed using visual graphic displays of the data points for each participant, under each condition. Graphic displays reveal immediate or delayed level changes, variability, and trends in the dependent measures across the changing intervention conditions and phases for each participant (Richards et al., 1999).

Statistical. Descriptive statistics (mean, median, mode) in addition to use of *t*-test augment visual data inspection across phases, especially when visual analysis did not provide a clear indication of the intervention's effectiveness. Analyzing mean differences in performance (trend and level changes) using a *t*-test allows inspection of between-phase shifts in performance, irrespective of visual trend analysis (Richards et al. 1999). Richards et al. suggest that checking for serial dependency, or autocorrelation between data points separated by time, is useful to rule out a Type I error, or an incorrect assumption that the SD intervention caused the significant effect. Finally, post-hoc effect size comparisons between pre- and post-study performance on three of the initial assessments (FIM©, G.A.S., and AIR) for significant effect size differences may further clarify relationships between motor skill assessment data, actual mobility skills performed, and changes in self-determination scores.

Qualitative. Qualitative analyses can bring practical significance to the quantitative and visual data findings for the participants within their real-world lives. I gathered qualitative data at the beginning of the study via the initial therapist and participant interview, throughout the study, and at the end of the study via a de-briefing interview. Qualitative data analysis complemented this single subject design by describing the problem under study, the perceptions of the participants at various phases of the study, and by enhancing social validity (Richards et al., 1999; Mertens, 2005).

CHAPTER FOUR

Results

According to the American Physical Therapy Association's (APTA) mission statement, physical therapists strive to prevent, diagnose, and treat people who have movement dysfunctions. We endeavor to enhance the physical health and functional abilities of our clientele, while doing no harm (APTA Mission Statement, 2010; Hiltz, 1995), and we hope that our interventions carry over into meaningful, real-life activities. To that end, all participants in the study made gains toward their mobility goals through physical therapy interventions; but did specific intervention approaches make a difference in mobility skill attainment?

I wanted to see how well young adults with severe and multiple disabilities gained a preferred functional mobility goal using PT interventions based on an established self-determination model, compared to more traditional clinician-directed interventions. I wanted to know if participants required fewer prompts to achieve their mobility skill steps during the self-determined interventions, and if their gains were maintained and demonstrated in new applied settings. Did participants demonstrate facets of the *Self-determination Learning Model of Instruction* (SDLMI) during interventions, and did their overall levels of self-determination pre-post interventions change? By involving young adults with severe and multiple disabilities in their own goal determination, relevant intervention activities, and progress evaluation, it is realistic to expect that PT interventions framed within the SDLMI can help them to attain, maintain, and generalize preferred mobility goals. Responses to each of my six research questions addressing these concerns follow.

Research Question One

Do individuals with severe and multiple developmental disabilities participating in self-directed physical therapy interventions achieve a higher percentage of functional mobility steps compared to when they receive clinician-directed physical therapy interventions? This question served to determine whether the self-determined PT interventions proved more, less, or equally effective as the clinician-directed interventions in helping participants to gain a greater number of discreet mobility skill steps, as well as their global mobility goal. I counted the number of discreet mobility skill steps achieved at the end of each intervention session and rated overall goal attainment using a Goal Attainment Scaling (Kiresuk, Smith, & Cardillo, 1994) for each participant.

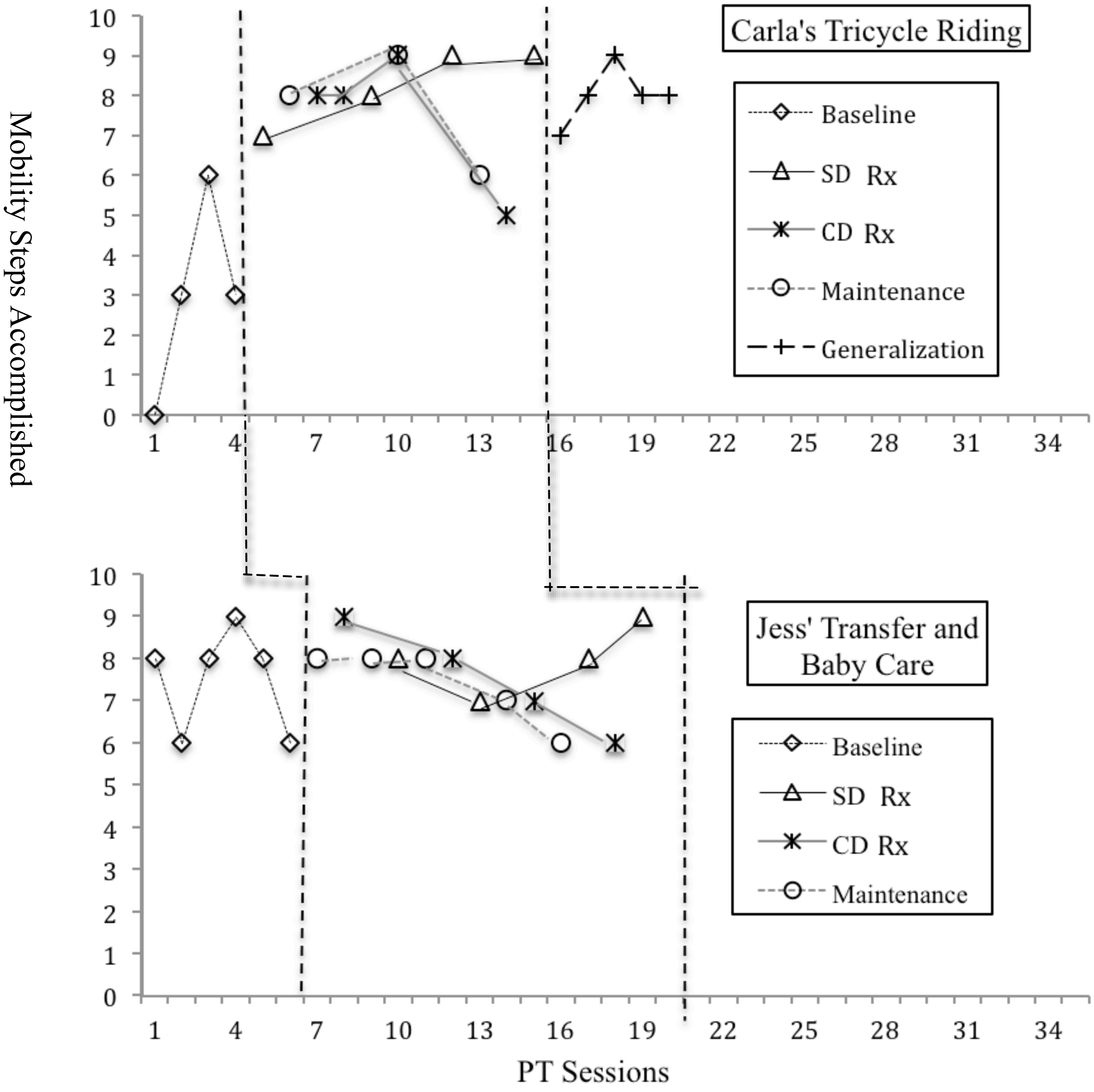
Mobility Steps Accomplished

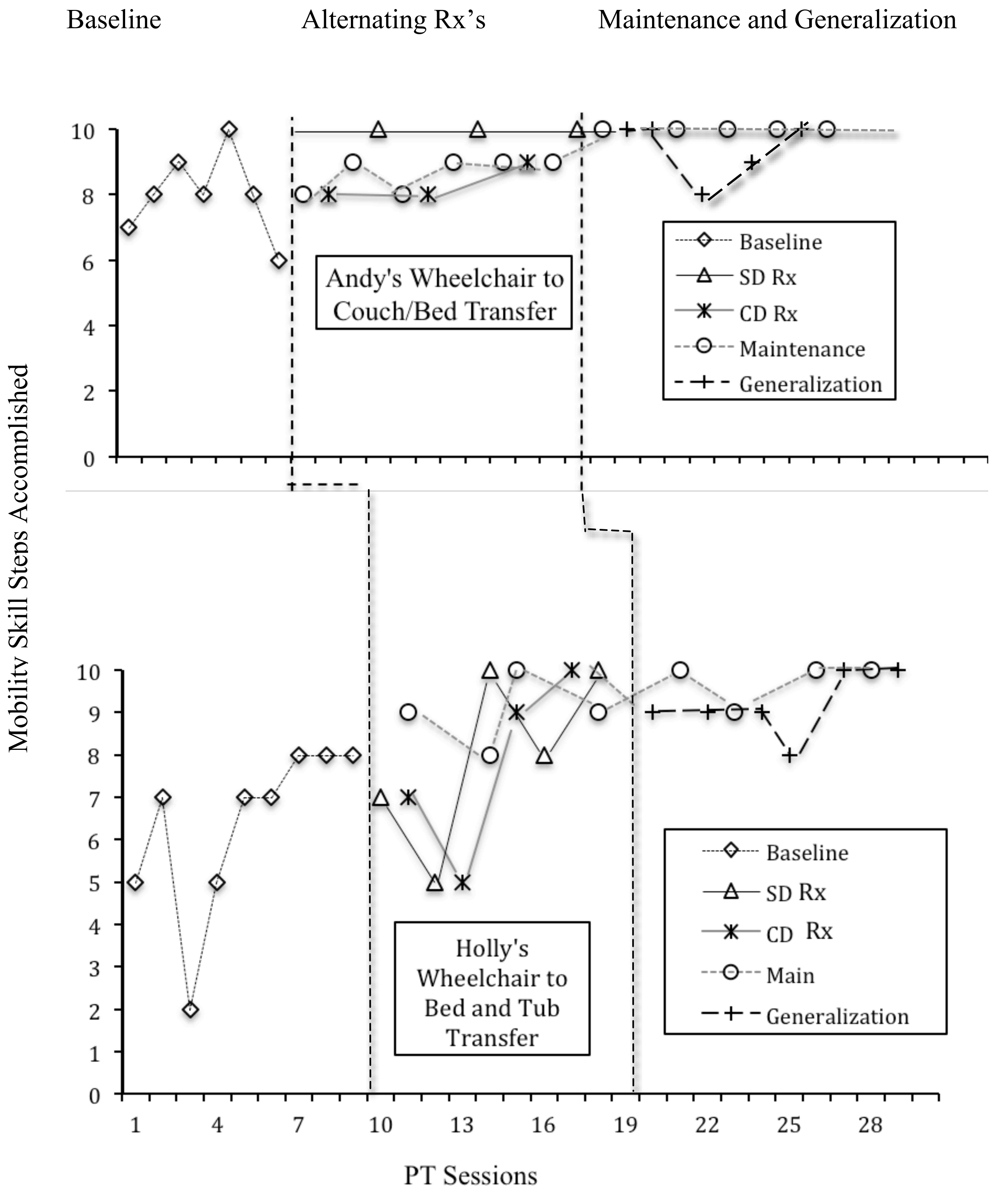
According to Kennedy (2005), visual inspection of a graph provides a comparative estimate of the level, trend (slope and magnitude), and variability of a behavior. Session-by-session data for the mobility skills accomplished for each participant, both within and between intervention phases, are shown in Figure 4.0. Mean level of mobility steps accomplished provides an estimate of central tendency for each phase of the participants' interventions. Data trends were estimated by visually inspecting the slope and magnitude of trend lines for the SD and the CD interventions according to least-squares regression. Least-squares regression "fits a straight line to the slope of data set by minimizing the sum of squared deviations of the observed data from the line" (Kennedy, 2005, p. 198). Upward trends noted during the SD interventions across all participants (except Andy's flat SD trend depicting consistent achievement of all ten mobility steps) reveals its slight advantage over the CD intervention for gain in mobility skills steps.

Based on the visual analysis of Figure 4.0, all participants except Jess and Toby initially achieved their entire mobility goal (as measured by achieving all ten discreet skill steps), and demonstrated goal maintenance and generalization in a new applied setting. Toby and his caregiver requested to stop interventions and try his mobility skills in a new applied setting (generalization phase) as a result of moving to a new house. Jess stopped participating and preferred not to continue into the maintenance and generalization phases due to her work schedule changes. An analysis of each participant's mobility skill progress follows.

Figure 4.0. Graphed Results Depicting Number of Mobility Steps Accomplished by Participant and Session

Baseline Alternating Rx’s Maintenance and Generalization




Baseline
Alternating Rx's
Maintenance and Generalization
Mobility Skill Steps Accomplished
Andy's Wheelchair to Couch/Bed Transfer
Baseline
SD Rx
CD Rx
Maintenance
Generalization
0
2
4
6
8
10
Holly's Wheelchair to Bed and Tub Transfer
Baseline
SD Rx
CD Rx
Main
Generalization
0
1
2
3
4
5
6
7
8
9
10
1
4
7
10
13
16
19
22
25
28
PT Sessions

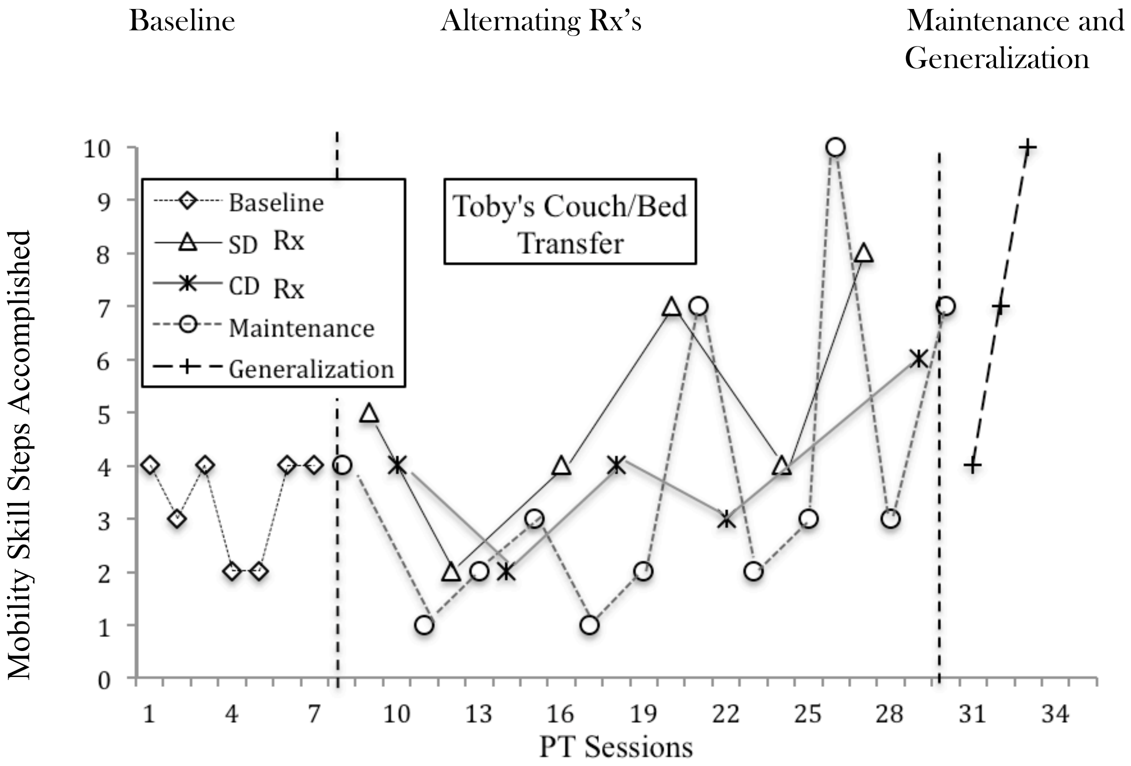
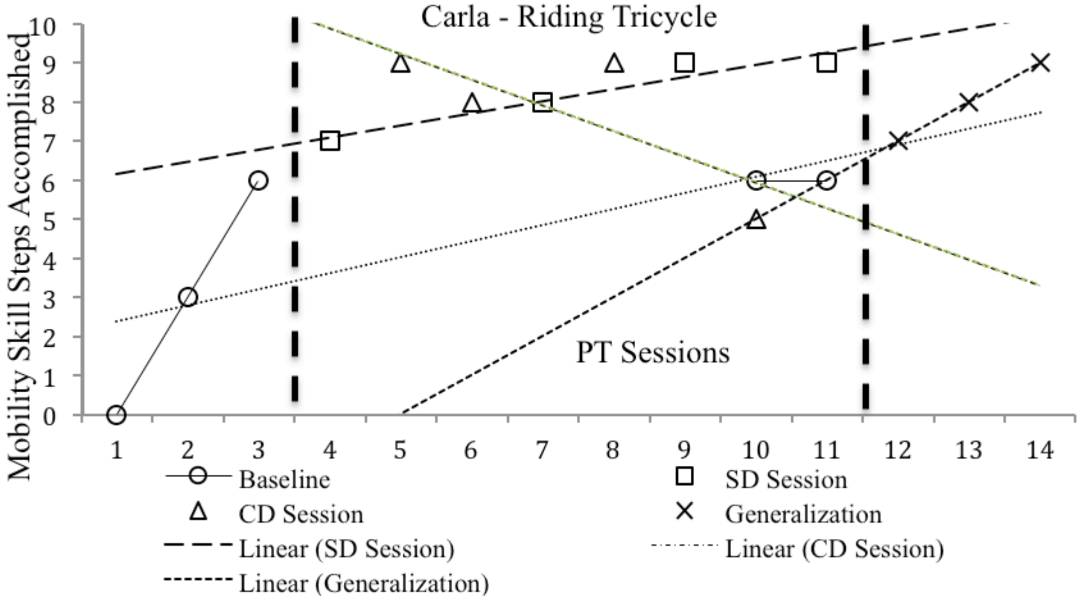


Figure 4.0. Graphs representing the number of mobility steps accomplished for Carla, Jess, Andy, Holly, and Toby each treatment phase.

Figures 4.1 through 4.6 provide visual displays of data points and least-squares trend lines for each participant. I describe each participant's progress via graphical analysis and mean mobility skill steps accomplished by treatment condition (see Table 4.0 and Figure 4.7).

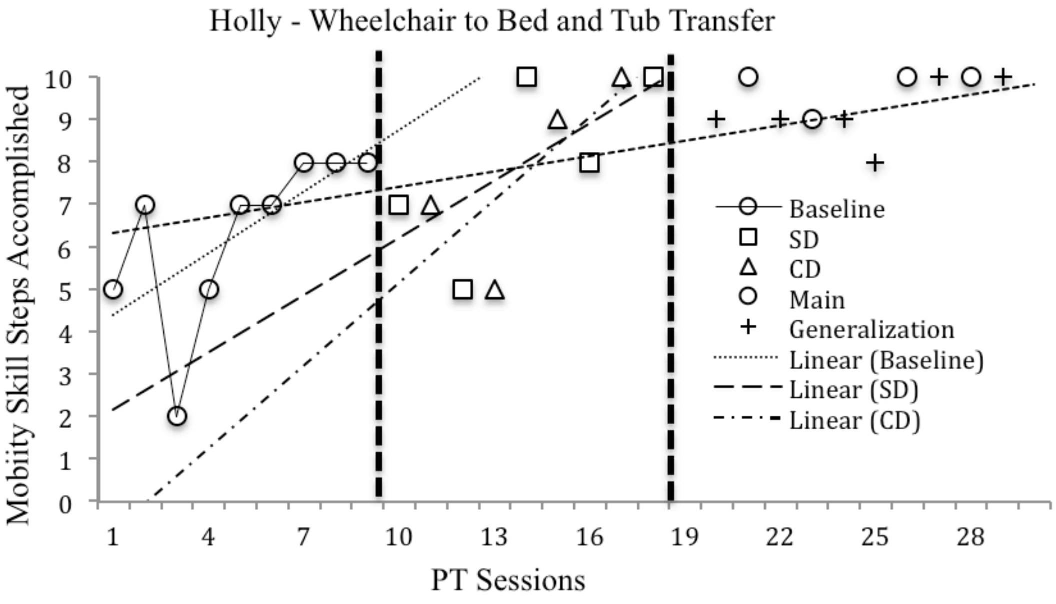
Carla. Carla chose to learn to ride her adult tricycle safely, without her mom's help, out in front of her home, and later in town. Figure 4.0 portrays Carla's mobility skill achievement during baseline, throughout interventions, and into the generalization phases. Moving Carla out of baseline was clearly premature given the upward trend noted during baseline. However, Carla's behavior (boredom and reluctance to keep doing the same skill repeatedly) dictated a decision to cease baseline probes and move on with the interventions. Carla showed less variability in mobility skill performance during the SD interventions and a slight upward trend in comparison to the downward trend and increased performance variability noted during the CD sessions (see Figure 4.1). With the exception of one CD data point, Carla's performance began and stayed higher than baseline during both the CD and SD interventions, and her mean mobility skill step gains were the same for both conditions (baseline mean = 3; SD mean = 8; CD mean = 8; generalization mean = 8). Nevertheless, her steady improvement notwithstanding the intervention suggests the presence of serial dependency and learning from the beginning.

Figure 4.1. Carla's Trends, Magnitude, and Variability in Mobility Skill Steps Accomplished



Holly. Holly's mobility goal was to transfer from her power wheelchair to her bed and back to her chair independently. She later chose to generalize this transfer skill to the bathroom by transferring from her wheelchair to the bathtub, and back to her wheelchair during generalization. Holly's initial and continuing baseline data in Figure 4.0 show that she steadily learned her wheelchair to bed transfer mobility skill steps, retained these skill steps at the same or higher level during the SD or CD interventions, and maintained them into generalization. Least-squares trend lines in Figure 4.2 reveal little difference in the overall level of mobility steps accomplished between conditions and means gains for the SD and CD interventions were identical (baseline mean = 7; SD mean = 8; CD mean = 8; maintenance mean = 9.8; generalization mean = 9). The generalization phase clearly showed the greatest magnitude of change in mobility skills accomplished, though the slight to moderate upward trends in all conditions indicated that Holly gained mobility skill steps regardless of the intervention provided. Holly's consistent motor gains suggest moderate autocorrelation (.445 as noted in Table 4.1), or carry-over effect between sessions. Practically speaking, some carry over effect is expected; however, these effects were minimized given the differentiation noted between baseline and both conditions, the high upward trend noted during generalization, and strict attention to fidelity of intervention throughout the study.

Figure 4.2. Holly's Trends, Magnitude, and Variability in Mobility Skill Steps Accomplished

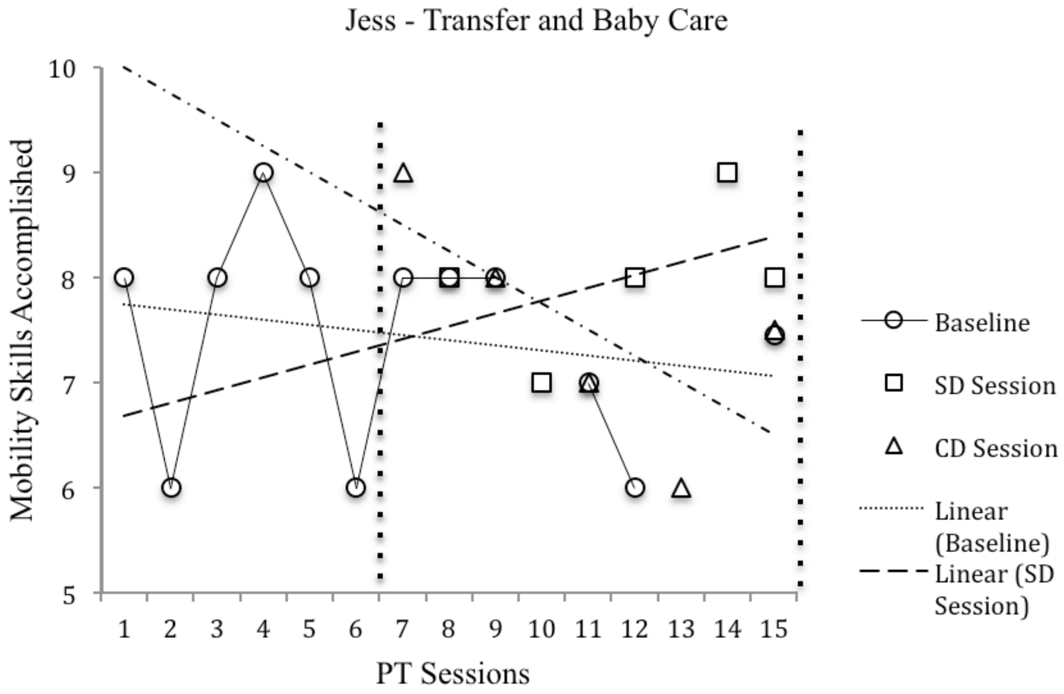


Jess. Jess chose a multi-faceted mobility goal: independent baby care at night. This goal required Jess to be able to transfer from her bed to her wheelchair when she heard a baby cry, go to the baby's crib, pick up the baby, feed the baby a bottle, diaper the baby, return the baby to crib, and then transfer back into bed from her wheelchair. Each of these steps could have been a separate goal alone.

As noted in Figures 4.0 and 4.3, Jess gained mobility skill steps in her baby care goal after a moderately variable baseline performance. The SD condition resulted in a higher magnitude of change with a moderate upward trend in Jess' performance compared to baseline and the CD intervention phases. While Jess' performance during the SD conditions showed more variability compared to the downward trend of the CD conditions, the SD interventions proved slightly more advantageous for Jess, though her mean scores were overall similar (baseline mean =

7.5; SD mean = 8; CD mean = 7.5). In fact, Jess' performance was more variable than the other participants, likely because hers was a more complicated and multi-dimensional skill. Given the upward trend during the SD sessions, it is unfortunate that Jess' work schedule did not allow her to continue participation into the maintenance and generalization phases.

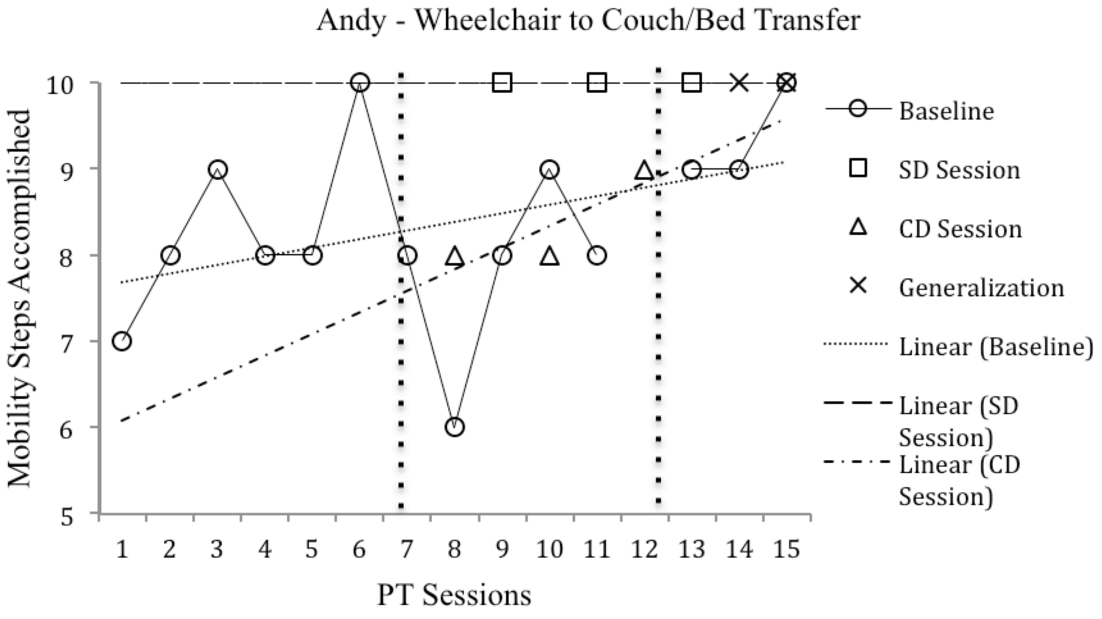
Figure 4.3. Jess' Trends, Magnitude, and Variability in Mobility Skill Steps Accomplished



Andy. Andy's mobility goal was to transfer from his power chair to a stable position on his couch, and get back into his wheelchair independently in a short time period. He stated that in the event of an emergency, he would have to get back into his chair quickly to vacate his home. Figures 4.0 and 4.4 clearly portray Andy's improved performance of his mobility skills steps during the SD interventions compared to baseline and CD sessions (baseline mean = 8; SD mean = 10; CD mean

= 8.3; maintenance = 10; generalization = 9.4). While his best performance occurred during the SD and generalization sessions, he showed slightly upward trends in baseline and CD sessions. Like Holly, Andy's clear performance difference between the SD and CD conditions suggests autocorrelation secondary to motor learning. Andy's consistent preference to practice his wheelchair to couch transfer, in lieu of all other activities is testimony to the power of motor learning.

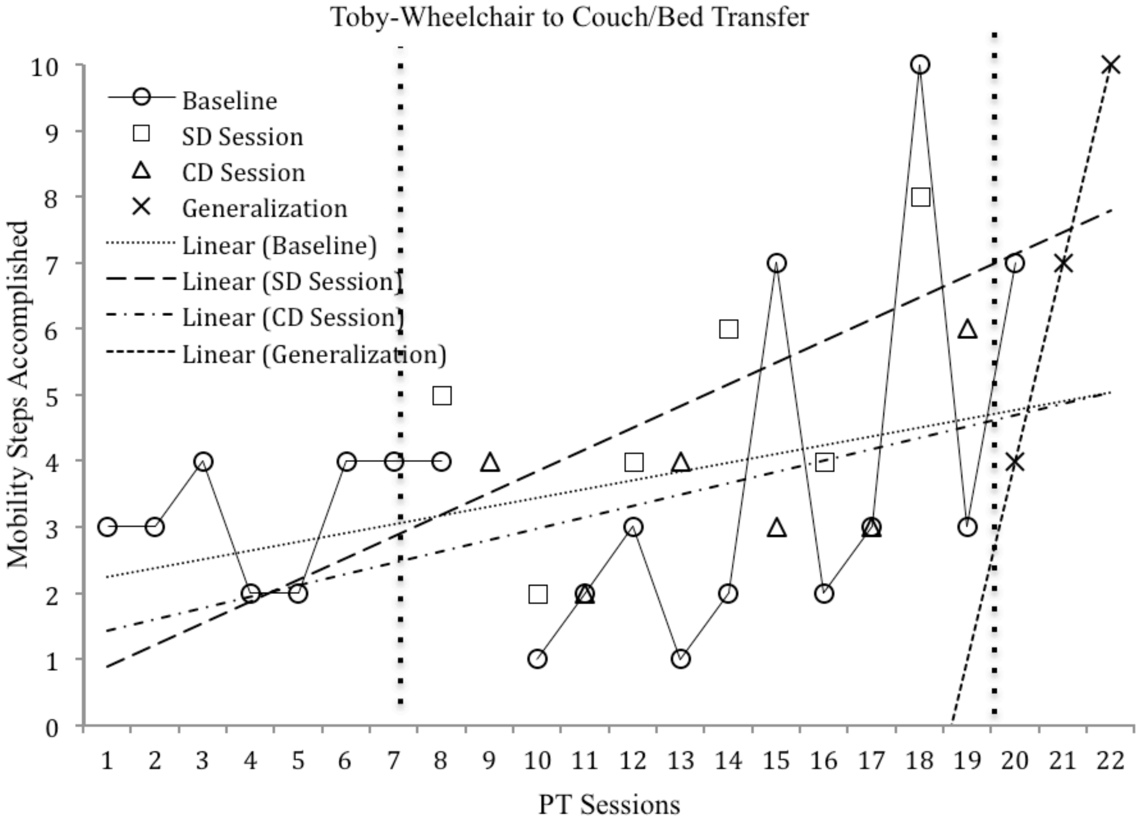
Figure 4.4. Andy's Trends, Magnitude, and Variability in Mobility Skill Steps Accomplished



Toby. Toby and his mom mutually chose to work on a wheelchair to couch/bed transfer while Toby communicated aspects of the transfer using augmentative and alternative communication modes. The considerable variability in all intervention conditions noted in Figures 4.0 and 4.5 depicts the challenges that Toby presented — the most severe mobility, communication, and apparent intellectual impairments of all the participants. He also required the most intense and ongoing supports for daily function. Although he did make gains, Toby achieved the lowest level of mobility skill steps overall; however his mean mobility skills steps accomplished during SD, maintenance, and generalization conditions were higher than baseline (baseline mean = 3.3; SD mean = 5; CD mean = 3.6; maintenance = 7; generalization = 7). Figure 4.5 shows Toby's mild upward trends though considerable variability in his performance during baseline and the SD intervention phase. The CD interventions, albeit quite variable, showed a more moderate upward trend in performance.

Though Toby never achieved all ten of his mobility skill steps, moving into the generalization phase was mutually decided when Toby's residence changed. Toby had been sleeping on his living room couch in his previous home; however, Mom needed to get him into and out of his bed in the new home. Generalizing Toby's transfer skill from his wheelchair to his bed showed the most positive performance in terms of trend and level changes, compared to the baseline and intervention phases.

Figure 4.5. Toby's Trends, Magnitude, and Variability in Mobility Skill Steps Accomplished

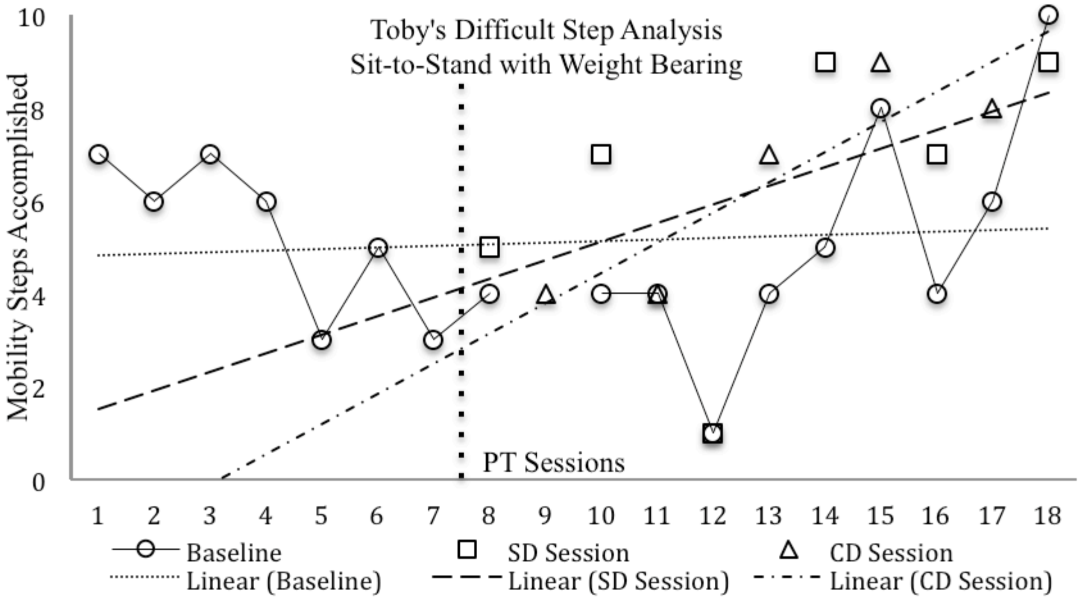


Toby exhibited many common physical and communicative challenges faced by physical therapists who work with youth and adults who have severe and multiple developmental disabilities. He showed less differentiation between the intervention conditions compared to the other participants, and certain steps in his mobility skill task were rarely achieved, and required specific instruction in order to move on. Noting these particularly difficult steps, I analyzed Toby's performance on one difficult step, breaking it down into its own ten mobility skill steps, to see the effect achieved, if any, of the CD and SD interventions.

Toby's difficult step analysis. I reviewed each session to see which steps were not achieved after intervention over at least 75% of the total intervention sessions. I counted how often steps were not achieved and ranked them most frequently to less frequently missed. I noted that Toby’s greatest difficulty surrounded two components of his sit to stand transfer steps, both at the beginning and at the end of the transfer mobility task. One component required Toby to stand with weight bearing through his feet while keeping his head and body centered, at the beginning of the transfer goal. That is, original steps 3 and 9 both required Toby to initiate standing with weight through his legs, keeping his head in midline at the beginning of the transfer. The second component, original steps 5 and 10, required Toby to take weight through his legs, support his arms, and keep his head stable as he sat down to finish the transfer. Therefore, steps 3 and 9 were combined as one component while steps 5 and 10 were combined as a second component of Toby’s difficult step analysis. I then assigned five benchmark tasks (a new task analysis) to each component of the difficult step, for a total of 10 mobility skill steps. Next, I reviewed video footage of all baseline and intervention sessions and graphed Toby’s achievement of the difficult component tasks for each session.

Visual analysis of Figure 4.6 shows no significant mean level differences between the CD and SD interventions for Toby’s achievement of his most difficult step (baseline mean = 5.12; SD mean = 6.33; CD mean = 6.4). Yet, the slight upward trends for both the CD and SD interventions suggest that both interventions helped Toby achieve more of the difficult steps compared to no-intervention baseline sessions. Comparing Toby’s difficult step analysis in Figure 4.6 to his original mobility skill step graph in Figure 4.5 shows that Toby’s performance slightly favored the SD sessions over the CD or baseline performance of his global mobility skill. Interestingly, even though Toby was non-verbal, he consistently achieved the original mobility skill steps that required him to communicate his comfort, positioning, next steps, and readiness to move on with the mobility skill steps in his goal. Toby's goal was more complex in that it included both mobility and communication components. Though I noted little change between intervention sessions in Toby's difficult step analysis, the findings helped me to validate the challenges and value persistent therapeutic intervention even when seemingly insurmountable blocks remain that prohibit an individual from achieving all of a preferred goal.

Figure 4.6. Toby's Trends, Magnitude, and Variability in Difficult Mobility Skill Steps



Summary of mobility skill steps accomplished. All participants gained mobility skill steps toward their motor goal, thought not all participants gained all ten skills steps prior to moving into maintenance and generalization phases. Visual analysis in Figures 4.0 through 4.5 showed that greater mobility skill step gains happened during the SD intervention compared to the CD intervention. When I isolated a difficult step for Toby to see the impact of the respective interventions, Toby's performance slightly favored the SD intervention. He gained skill steps toward his most difficult step in both the SD and CD interventions, and his performance was less variable during the SD and CD interventions compared to baseline and maintenance (Figure 4.6).

Across all participants, the greatest number of mobility skill steps achieved in any therapy session ranged from 7 to 10. Across all interventions, Holly and Andy demonstrated a mean gain of at least 8 out of their 10 (8.76 and 8.61) mobility skill steps; Jess and Carla gained a mean of greater than 7 out of 10 (7.52 and 7.13) mobility skills steps, and Toby's mean gain approached 5 out of his 10 (4.67) mobility skill steps. Comparing just the two interventions (SD and CD) the greatest mean gains for each participant occurred during the SD interventions. With the exception of Toby, participants achieved their highest number of mobility skill steps during the SD interventions; Jess and Carla achieved the same high number during CD interventions. Holly, Andy, Toby and Jess achieved their highest number of mobility skill steps during generalization, initial baseline, or maintenance phases. Carla and Jess also achieved their greatest number of mobility skill steps during initial baseline or later maintenance phases. All participants except Toby achieved their lowest number of mobility skill steps during baseline. Toby achieved his lowest number of mobility skills steps during the maintenance phase, while Jess' lowest number of mobility skills steps achieved occurred identically during baseline, CD, and maintenance phases. Table 4.0 summarizes and compares the ranges and means of mobility skill steps accomplished for each participant across conditions. Mean gains in mobility skills steps also favored the SD intervention over the CD intervention, and skills were clearly maintained and generalized at the highest levels as depicted in Figure 4.7.

Table 4.0.

Participants' Condition-specific High and Low Scores, Means, and Global Means Across Conditions for Mobility Steps Accomplished

Participant	High	Condition(s)	Low	Condition(s)	Mean	Condition(s)	Global Mean
Holly	10	SD, CD, Main, Gen	2	B	7	B	
					8.5	BLSD	
					8.0	SD	
					9.5	BLCD	7.31
					8.0	CD	
					9.8	Main	
					9.2	Gen	
Jess	9	B, SD, CD	6	B, CD, Main	7.5	B	
					7	BLSD	
					8	SD	7.52
					7.6	BLCD	
					7.5	CD	
Andy	10	B, SD, Gen	6	B	8	B	
					9	BLSD	
					10	SD	
					5.6	BLCD	8.61
					8.3	CD	
					10	Main	
					9.4	Gen	
Carla	9	SD, CD, Gen	0	B	3	B	
					9	BLSD	
					8.3	SD	
					7	BLCD	7.13
					7.5	CD	
					8	Gen	
Toby	7	Gen, Main	1	Main	3.3	B	
					3.6	BLSD	
					5	SD	
					3.2	BLCD	4.67
					3.6	CD	
					7	Main	
					7	Gen	

Note: B = baseline; BLSD = baseline before SD session; SD = self-directed session; BLCD = baseline before CD session; CD = clinician directed session; Main = Maintenance; Gen = generalization. Global mean is the mean mobility steps accomplished across all conditions. Global mean mobility steps measured across all conditions.

While therapists hope that individuals learn and make gains through their interventions, the resulting statistical issue of serial dependency can make data analysis beyond graphical displays problematic for researchers. Even though visual analysis of motor skills steps accomplished in Figures 4.0 through 4.5, and data in Table 4.0 suggest greater participant gains during the SD intervention, all participants demonstrated steady improvement and maintained gains toward their mobility goal, regardless of the intervention. In fact, participants' data suggests that improved motor skill performance occurred through learning and frequent practice of the motor skills as described above. Yet, visual inspection of participants' data trends and slopes is descriptive, but insufficient to determine actual intervention effects. This data suggests that the successive observations throughout conditions are correlated, or serially dependent (possibly due to motor learning and practice) which nevertheless resulted in violations of independence assumptions needed for any inferential statistical tests. I next discuss serial dependency as it relates to practice and motor learning, and conduct analysis to verify serial dependency.

Motor learning and serial dependency. It is clear that serial dependency, even with motor learning as the cause, impacted my ability to accurately interpret the overall intervention effects for either treatment on motor skill gains. The small sample made failure to meet assumptions of normality and serial independence likely and prohibited typical inferential statistical analysis. Given the gradual and consistent improvement noted for all participants during all sessions, I suspected that serial dependence as a result of repeated skill practice, regardless of the intervention applied, confounded the ability to distinguish or compare actual intervention effects.

Motor learning occurs as a result of practicing a motor skill, and is classically defined as a "set of processes associated with practice or experience leading to relatively permanent changes in the capability for responding" (Schmidt, 1988, p. 346). Motor learning involves frequent practice, feedback, and performance. Even practice resulting in sub-maximal performance can result in learning of a motor skill (Berg & Lundin, 2010). Indeed, Toby and Jess demonstrated sub-maximal performance gains through repeated practice (with and without interventions); yet, both improved their motor skill outcome.

Regardless of the explanation, this autocorrelation between data points threatened internal validity and could lead to the false conclusion that a significant intervention effect occurred, a Type I error (Richards, Taylor, Ramasamy, & Richards, 1999). Visual evidence for serial dependency in this study was strong given that the no-treatment baseline probes conducted during interventions did not result in a return to initial pre-treatment baseline for any participant (Figures 4.0 through 4.6, and Table 4.0). In order to confirm suspected serial dependency, I conducted a Lag 1 autocorrelation analysis. Autocorrelation factors near or at zero suggest that there is no significant relationship between pairs of data points, and factors considerably distant from zero suggest significant correlation (Richards et al., 1999). Data in Table 4.1 revealed significant autocorrelation using Lag 1 analysis, violating independence assumptions for all participants (except Jess), prohibiting further inferential statistical analysis, and threatening external validity (Kratochwill, 1978; Richards et al.1999).

Table 4.1

Time Series Autocorrelation Factors

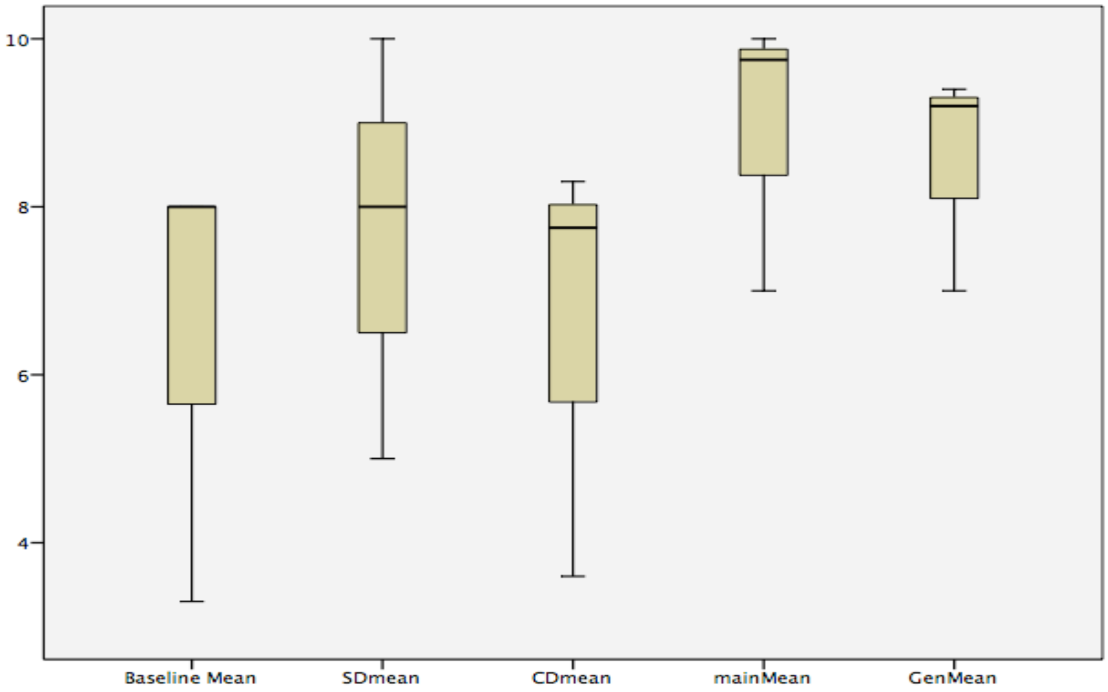
Carla	Jess	Andy	Holly	Toby
.802	-.091	.334	.445	.886

Post Hoc Analyses.

Comparing group means. Given the significant autocorrelation findings in Table 4.1, I next analyzed group means for the SD and CD interventions for this alternating treatments design in the hopes of clarifying the interventions' impact, and hopefully reducing the impact of serial dependency (Richards et al.1999). Transforming participant data into grand means allowed analysis of trends and slopes using t values because visual analysis of individual graphs was not sufficiently informative. A paired samples t test was conducted to determine which intervention (SC or CD) resulted in the greatest mean number of mobility skill steps accomplished, compared to baseline. Comparing the grand means of the two interventions (SD and CD) helped clarify level changes in motor skill steps accomplished across conditions and diminished the effects of autocorrelation.

The results indicated that the participants' mean number of mobility skill steps accomplished during the SD intervention ($M = 7.86$, $SD = 1.80$), was significantly greater than their mean performance during the CD intervention (M = 6.93, $SD = 1.89$), $t(4) = 3.42$, $p <.05$ (.027). The standardized effect size index, *d,* was 1.53, with minimal overlap between the groups as noted in Figure 4.7. Given the established effectiveness gauge for *d* (0-.2 = small; .3-.5 = moderate; .6-.8 or higher = large), the SD intervention resulted in a larger effect for motor skill steps accomplished compared to the CD intervention. Yet, given the high levels of autocorrelation determined above, cautious interpretation of *d* is prudent. The 95% confidence interval for the mean difference between the SD and CD interventions was .175 to 1.68, a rather large interval suggesting low precision in the effect size, and limited power to measure small or medium effects of the respective interventions.

Figure 4.7 Box Plot Comparing Mean Mobility Steps Gained Across Conditions



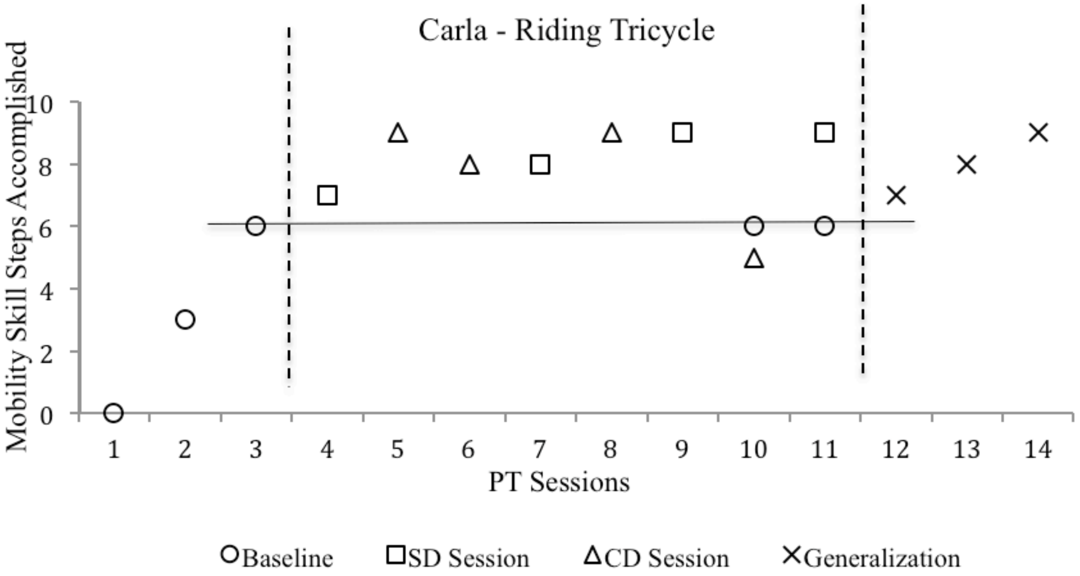
*Effect size analysis for small-n studies***.** The constraints typical of small-n studies (autocorrelation and small sample size) prohibit parametric analysis in order to make comparative statements about the effectiveness of the SD and CD interventions. Visual inspection of data overlap between baseline and intervention phases did provide an indication of change in mobility skill performance, but not a quantifiable measure across conditions.

The Percent of Non-overlapping Data (PND) is an alternative method for analyzing effect size for single-case research (Parker & Vannest, 2009). The PND helps reduce bias with small observations, agrees well with visual inspection of data trends, and is easy to calculate. Limitations of the PND include less sensitivity to slope, and has problems handling baseline data with high outlying data points (Ma, H., 2006; Parker & Vannest, 2009; Shadish & Rindskopf, 2007). Nevertheless, the PND provides an associated metric of effectiveness: 0% - 50% = ineffective; 51% - 70% = questionably effective; 71% - 90% = moderately effective; and 91% - 100% is considered highly effective (Scruggs, Mastropieri, & Casto, 1987).

I calculated PND by first counting the number of points in each treatment phase. Then I identified the highest initial baseline data point and drew a horizontal line from this point through the treatment phase. Next I counted the number of points above the line in the treatment phase separately for the SD and CD treatments. Finally I divided the number of points in each treatment phase that fell above the line by the total number of points in the treatment condition, X 100%. Figures 4.8 through 4.13 give participant-specific PND calculations and Table 4.2 summarizes PND findings across all participants and intervention conditions.

Carla had three CD interventions that fell above the highest initial baseline point value of 6, and one that fell below. She had four SD interventions resulting in a value higher than 6. Using the formula (number of points above the line/total number of points in each treatment phase X100% yielded a PND for Carla's SD treatment of 100% (4/4 X 100% = 100%). Using the same formula for her CD condition, Carla scored above the initial baseline value of 6 three times, and once below this value. PND for Carla's CD interventions was 75% (3/4 X 100%) = 75%.

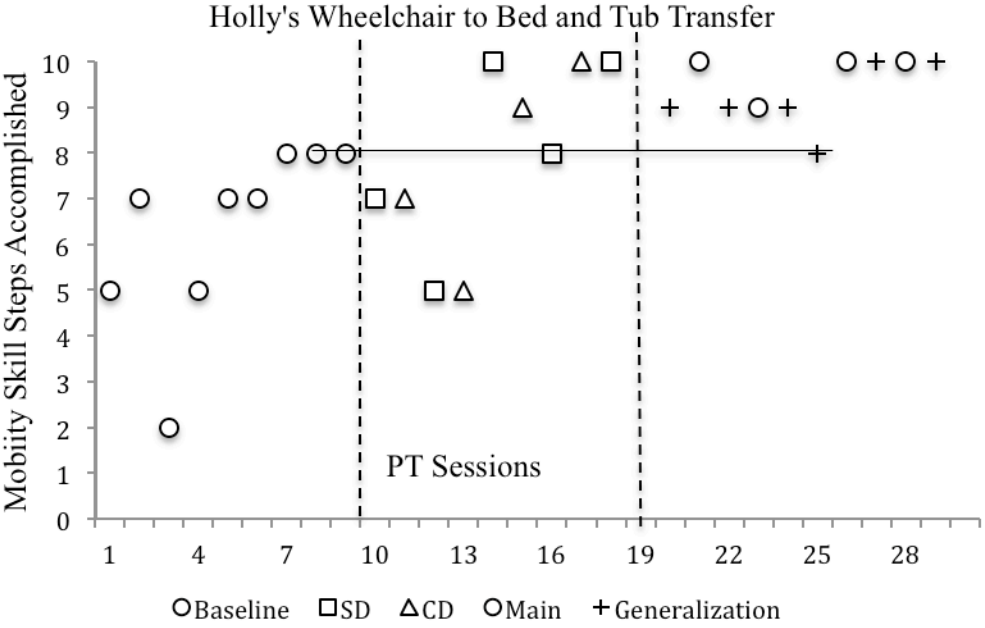
Figure 4.8. Carla's PND



The established PND metrics for effectiveness suggest the following interpretation of treatment effectiveness for Carla: 0% - 50% = ineffective, 51% - 70% = questionable effectiveness, 71% - 90% = moderately effective, and 91% - 100% = highly effective. For Carla, both the CD and SD interventions were effective when compared to her initial baseline scores. However, the SD intervention proved highly and more effective than the moderately effective CD interventions for Carla. The visual depiction of Carla's motor skill performance in Figure 4.1 reflects her PND findings in Figure 4.8.

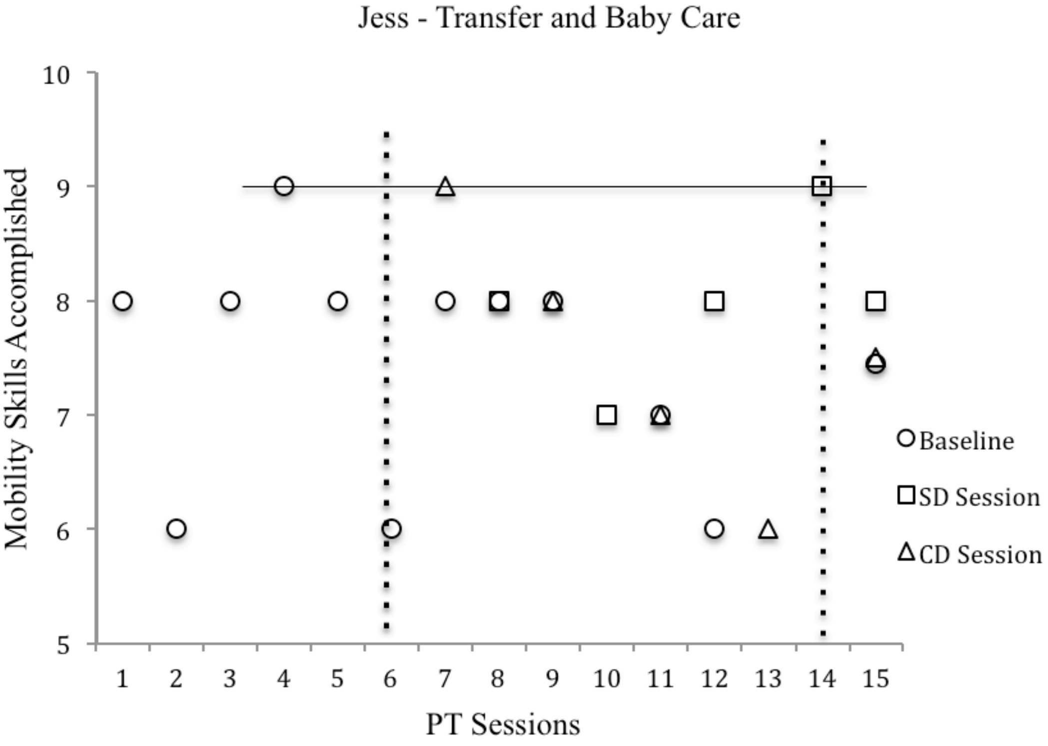
Holly's PND calculation for treatment effectiveness is depicted in Figure 4.9. Holly scored higher than her initial baseline value of 8 in two out of her total of three SD interventions (2/4 X 100% = 50%). During her five CD interventions she scored higher than her baseline value of 8 twice (2/5 X 100% = 40%). Using the same metric of effectiveness described for Carla above, the SD intervention was slightly more effective (but questionable) compared to the ineffective CD interventions helping Holly to attain her mobility skills steps. Holly's PND scores reflect findings from the visual analysis of her performance displayed in Figure 4.2

Figure 4.9 Holly's PND



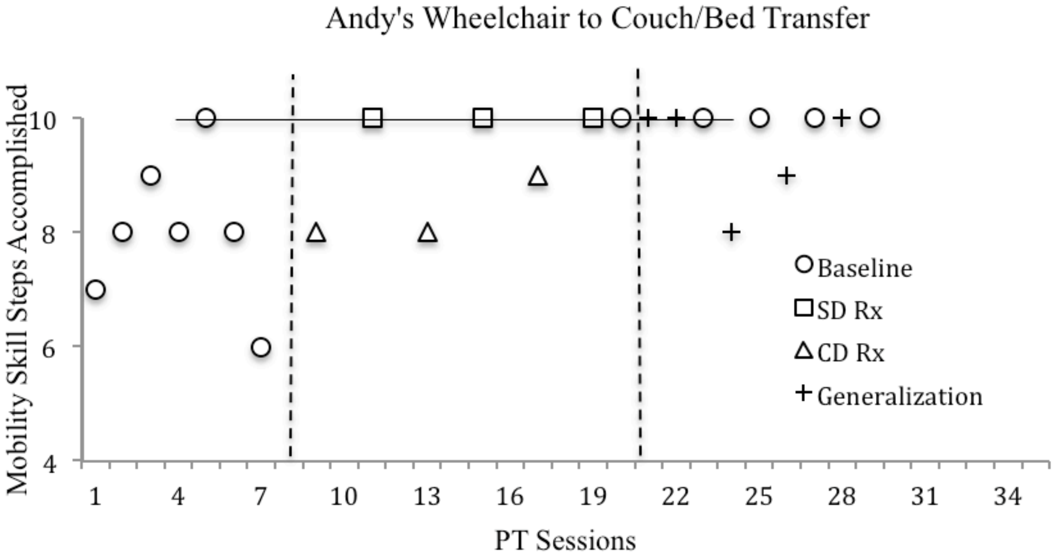
Jess showed no difference between her CD and SD interventions in terms of effectiveness for gaining motor skill steps as indicated by her PND scores in Figure 4.10. Her PND scores revealed 0% (0/5cd X 100% = 0; 0/6sd X 100% = 0) effectiveness for both the CD and SD interventions. Using the PND metric of effectiveness, both the SD and the CD interventions were ineffective for Jess. Her PND scores matched her scattered visual display noted in Figure 4.3, and suggest that her mobility goal was more complicated. That is, her task analysis may have contained insufficiently discreet mobility skill steps.

Figure 4.10. Jess' PND



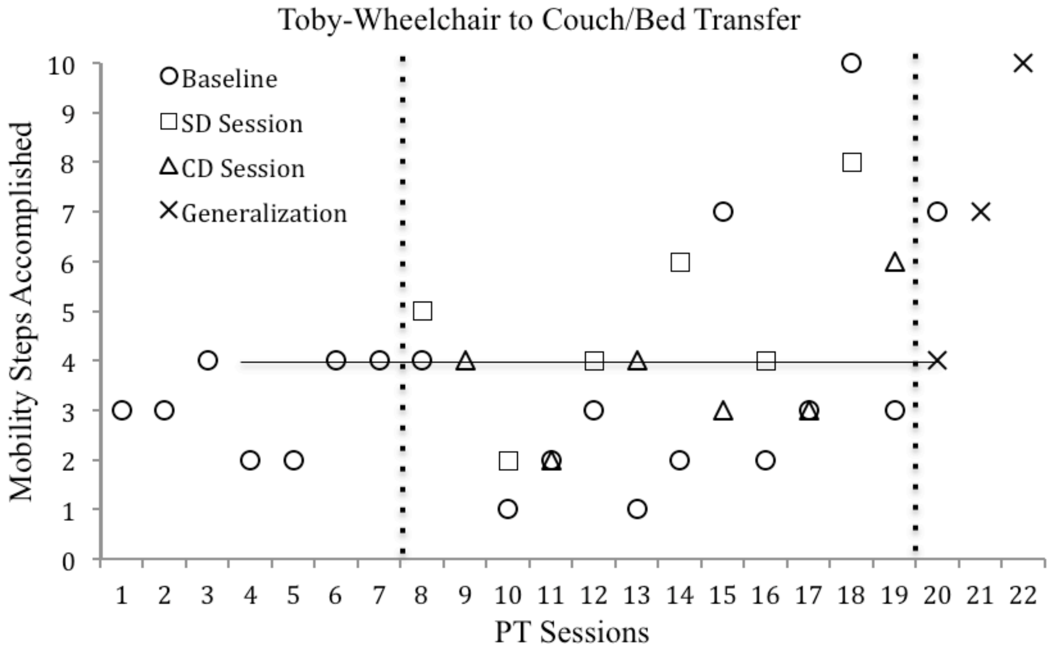
Andy's PND calculations (Figure 4.11) revealed findings similar to his visual display in Figure 4.4. Figure 4.11 shows that the SD intervention proved more effective than the CD intervention for helping him to gain his mobility skill steps. However, Andy also scored identical and highest value (counted ties for ceiling effect) for initial baseline and SD interventions (3/3 X 100% = 1.00). All of Andy's CD intervention scores were below his SD scores (0/3 X 100% = 0), demonstrating the relative ineffectiveness of the CD sessions.

Figure 4.11. Andy's PND



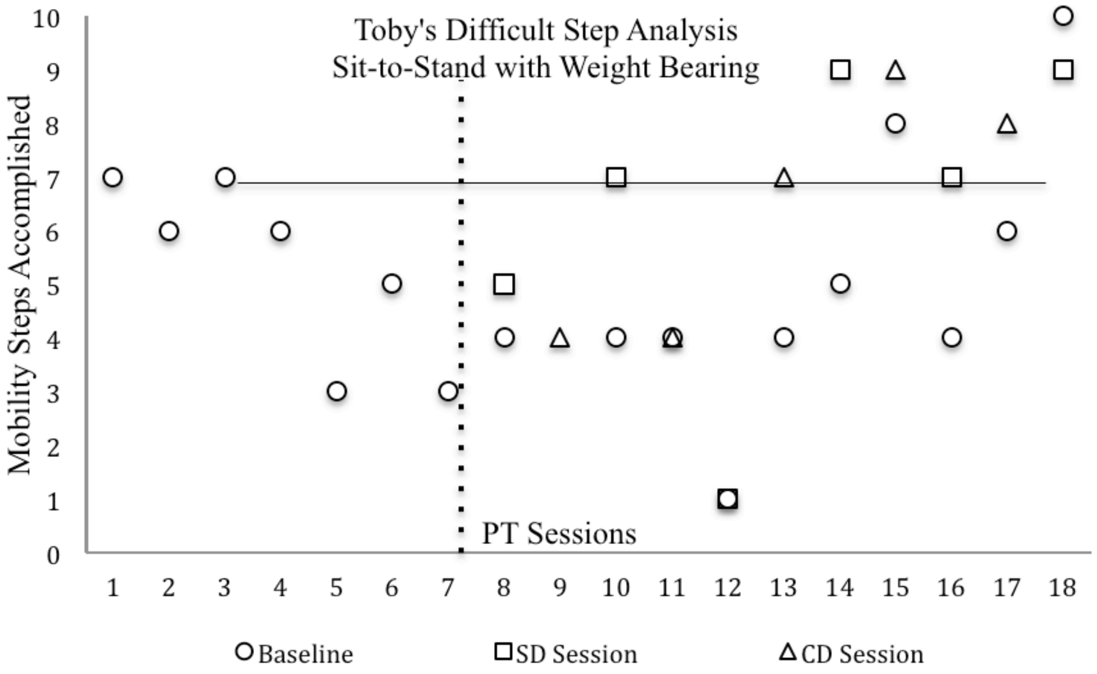
Toby presented the most challenges to gaining mobility skill steps from a motor and communication standpoint. Comparing initial baseline and CD intervention in Figure 4.12 resulted in a PND index of 17% (1/6 X 100% = .17), demonstrating the ineffectiveness of the CD intervention for Toby. The SD-baseline comparison revealed a 50% PND index (3/6 X 100% = .50) for a questionably effective SD intervention, but obviously more effective than the CD intervention for Toby. Compared to the other participants, visual analysis of Figure 4.5 showed greater variability with a few outlier data points, and PND tends to confirm this variability in his mobility skill steps accomplished, though slightly less so during his difficult step instruction (Figure 4.13).

Figure 4.12. Toby's PND



Analyzing Toby's most difficult step, weight bearing during sit-to-stand transfers, still showed both the SD and CD interventions to be ineffective when compared to initial baseline measures (CD: 3/5 X 100% = .40; SD: 2/6 X 100% = .33), with a slight advantage to the CD intervention. Again, the scattered data points and outliers suggest our collective difficulty helping Toby to achieve his mobility goal. The PND data is reminiscent of the visual analyses provided by Figure 4.6 for overall mobility skill steps accomplished and Figure 4.12 (overall PND).

Figure 4.13. Toby’s PND for Difficult Step Analysis



Summary of PND analysis. In order to discern some overall estimate of intervention effectiveness, I calculated the grand mean PND for each intervention (see Table 4.2) to get an overall estimate of the intervention effects (not including Toby’s difficult step analysis). PND mean for the SD intervention was 63%, suggesting that the SD intervention proved to be questionably effective compared to baseline, and more effective than the CD intervention. The PND mean for the CD intervention was 32%, suggesting its relative ineffectiveness compared to baseline and the SD intervention for helping participants in this study gain mobility skill steps. Considering the outlier points noted for Toby, Jess, and even Holly, the median PND may prove to be a better estimate of overall effectiveness. The respective PND median values for the SD and CD interventions were 66% and 17% respectively, concurring that the SD intervention was somewhat (but still questionably) more effective than the CD intervention for changing baseline performance. PND calculations matched fairly well with visual analysis of graphed mobility skills for all participants, as Parker and Vannest (2009) found. Both analyses revealed that Toby exhibited more scattered data with some outlier data points, while the remaining participants' data demonstrated more uniform performance. Overall, the SD intervention was slightly more effective than the CD intervention according to grand mean and median PND values.

Table 4.2

Percent of Non-Overlapping Data Points (PND) Across Participants and Conditions

Participant	SD Condition (%)	CD Intervention (%)
Carla	100	75
Holly	50	40
Jess	0	0
Andy	100	0
Toby	50	17
Toby-Difficult Step	33	40
Grand Mean PND	63	32
Grand Median PND	66	17

Note: PND metric of effectiveness: 0-50% = ineffective; 51-70% = questionably effective; 71-90% = moderately effective; 91-100% = highly effective.

Though fairly well matched in findings, the above analyses reveal the difficulty inherent in distinguishing between the SD and CD interventions on discreet mobility skill steps accomplished toward participants' overall mobility goal; but what about overall goal attainment? I next looked at a more global aspect of goal achievement using the Goal Attainment Scale (G.A.S.).

Global Mobility Goal Achievement

Goal attainment scale. As stated in chapter three, Goal Attainment Scaling (G.A.S.) is relevant for physical therapists and their patients to help establish goals and track global goal progress within a reasonable time frame. G.A.S. is clinically used to measure important and person-centered client outcomes within their natural environments (Turner-Stokes, 2009; Turner-Stokes & Williams, 2010). While the previous data concerning mobility skill steps accomplished in a task analysis is more precise and minute, G.A.S. gives a bigger picture of personal goal attainment in terms of expectations and actual accomplishments. With input from each person and practice, I developed a unique G.A.S. for each participant that was based on predicted performance and level of assistance needed (see Appendix C). Figures 4.14 - 4.17 graphically depict each participant's G.A.S. scores assigned at the end of each session. A score of 0 indicated the expected goal achievement level. A score of +1 signified a better than expected outcome, while a -1 indicated a less than expected outcome. A much better than expected outcome was scored as +2 while a much less than expected outcome was scored at -2. I used the same visual analysis process above for mobility skill steps accomplished to analyze G.A.S. scores by conditions. Explanation and analysis of G.A.S. for each participant follows.

Holly's goal attainment. Holly's G.A.S. score was based upon her ability to accomplish her wheelchair, to bed (or tub), and back to wheelchair independently, with visual observation only (see Appendix C3). Holly's G.A.S. levels, magnitude of change, and upward trends for the CD and SD interventions were parallel, with both conditions showing better performance compared to baseline and generalization (Figure 4.14). Baseline and generalization G.A.S. levels, magnitude and trends were also parallel, showing more moderate gains overall compared to the two intervention conditions. Holly's performance trends were similar and magnitude change more steep compared to her mobility skill steps accomplished in Figure 4.2. There were also a greater number of data points for baseline and generalization phases (including baseline maintenance checks) compared to intervention phases, which provides a more accurate assessment of trends.

Figure 4.14. Holly's Goal Attainment Scale

Scores

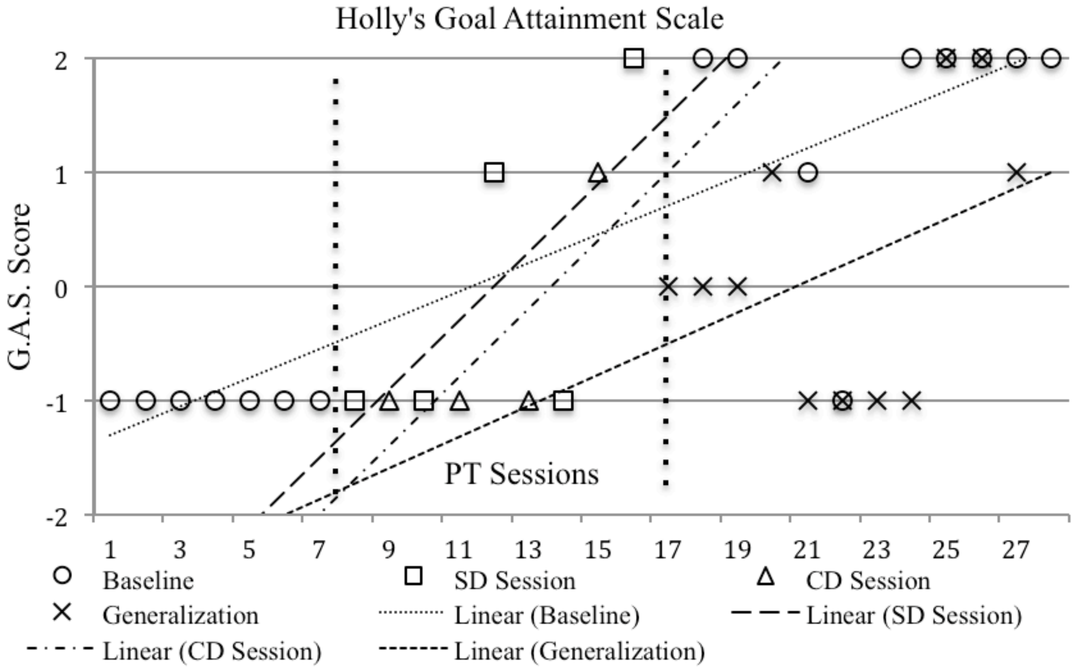


Figure 4.7. Holly's level, magnitude, and trends of G.A.S. scores noted by condition.

Jess' goal attainment. Jess' Goal Attainment Scale (Appendix C2) reflected her ability to transfer from her wheelchair, care for a baby at night, and return to her bed, all things she pictures herself doing after she is married. Jess' G.A.S. scores in Figure 4.15 showed minimal difference between conditions over time. However, her G.A.S. scores started and remained consistently higher in the SD condition compared to the baseline and CD conditions, though the magnitude of change was slightly greater in the upward direction for the CD condition. Jess' G.A.S. for the SD interventions reflected similar progress compared to her mobility skills steps graphed in Figure 4.3. The slightly upward trend for Jess' G.A.S. during the CD interventions was opposite the downward trend noted for her mobility skill steps accomplished graphed in Figure 4.3.

Figure 4.15. Jess' Goal Attainment Scale Scores

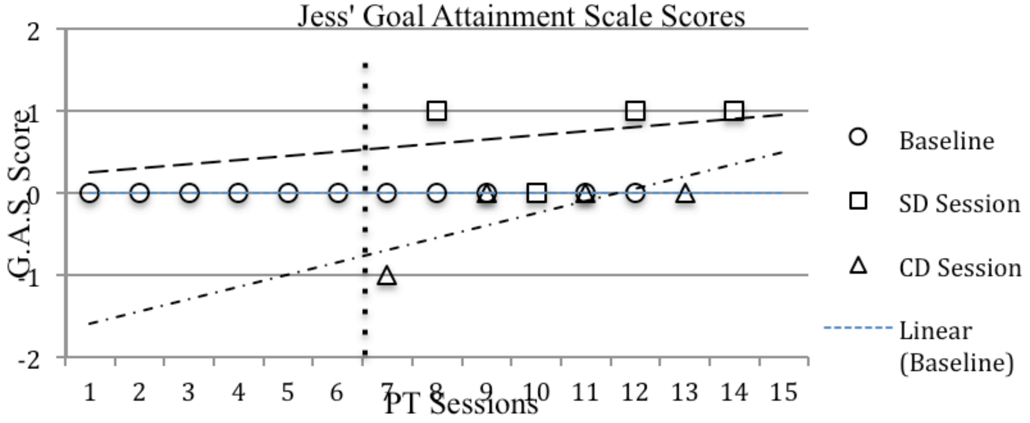


Figure 4.15. Jess' level, magnitude, and trends of G.A.S. scores by condition.

Andy's goal attainment. Andy's Goal Attainment Scale (Appendix C1) reflects his desire to get onto his living room couch (and bed) from his wheelchair, and back into his wheelchair within a short period of time, without personal assistance. His G.A.S. scores in Figure 4.16 demonstrated a slight upward or even trend and similar level changes in overall goal attainment across conditions, reflecting progress similar to his achievement of mobility skill steps in Figure 4.4.

Though demonstrably more scattered during baseline, Andy's G.A.S. scores yielded to more precise gains during the SD interventions, and less so during the CD interventions.

Figure 4.16. Andy's Goal Attainment Scale Scores

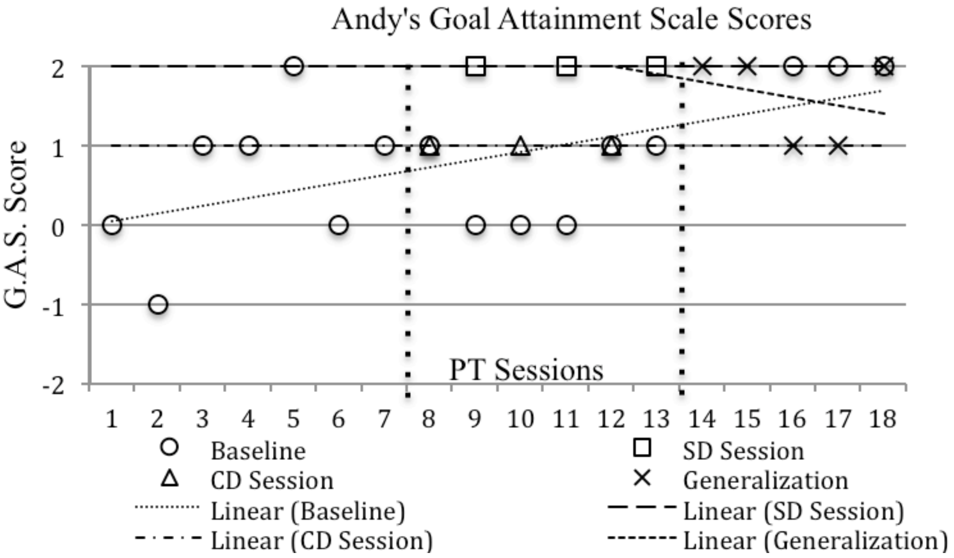


Figure 4.16. Andy's level, magnitude, and trends of G.A.S. scores by condition.

Carla's goal attainment*.* Carla's Goal Attainment Scale shown in Appendix C5 depicted her desire to ride her adult tricycle with more independence, and without constant assistance from another person. Figure 4.17 shows Carla's higher G.A.S. scores and moderate upward trends associated with the SD interventions and generalization condition, compared to the flat baseline and minimal upward trend during the CD interventions. Her G.A.S. scores trend lines also mirrored her mobility steps accomplished noted in Figures 4.1.

Figure 4.17. Carla’s Goal Attainment Scale Scores

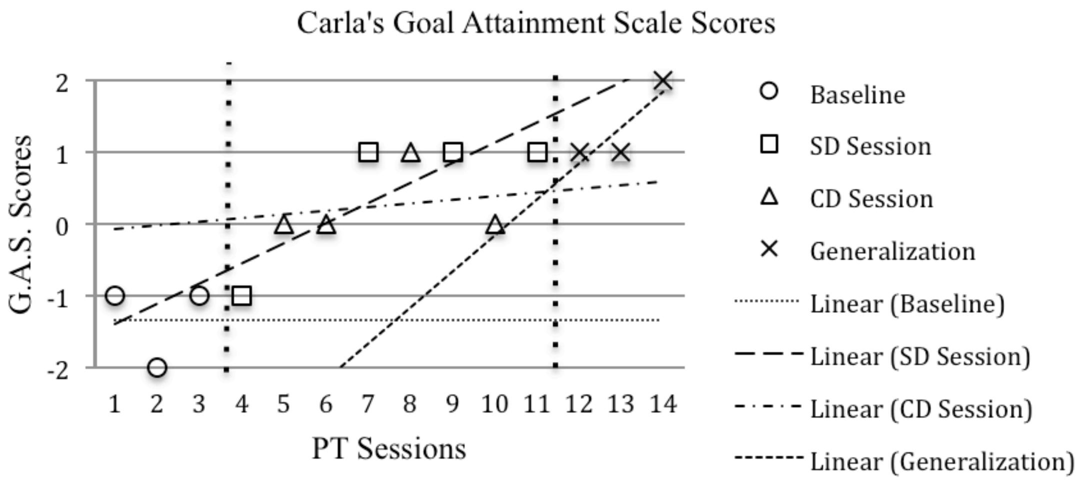


Figure 4.17. Carla’s level, magnitude, and trends of G.A.S. scores by condition.

Toby’s goal attainment. The Goal Attainment Scale in Appendix C4 reflected a mutual desire for Toby and his mom to communicate more effectively with each other, and for mom to more easily and safely move Toby from his wheelchair to the living room couch (and bed). Mom agreed that Toby would likely never accomplish a weight-bearing transfer independently; however, she thought that he might assist by supporting more of his body during a caregiver-assisted transfer. Also, she wanted Toby to direct as much of his transfer as possible by communicating his comfort, positioning, and next steps in the process. Finally, she knew Toby would need to self-evaluate at the end of each session, which required consistent communication.

Figure 4.18.Toby's Goal Attainment Scale

Scores

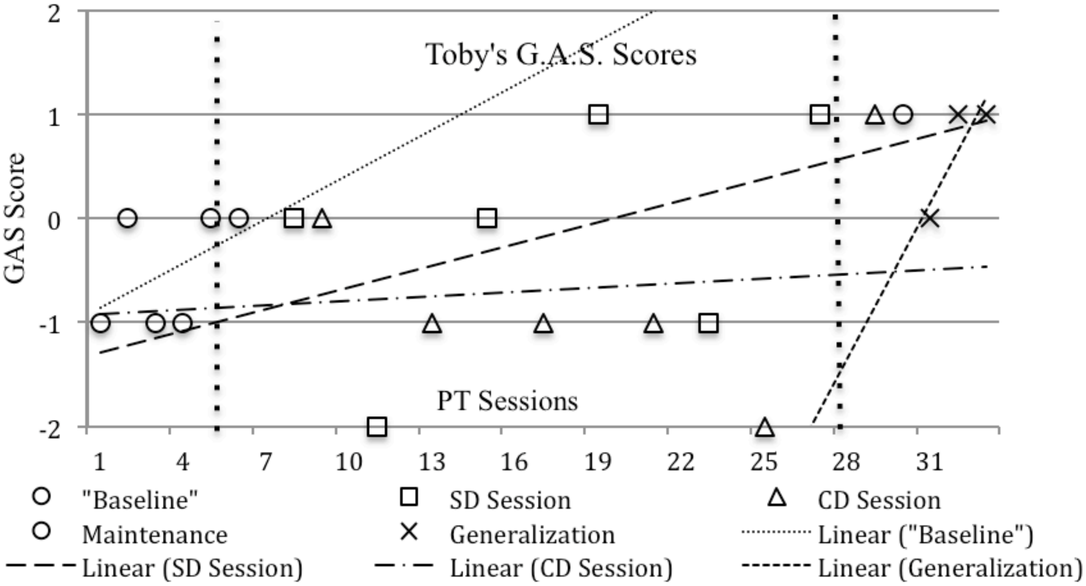


Figure 4.11. Toby's level, magnitude, and trends of G.A.S. scores by condition.

Summary of Goal Attainment. Overall, visual analysis of magnitude and trends for goal attainment using the G.A.S. scores favored the SD intervention over the CD intervention for all participants. G.A.S. scores for Holly, Andy, and Toby, were more variable, especially when compared to baseline. Andy and Holly's G.A.S. scores were most similar for maintenance and generalization conditions. The magnitude and trends for G.A.S. scores, visual analysis of overall mobility skill steps accomplished, and relative intervention effectiveness determined by PND calculations were similar across participants.

Research Question Two

Do individuals with severe and multiple developmental disabilities participating in self directed physical therapy interventions require fewer and less intrusive prompts to complete their functional mobility task compared to when they participate in clinician-directed interventions? Determining the number and level of therapist-driven prompts an individual needed provided a measure of independence as well as the participants' ability to remain focused on and attentive to the mobility task. These prompts were not solicited by the individual and were provided by the therapist to guarantee safety and to help keep the participant on task. So, fewer and less intrusive prompts from the therapist reflected greater participant independence and attention to the mobility skill tasks.

Frequency and Level of Prompts

Table 4.3 depicts the mean number and type of prompts given by the therapist during the test of motor skill performance after the CD and SD interventions. Available prompts typified a continuum of support intensities ranging from physical (most intrusive), touch (less intrusive) to verbal (least intrusive); no prompts equaled independent performance. I provided prompts and noted the intensity for participants as they performed each discreet mobility skill step. Participants demonstrated no statistically significant difference in the number and intensity of prompts between the two interventions. However, effect sizes (Cohen's *d*) reflected only a small main effect for physical and verbal prompts, and a minimally moderate effect for touch prompts to account for reliable mean differences in number of prompts due to the interventions (see Table 4.4). The small sample size prohibited reliable determination of variance resulting from either intervention.

Table 4.3. Mean Number Prompts by Intervention

Participant	Student Directed	Clinician Directed
Holly	P = 0	P = 0
	T = 2	T = 4
	V = 3	V = 4
	Total = 5	Total = 8
Andy	P = 0	P = 0
	T = 0	T = 0
	V = 1	V = 0
	Total = 1	Total = 0
Jess	P = 1	P = 2
	T = 2	T = 1
	V = 0	V = 0
	Total = 3	Total = 3
Toby	P = 8	P = 7
	T = 1	T = 1
	V = 6	V = 9
	Total = 15	Total = 17
Carla	P = 0	P = 1
	T = 0	T = 0
	V = 1	V = 0

Note: V = verbal; T = touch; P = physical

Table 4.4. Mean Differences on Prompts by Interventions

Prompt	Rx	N	Mean	Std. Deviation	Std. Error Mean	*t*	Sig.	Effect Size (Cohen's d)
pp	SD	5	1.66	3.439	1.538			.107
pp	CD	5	2.00	2.915	1.304	.169	.870	.107
tp	SD	5	.86	.942	.421			.332
tp	CD	5	1.31	1.766	.790	.503	.629	.318

vp	SD	5	2.11	2.329	1.041			.264
vp	CD	5	2.91	3.735	1.671	.406	.695	.257

Note: pp = physical prompt; tp = touch prompt; vp = verbal prompt

Participants showed no significant difference in the number of unsolicited therapist-driven prompts needed to complete their mobility skills between the SD and CD interventions. But, did the SD intervention enable participants and caregivers to self-identify supports they needed to increase success as they pursued their mobility skill steps, compared to the CD intervention?

Research Question Three

Self-identifying supports in order to accomplish a goal, or to make changes that impact performance is an aspect of self-evaluation that is integral to the *Self-determined Learning Model of Instruction (SDLMI).* Specifically, phases two and three of the *SDLMI* for the physical therapy sessions (Table 3.13) promoted self-evaluation activities where the participants identified barriers to taking action and adjusted their plan to enhance their performance outcomes (Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000). The level of impairment exhibited by the participants presumes that they may require continued supports to achieve their activity-related mobility skill steps. Yet, are they aware of and can they direct others to provide the supports they need to be successful? My third research question investigated whether the SD compared to the CD intervention enabled participants and their caregivers to identify supports needed to accomplish their chosen mobility task.

Frequency and Type of Self-Initiated Support Requests

Table 4.5 summarizes the mean number of participant and caregiver-identified (without therapist's solicitation) supports needed to improve their mobility skill performance by session type. Except for Toby, all participants requested supports more often in SD and CD interventions compared to maintenance and generalization sessions. Except for Jess and Toby, participants' greatest number of requested supports occurred in the SD and CD sessions compared to baseline. No statistical difference was noted between the SD and CD interventions for the number of participants' self-initiated support requests. It was clear that Toby's communication deficits may have resulted in his inability to clearly request support (mean of less than one per condition); however, his caregivers also requested few supports. Carla and Jess requested more supports during the SD session compared to any other session, while Andy requested more supports during the CD intervention.

Across all participants, the highest mean number of self-initiated support requests was demonstrated in the SD session, though not significantly different from the CD session. Yet, more self-initiated support requests were voiced in both interventions compared to baseline, maintenance or generalization. A paired samples *t* test was conducted to determine the difference in number of voiced self-initiated supports between the SD and the CD interventions. The results in Table 4.5 showed no significant difference in the mean number of self-initiated supports voiced in the SD condition ($M = 1.35$, $SD = .769$) compared to the CD condition (M = 1.22, $SD = 1.03$), $t(4) = .41$, $p = .702$. The standardized effect size, *d,* was small at .143, and the 95% confidence interval for the mean difference was -.760 to 1.02, a rather large interval. Again, low precision in the effect size, and limited power to measure small or medium effects is evidence of the small sample size and serial dependency.

Table 4.5

Mean Number of Self-initiated Support Requests by Session

Participant	Baseline	SD Session	CD Session	Maintenance	Generalization
Carla	.30	1.50	.75	-	.30
Toby	.30	.16	0	0	.66
Holly	.55	2.30	2.3	.25	.50
Jess	1.30	1.50	.75	-	-
Andy	1.10	1.30	2.30	.60	.60
Grand Mean	.71	1.40	1.20	.28	.52

A participant's ability to self-initiate supports during motor skill performance is one aspect of self-evaluation that typically results in changed performance. Recognizing and accurately evaluating ones entire motor skill performance is also an essential part of the *SDLMI*, and pursuant to one's ability to adjust and make future plans about a goal.

Research Question Four

Self-determined people articulate the support they need to successfully perform a goal, and they evaluate outcomes achieved (Martin & Marshall, 1996). Self-determined individuals set their own goals, plan and evaluate their performance, and adjust their performance based on self-evaluation in order to successfully achieve a goal (Mithaug, 2005). Using the therapist's benchmarks to gauge performance, did participants more accurately self-evaluate their motor skill performance during the SD sessions compared to the CD interventions? I determined the accuracy of self-evaluation by calculating the percent match between the participants' self-evaluation and the therapist's evaluation of motor skills accomplished.

Percent Match Between Participant and Therapist Evaluations

This research question investigated each participant's ability to accurately self-evaluate their motor skill performance during the SD and CD interventions, based on the match between their own self-evaluation at the end of PT sessions compared to the therapist-determined evaluation responses. Each post-intervention evaluation included 15 items: five questions about overall mobility goal achieved, plus the participants' unique ten discreet mobility skill steps (Appendix C1-C5). Table 4.6 summarizes the percent match between each participant's self-evaluation compared to the therapist's post-intervention evaluation of motor skill performance.

Four of the five participants showed fairly decent self-evaluation abilities at the outset, and throughout the study. While only slightly higher match was noted during the SD session compared to the CD intervention, with the highest match noted during maintenance and generalization phases, the differences are insignificant. While nearly 80% match between the participant and the therapist's post-evaluation indicated fairly accurate self-evaluations, it is notable that participants maintained or improved this level of accuracy (match) into maintenance and generalization phases.

Table 4.6.

Mean Percent Evaluation Match by Condition

Participant	Baseline	SD Session	CD Session	Maintenance	Generalization
Carla	80%	81%	78%	87%	92%

Toby	59%	60%	71%	73%	63%
Holly	80%	81%	78%	87%	92%
Jess	77%	82%	65%	-	-
Andy	82%	93%	77%	-	91%
Grand Mean	76%	79%	74%	82%	85%

At a minimum, participants achieved nearly 75% accuracy match in their mobility skill performance evaluations, compared to the therapist's benchmark evaluation responses, and this accuracy match improved during maintenance and generalization phases. The *SDLMI* suggests that individuals with disabilities identify adjustments, or changes they will make to enhance performance, as a result of the self-evaluation process. Did accurate self-evaluation of motor performance translate into participants suggesting a greater number of adjustment topics in order to better achieve their mobility goal during subsequent sessions?

Research Question Five

Do individuals with severe and multiple developmental disabilities and their caregivers participating in self directed PT interventions suggest more adjustments to achieve targeted mobility skills compared to when they participate in clinician-directed PT interventions? Phase three of the *SDLMI* promotes the participant's ability to suggest changes or adjustments based on self-evaluation that might enhance performance during the next session (Mithaug, 2005). I defined adjustment topics as concrete statements made by the participant or caregiver that reflected awareness of his or her self-evaluation performance on the mobility skill tasks, and that the participant could attempt to do or change in the next PT session.

Frequency of Adjustment Topics

After completing the self-evaluation at the end of each session, I verbally asked each participant the final question listed on their evaluation: “Based on your performance today, what will you do differently in the next session”? Table 4.7 summarizes the number of adjustment topics that participants and caregivers made by therapy session. Carla and Holly suggested more adjustment topics during the SD intervention compared to the CD intervention, while Jess, Toby, and Andy suggested more adjustments during the CD intervention. Carla suggested the greatest number of adjustment topics during her generalization phase, while Andy suggested the second highest number of adjustment topics during his baseline condition. Grand means were greatest and identical across participants for the SD and CD sessions, followed closely by the baseline and generalization sessions. During the maintenance phase, participants expressed the fewest number of adjustment topics. I conducted a simple *t* test to discern any mean differences between conditions, finding one difference that approached significance: fewer adjustments topics were voiced during maintenance compared to initial baseline (*M* = 2.0, *SD* = 1.0), *t*(2) = 3.464, *p* = .074). The standardized effect size index, *d*, was .744, indicating a large part of the change (decrease) in adjustment topics occurred during maintenance; however, neither the SD nor the CD interventions had any effect on number of adjustment topics offered. It is unclear whether their ability to identify even a few adjustment topics during the SD and CD interventions enabled participants to subsequently achieve mobility skill steps.

Table 4.7

Mean Number of Adjustment Topics Suggested by Condition

Participant	Baseline	SD Session	CD Session	Maintenance	Generalization

Carla	1.30	2.25	1.75	-	3.00
Toby	1.14	.16	1.16	0	.66
Holly	1.10	2.30	1.00	.25	1.00
Jess	.83	1.75	2.25	-	-
Andy	2.60	1.00	1.30	.40	.80
Grand Mean	1.40	1.50	1.50	.23	1.40

Research Question Six

My final research question investigated participants' ability to maintain their learned mobility skills in the familiar setting and generalize to a new setting, without intervention. Therapists strive to make realistic, functional differences in the lives of the individuals with whom they intervene during actual therapy time, but also outside of the clinical environment when our hands are unavailable. Individuals with severe and multiple developmental disabilities rely upon physical therapists to help them identify, pursue, and achieve meaningful mobility goals. Participants' more accurately assessed their global and discreet mobility skill performance slightly more during maintenance and generalization phases (Table 4.6). Yet, how many mobility skill steps did participants actually maintain in their familiar setting, and how many generalized to a new applied setting? Together we wanted to know if these newly learned mobility skills could be maintained without the therapist's intervention in the familiar, and in a new applied setting (generalization). After working hard to achieve a new mobility goal, did participants complete the same, higher, or a lower percentage of functional mobility steps in a new applied setting of their choice, compared to the familiar setting, without intervention?

Mobility Skill Steps Maintained and Generalized

Repeating visual analysis of Figures 4.0-4.5 shows how well the five participants with severe and multiple developmental disabilities in this study maintained and generalized their newly learned mobility skills. Table 4.8 summarizes the mean number of mobility skill steps accomplished by four of the five participants. Holly, Andy, and Toby completed maintenance and generalization phases. Jess withdrew from the study before entering the maintenance and generalization phase, and will not be considered here. Carla participated in generalization (no maintenance) sessions because the familiar setting where she learned her cycling skill (her home property) was geographically distant from her chosen generalization site (a park with trails about 10 miles from her home). Whereas maintenance and generalization probes were done during the same intervention sessions with Holly, Andy, and Toby, distance did not allow for maintenance and generalization probes to be conducted on the same day, and scheduling issues prohibited separate additional days for maintenance probes for Carla.

Table 4.8

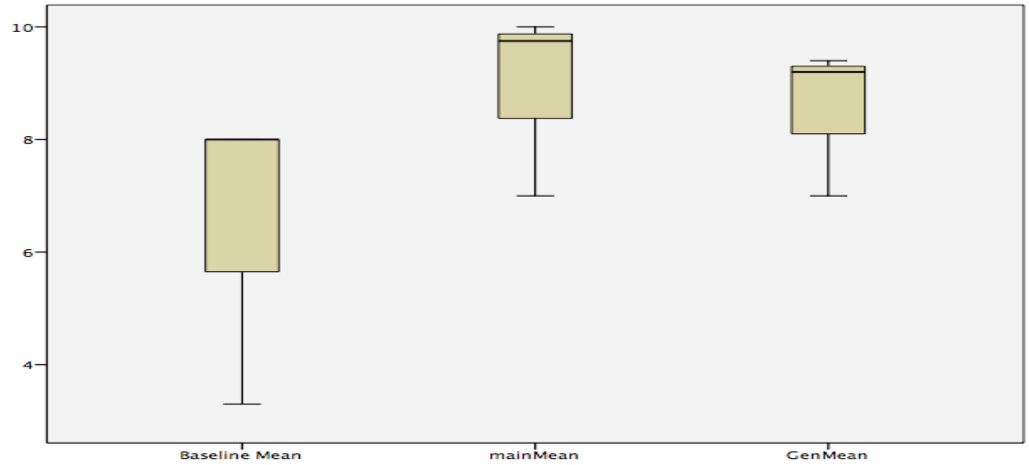
Mean Number of Mobility Skill Steps Accomplished Across Conditions

Participant	Baseline	SD	CD	Maintenance	Generalization
Holly	8	8	7.75	9.8	9.2
Andy	8	10	8.3	10	9.4
Toby	3.3	5	3.6	7	7
Carla	3	8.3	7.5	-	8
Grand Mean	5	8	7	9	8

Viewing Figure 4.7 again shows that participants maintained the greatest number of mobility skill steps in their familiar setting compared to all conditions. Participants generalized a slightly greater number of mobility skill steps as they gained during the SD intervention, and generalized more skills than they achieved during baseline and CD sessions. Visual analysis of Figure 4.19 shows that participants maintained their mobility skills without intervention in their familiar setting, and applied these newly learned skills in an unfamiliar setting at significantly higher levels compared to their baseline performance.

Figure 4.19 demonstrates a significant level change for mean mobility skill steps accomplished between the maintenance and generalization phases. I conducted a paired-samples *t*-test to determine mean differences in mobility skill steps maintained and generalized, compared to participants' baseline performance. Compared to baseline, the mean number of mobility skill steps accomplished during maintenance ($M = 8.91$, $SD = 1.66$), was somewhat greater than the mean performance during generalization (M = 8.53, SD = 1.33), $t(2) = 4.05$, $p = .056$, just approaching significance at $p < .05$. The standardized effect size index, *d,* for baseline-to-maintenance change was large at 2.34. Baseline-to-generalization effect size of 1.51 shows a smaller effect compared to maintenance, but still considerably large. The 95% confidence intervals for mean differences between baseline/maintenance and baseline/generalization performance were -5.12 to .152 and -5.55 to 1.35 respectively, considerably large for both phases. Like the comparisons between CD and SD interventions in the first research question, effect sizes (*d)* must be cautiously interpreted for maintenance and generalization performance due to the small sample and significantly autocorrelated data. The large confidence intervals again limit precision and power to measure any smaller and medium effects.

Figure 4.19. Box Plot Comparing Mean Mobility Skill Steps Accomplished During Baseline, Maintenance, and Generalization



There were no significant differences in the number of mobility skill steps accomplished during generalization compared to the maintenance phase. However, the slight increase during maintenance intuitively suggests that familiarity with the training setting makes skill accomplishment easier when no intervention is applied.

Carla. As stated above, Carla's chosen new applied setting for generalization probes occurred about 10 miles away from her home, making scheduling of maintenance probes impossible. In fact, she chose two slightly different community settings: (a) community park with trails twice, and (b) community riding around town. Yet, compared to baseline, SD, and CD interventions, Carla achieved more of her mobility skill steps during generalization (Table 4.8), suggesting she successfully applied 80% of her learned mobility skill steps new settings, sans intervention. Least squares trends in Figure 4.1 demonstrated Carla's progressively positive trend gaining her cycling mobility skill in two distinct unfamiliar applied settings.

Andy. Table 4.8 shows Andy's mean mobility steps accomplished to be higher during his maintenance (wheelchair to couch transfer) and generalization (wheelchair to bed transfer) phases. His maintenance (familiar setting) performance was again only minutely higher than generalization (new setting). Andy's mobility skills accomplishment during maintenance and generalization were similar to his SD intervention performance, and improved over the baseline and CD interventions. Least squares trend lines in Figure 4.4 verify Andy's consistent high performance gains for mobility skill steps accomplished.

Toby. Table 4.8 reflects Toby's higher and identical mean gains for mobility skill steps during his maintenance (wheelchair to couch transfer) and generalization (wheelchair to bed transfer) sessions. Figure 4.5 shows that Toby was able to maintain seven out of his ten mobility skill steps toward his wheelchair to couch to wheelchair transfer, without intervention. Toby and his family moved into a new home before he completed all ten of his mobility skills steps, and his mom requested we move on with the study into the next phase. Once in the new home, Toby also had his own bedroom, with a hospital bed (which he had not been using in the old home). Therefore, Toby's mom chose to assess generalization of his transfer skill to the bed. Visual analysis of Figure 4.5 showed that Toby initially achieved only four mobility skill steps in the wheelchair to bed transfer; but he improved consistently to achieve seven, and finally all ten of his mobility skill steps before ceasing participation, resulting in a progressively positive least squares trend during generalization. Toby posed the most challenges for achieving consistent and reliable objective measurements of his skill acquisition skill steps requiring weight-bearing status. Toward the latter part of Toby's intervention cycle, we implemented a scale to measure weight bearing in pounds, which resulted in more accurate and consistent measurement of his weight-bearing status.

Holly. Holly's mean gain for mobility skill steps was slightly higher during maintenance (wheelchair to bed transfer) compared to generalization (wheelchair to tub transfer) phase. She achieved a mean of at least 9 mobility skill steps during SD, maintenance, and generalization phases, compared to 7 and 8 during baseline and CD phases as noted in Table 4.8. Visual analysis again of Figure 4.2 shows Holly's progressively positive and higher magnitude of gain for mobility skill steps accomplished during generalization and maintenance. Like Carla, Holly's continual and consistent gains in motor skill performance, regardless of the interventions, suggests the impact of motor learning for Holly throughout the intervention phases, rather than just autocorrelation.

Yet again, the miniscule advantage during maintenance may reflect the inherent safety challenges presented during the tub transfer (generalization). That is, if Holly lost her balance on her bed, there was no safety issue…just a soft mattress. If she lost her balance in the tub, injury was more likely due to the tub and tile architecture that was sometimes wet and slippery.

Summary of Quantitative Research Findings

At the beginning of this chapter, I stated that physical therapists provide interventions in the effort to enhance the physical health and functional abilities of individuals with severe and multiple developmental disabilities, while doing no harm (APTA Mission Statement, 2010; Hiltz, 1995). I hoped that my interventions carried over into meaningful, real-life activities for each participant. I utilized the *Self-determined Learning Model of Instruction* to guide the SD intervention, and provided strictly clinician-directed interventions without consideration of student self-determination during the CD interventions.

Mobility skill steps. All of the participants gained discreet mobility skill steps toward their chosen mobility goal, regardless of the type of intervention applied. Visual analysis of participants' performance trends suggests that the SD intervention was at least as effective as the CD intervention for Holly, Carla, and Jess. The SD intervention proved slightly more effective for Andy and Toby. Carla, Holly, and Andy made steady mobility skill step gains beginning in baseline (less so for Jess and Toby), and continued this trend throughout the study's course, suggesting a practice effect at work.

Visual and PND analyses revealed similar findings regarding mobility skills performance during SD and CD interventions, with minimal advantage for motor skill gain during the SD intervention, compared to the CD intervention for some participants. Four of the participants gained a greater percentage of their mobility skill steps during maintenance and/or generalization phases, indicating maintenance and transference of a newly learned skill into real-life activities.

Goal attainment. Participants' global progress toward their respective mobility goals as measured by their G.A.S. scores was commensurate with visual analyses of their discreet skill achievement. Magnitude and trends for global goal attainment favored the SD intervention over the CD intervention for all participants, mimicking the graphic results of mobility skill steps accomplished. The visual analysis of overall mobility skill steps accomplished, the relative intervention effectiveness determined by PND calculations, and the magnitude and trends for G.A.S. scores consistently suggested that all participants improved their motor skills with both the SD and CD interventions. Results also showed that for some participants, the SD intervention had a greater effect on motor skill performance.

Frequency and type of prompts. Two of the five participants utilized more unsolicited therapist-driven prompts during the CD compared to the SD intervention. Overall, results revealed no significant difference between the SD and the CD interventions for the number of unsolicited therapist-driven prompts that participants needed to complete their mobility skill steps. Though statistically insignificant, the overall effect sizes for the SD intervention were small for requiring physical prompts, and moderate for requiring touch and verbal prompts.

Frequency of self-initiated supports. Overall, participants requested supports or assistance in order to ensure safety and greater success as they pursued their mobility skill steps more often during both the SD and CD interventions, compared to maintenance and generalization phases. Although the mean number of self-initiated supports was greatest during the SD intervention, no significant differences were noted compared to the CD intervention.

Percent match between participant and therapist evaluations. The highest percent match between participant and therapist's evaluation of mobility skills accomplished occurred during the maintenance and generalization phases. Compared to the CD intervention, the SD intervention resulted in a slightly higher match between participant and therapist's post-session evaluation. Nevertheless, the overall between-session differences were insignificant.

Frequency of adjustment topics. Neither the SD nor the CD intervention significantly influenced the number of adjustment topics that participants voiced. Two of five participants voiced more adjustment topics during the SD intervention, while the remaining three voiced more topics during the CD intervention. The only significant finding showed that fewer adjustment topics were offered during the maintenance phase. The intervention applied did not significantly influence the number of adjustment topics offered by the participants.

Mobility skill steps maintained and generalized. Participants maintained a greater number of mobility skill steps in their familiar setting, compared to baseline and CD interventions. In a new applied setting, participants generalized the same number of mobility skill steps as they gained during the SD intervention, and generalized more skills than they achieved during baseline and CD sessions. Between the maintenance and generalization phases, I found no significant differences in the number of mobility skill steps accomplished. Participants' familiarity with the training setting may make skill accomplishment easier when no intervention is applied, thus, accounting for the slight, though insignificant increase in number of mobility skill steps achieved during the maintenance phase.

In general, the *SDLMI* proved to be at least, if not more effective for facilitating new motor skill acquisition, maintenance, and generalization with youth and adults who have severe and multiple developmental disabilities. Yet, important facets of the *SDLMI* that enable individuals to critically evaluate their performance, make changes in their performance based on evaluation feedback, self-initiate supports, and require fewer prompts to complete a skill appeared statistically insignificant in the process. However, did the participants demonstrate any measurable change in self-determination? I used the educator form of the AIR Self-determination Assessment to objectively detect any change in self-determination from the beginning to the end of the study.

AIR Self-Determination Assessment

Understanding the impact of a self-determined physical therapy paradigm on mobility skill development is incomplete without some measure of participants' self-determination. I evaluated participants' pre- and post-study self-determination scores using the educator form of the AIR Self-determination Assessment. Not all participants completed pre- and post-study student versions of the AIR due to personal choice or scheduling conflicts. Neither parents nor caregivers were consistently available to complete pre- and post-study AIR assessments. Therefore, I considered only pre- and post-scores relative to the study's time-limited activities using the therapist/educator form. Table 4.9 reports the raw and percentage AIR scores for participants, parents, and therapist. While data is insufficient to statistically compare participant and parent AIR scores, it is interesting to note some individual differences in raw scores. Carla (pre-test) and Holly (post-test) both scored themselves higher in self-determination than their parents scored for them. Unfortunately, Toby's inconsistent communication prohibited his self-AIR assessment. Not surprisingly, I assessed each participant higher on the AIR post-assessment compared to initial measures. Lack of inter-rater reliability on the therapist's AIR pre- and post-assessments renders these findings suspect to the effect of researcher bias, and thus useful for descriptive purposes only. Carla, Jess, and Andy demonstrated fairly high self-determination levels, and Andy increased his score on the post-test, suggesting he felt even stronger about his ability and the opportunities he had to choose, make changes, and know how to proceed with his mobility goal.

Table 4.9. AIR Self-determination Assessment Scores

	Participant				Parent				Therapist/Educator			
	Pre		Post		Pre		Post		Pre		Post	
	Raw	%	Raw	%	Raw	%	Raw	%	Raw	%	Raw	%
Carla	103	85	-	-	41	45	-	-	65	45	114	78
Holly	-	-	83	70	-	-	54	60	73	50	112	75
Toby	-	-	-	-	26	30	51	55	33	22	109	75
Jess	114	95	-	-	-	-	-	-	94	65	128	85
Andy	87	72	104	85	-	-	-	-	83	58	128	85
Mean	101	84%	94	78%	34	38%	53	58%	70	48%	118	80%

This investigation examined the utility of the *Self-determined Learning Model of Instruction (SDLMI)* within a physical therapy setting. My results were simultaneously expected, encouraging, bewildering, consistent, and sometimes incongruous with my hypotheses and existing research surrounding the implementation and effectiveness of the *SDLMI.* Quantitative results revealed no significant differences between the SD and CD interventions on participants' ability to self-initiate supports, make adjustments in the goal or activities; however, they showed fair ability to self-evaluate regardless of the interventions. The *SDLMI* demonstrated its utility for these five participants to gain preferred motor skills. While initially high at the beginning of the study, the participants' levels of self-determination as measured by the AIR assessment only increased at the end of the study. This descriptive finding appeared related to the increased opportunities the participants had to exercise choice, control, and self-evaluation during the SD sessions.

So, if the data showed no statistically significant impact of the SD intervention on three key aspects of the *SDLMI*, why bother to incorporate it into physical therapy interventions? Did participants exhibit any changes that were attributable to the *SDLMI?* The following qualitative data supports the social validity of the study and sheds some light on the *SDLMI*'s utility for these five participants.

Utility of the *SDLMI* – Qualitative Data

At the outset of the study I promoted self-determined behavior when I facilitated each participant's self-regulated process to express their choices for a motor skill that they wanted to accomplish. With my guidance, each participant set a goal and made a plan to accomplish it by determining the intervention settings and by compiling a list of exercises and activities to use during interventions. Admittedly, I implemented the initial phase of the *SDLMI* from the very beginning, but equally so for all participants to ensure that they were working toward something meaningful. However, as Wehmeyer (2005) suggested, there is more to self-determination than making choices. I also wanted to determine if the participants learned to self-evaluate, request support, and self-adjust as they pursued their chosen goal. Data from Tables 4.5 and 4.7 revealed no significant differences between the SD and CD interventions on participants' ability to self-initiate supports or make adjustments in the goal or activities; however, participants could self-evaluate regardless of the interventions, as noted in Table 4.6. So, if the date showed no significant impact of the SD intervention three key aspects of the *SDLMI*, why bother to incorporate it into physical therapy interventions? Did the participants exhibit any changes that were attributable to the *SDLMI*?

Social Validity of the *SDLMI*

Pre-intervention activities modeled the *SDLMI* by reflecting each participant's unique mobility, self-care, or other functional activities that they wanted or needed to achieve at the outset. Each participant provided feedback on his or her respective ecological task analysis before embarking on the study. Each task analysis received approval by an outside person (sometimes the parent or other family member and sometimes a paid caregiver), before beginning the study. This collaborative process allowed step modifications based on the participants' actual performance, a process to which the participants were unaccustomed.

Participants expressed personal preferences at the start; they developed expectations for gaining a new mobility skill; they chose the intervention settings (see interview questions in Appendix B1). In retrospect, using facets of the *SDLMI* to establish study parameters at the beginning may have contributed to the insignificant findings surrounding the facets of self-determination that I measured: self-initiated supports, adjustment topics, and self-evaluation. The participants may have been too well prepared at the outset given the *SDLMI* emphasis in planning each participant's program. Nevertheless, each participant demonstrated elements of the *SDLMI* throughout the study. Specifically, I present qualitative evidence surrounding the participants and family members' ability to make informed choices, have positive yet realistic expectations, and relate therapy activities to their chosen mobility goal.

Informed choice, expectations, and the transition IEP. Participants and families preferred choosing mobility goals, settings, and activities that were real and meaningful. Each participant chose a goal in the realm of adult living; that is, they each wanted to accomplish something that would make their (or caregiver's) lives easier at home or in the community. Along with choosing a mobility goal, participants all held realistic expectations for achieving their goal. During initial interviews, participants and their family members consistently reported that they rarely, if ever were asked what they wanted to accomplish during physical therapy.

None of the participants' transition IEPs reflected independent living postsecondary goals, though all felt these activities to be important for life as an adult. Furthermore, participants and caregivers reported no involvement in PT activities at school or in their current residential setting that supported adult-living skills. Neither Carla nor Holly had PT during high school. Neither Holly nor Toby's moms said they ever really knew what their children did in PT while they were still in high school. Andy received PT at school, but stated that he never did anything that helped him live better at home. Jess, who lived in an institution reportedly to gain motor skills relative to daily living that would prepare her to live independently in an apartment, received no physical therapy at all.

Holly. Holly wanted to go to her local four-year college to become a special education teacher after she graduated high school. Her parents said that neither Holly's high school teachers nor her vocational rehabilitation counselor thought she could realistically achieve this postsecondary educational and employment goal. Holly's stated goals and needs did not match what was documented on her transition IEP. Holly's mom held similar concerns about Holly's lack of motivation especially if she considered a task to be too challenging, because Holly typically gave up. Holly had trouble problem solving, and often needed to see an example before she tried whatever was expected of her.

Holly demonstrated relatively little distinction between mobility skill gains during the SD compared to the CD interventions. The SD intervention impact was less distinct because Holly may have utilized skills learned in the SD session during her CD sessions. That is, Holly picked up activities or procedures during the SD sessions, and later used them in a CD session. For example, during one SD session, I asked her to try the wheelchair to bed transfer another way because she was having trouble coming up with a method to make it easier. When I said "maybe another part of you can go on the bed first," she came up with a leg-first transfer. While Holly did not initiate the adjustment on her own, the experience informed her decision to alter the transfer during the next CD intervention. Unsolicited, Holly said, "I decided to try the way you suggested last time," giving the CD intervention credit for the mobility skill and the adjustment topic learned in the SD session.

Toby. Toby's mom was particularly happy to go through the initial study process because she was rarely if ever consulted by school therapists about his interventions. She remarked that the therapist recommended a new wheelchair for

Toby during a PT session at school without consulting her. When the wheelchair arrived, Toby's mom was surprised and dismayed when the chair fit neither Toby nor her home environment. One major PT activity during the study involved evaluating Toby for a new wheelchair, and not pursuing the study activities, at mom and Toby's request. The end result was a well-fitting wheelchair that Toby's mom can push outdoors without tipping it over. It can also go into Toby's bedroom, facilitating the wheelchair to bed transfer goal.

Toby and his mom wanted to communicate more efficiently together. Mom wanted to transfer Toby more safely and efficiently, without using a mechanical lift that his house did not accommodate. Toby's IEP goals were extremely impairment-based, reflecting no postsecondary employment, education, or adult living goals. He had PT goals for improving ROM of his wrists and for initiating kicking with his legs. Mom voiced her desire to communicate more effectively with Toby and have him participate in activities around the house. Yet, Toby's first transition IEP goal asked Toby to demonstrate knowledge of daily living skills by appropriate performance with 80% accuracy; but Toby's IEP had no measurement criteria documented. The wording of this goal leaves one wondering if he simply needed to indicate his knowledge of some daily living skill (maybe he would hit a switch or nod his head), or if he actually needed to do some aspect of an un-named daily living skill. Another short-term goal required Toby to use a switch to activate a cup to pour a drink during snack time. Another benchmark required Toby to use his eyes to gaze at yes and no flash cards when asked a simple question, presumably to answer yes or no, but the goal only indicated his need to gaze at the cards.

Eye gaze and head movement to hit a switch to answer yes and no during the study proved to be Toby's biggest strength. Someone at school also recognized this strength for Toby, and decided to implement the same activity (hitting a switch) to have Toby staple paper for an employment goal—something Toby had neither the desire nor skill to accomplish, even with assistive technology supports.

Mom admitted, school "didn't know what to do for Toby, or what to expect from him." For Toby and his mom, the *SDLMI* approach enabled her expect Toby to communicate more consistently with his eyes and head, to become more involved in his home life by using a switch to play games with his cousins, and to expect a more efficient, but not unsupported transfer from his wheelchair to his couch or bed—all things he achieved.

Carla. Carla wanted to work part time in food service and live independently, though mom was fine with her living at home indefinitely. Mom's primary concerns surrounded Carla's overall lack of conditioning for work, daily hygiene challenges, and lack of judgment due to her compromised cognition. Contrary to the other participants, Carla's IEP did reflect these concerns.

Carla wanted to go on bike rides with her mom using their adult tricycles, and mom did not want to worry about Carla getting injured either through falling, or getting into an accident with property or a vehicle. Mom also wanted Carla to use the tricycle for daily exercise and weight management given that Carla was obese. Carla chose riding her tricycle from her barn for a designated distance, with no physical help, and as little verbal assistance as possible. Carla and her mom decided that riding the adult tricycle together would be great for fitness and fun; but Carla needed to learn safety issues, signs, and skills to ride independently. Carla had difficulty explaining things, and often talked to the bike as if it was alive. As Carla became more familiar with the activities in the study, her bike talk lessened. She appeared to use the bike talk as a delay tactic on days when she did not want to participate, more often during the CD interventions. Carla very quickly learned the difference between the two interventions. During the CD sessions, I often had Carla doing more aerobic exercises from her list. She grew tired quickly, and soon started saying, "I want to be in charge." She obviously preferred the SD interventions because she could pick easier, or different activities. In fact, I noted that Carla performed her cycling skill better during the SD sessions, possibly because she was not as tired. Carla also was the only participant who realized that she could add new things to her activity list on days when she was in charge (SD sessions).

Andy. In reviewing Andy's transition pages from his IEP when he was 18 years old, it was apparent that he was ready to graduate. That was his primary goal—to graduate, or to get out of high school at all costs. Andy did not graduate, but dropped out due to frustration at trying to learn things that he would never do, or because he did not learn things that he needed. For example, Andy had goals on his IEP that related to verbally telling the teacher the weather, and reading things. He can read, and he can hold a cogent, clear conversation on a variety of topics, including the weather! He can ask his caregivers for a raincoat if he suspects rain on his way to work. Andy also had PT goals to improve his sit-to-stand ability, and to get from his wheelchair to another surface. These were critical features of his study-related goal; however, Andy said that while he worked on these things some (not a lot of PT when he was in high school), he never practiced or used the skill in real life. He chose this transfer goal because he did not want his paid staff to lift him onto and off the couch while he was with his fiancé; he wanted to get into and out of bed on his own time schedule.

At 18, Andy decided (or was recommended) to enroll in a vocational training program associated with an ICFMR residential program, in which he was slated to live. This is the same program where another participant, Jess, lives and works. Neither Andy nor Jess felt that the special program was of particular value and it may have hindered their ability to live independently. Andy spoke very poignantly about his high school experiences and why he was so desperate to leave. He said no one ever consulted him about his particular needs and strengths relative to his chosen postsecondary goals. He hated not being given credit for things he could do (like make his own decisions) while people always put tons of pressure on him to do things that he knew he would never accomplish (like walk, and do his laundry) without help. Even during the study, a paid caregiver commented at the end of a session, “Gee, Andy. If you can do that well getting in and out of your wheelchair by yourself, I bet you could walk if you tried hard enough!” Andy became very upset, stopping the study that day. He said that the caregiver’s comment reminded him of when people would say similar things in school. Later he requested to do a taped interview about how it makes him feel when people have either very limited or unrealistically optimistic expectations for him. He wanted people to know that he has a good mind, he can make his own choices, he can live with the consequences, and yes, sometimes he needs help, but he could seek help when he needed it!

In high school, he had difficulty expecting to live anywhere or do anything except in the institution. Others held no higher expectations for him. Andy later moved into the community with some friends, and married his long-time girlfriend a month or so after the study ended. More than any other participant, Andy knew exactly what he did and did not want to do. He often came up with ideas about how to make his standing transfer easier. He valued the “what if” questions, and often posed them during therapy sessions. Andy recognized the value of practice for learning a motor skill. He said once during a CD intervention that he saw no reason to do those exercises because all he needed to do was practice repeatedly. During SD sessions, he always chose to practice his mobility skill rather than choose any other exercises. His preference for the SD session was clear by all measures, including his own admission…”I don’t like being told what to do…I just want to practice”.

Jess. Jess, who is a few years younger than Andy, lived in the same congregate care facility for the duration of the study. She graduated almost two years before starting the study; her IEP was not available for review. She was not happy living in the ICFMR (Intermediate Care Facility for the Mentally Retarded). She knew exactly what this meant, and that it required her to have an IQ of 70 or below, though her IQ was documented right at 69-70. Jess said that she agreed to live temporarily in the ICFMR so that she could get PT services and learn how to move herself about so that she could be more independent and live on her own. Jess’ main goal was to get married and have a family. She said that people didn’t think she was ready to move out on her own. Jess has a higher GFMCS score than Andy, and is much more physically capable of caring for herself now. Yet, she was told that the

ICFMR was the best residential option now because it offered the PT programs she needed to strengthen her legs so that she could stand better. Incredulously, Jess revealed that she had received no PT services (outside of what we accomplished in the study) since she began living in the ICFMR over two years ago. She said that she worked for sub-minimum wage, performing tasks she has no desire to perform (unpacking sanitary napkins from one box, and then packaging them into another package).

Jess' mobility skill choice in this study revealed her desire to live on her own and safely care for a baby. She did not want to work on just one aspect of caring for a baby. The fact that her mobility goal seemed to encompass a series of mini-goals contributed to the variability noted in her performance. Like Andy, Jess' expectations for herself well exceeded the expectations that others held for her regarding her goals to live independently, get married, and have children. Jess also recognized and verbalized some of the supports she would need to achieve her goal.

It was clear that all of the participants valued the ability to make their own choices at the beginning, and throughout the study. Each participant distinctly had expectations for themselves surrounding how they wanted to live, work, or go to school; however, others' expectations of them were typically very low, or at times unrealistically high. The expectations of others did not account for the participants' preferences, strengths, or current skills. Nevertheless, all of the participants understood their mobility goal, and could explain how the intervention or exercises facilitated goal achievement. Implementing the *SDLMI* within the physical therapy settings enabled participants to 1) understand the difference between self-directed and clinician-directed interventions, and 2) promoted self-determined behaviors in the participants.

Goal relevance. Goal relevance is intrinsic to the *SDLMI* when individuals self-evaluate or make adjustments in their plan. Though I did not formally investigate goal relevance, I did probe participants for a response to a specific question during the SD sessions. All participants gave astute and cogent responses to this question: "How do these exercises or activities influence your ability to perform your chosen goal?"

Carla. Carla clearly learned the relevance of physical activity to her bike-riding goal, and she verbalized the importance of exercise in terms of losing weight, and staying fit for work. During the SD sessions I asked: "Why are you learning to ride a bike?" Carla said, "lose weight;" "not fat;" "it's fun;" "it's good." Carla and her mom later joined a community-based exercise program for women. She loves being part of a group where she can control her own program and activities. At this fitness facility, Carla chooses to do as many or as few of the stations as she wishes. She can workout as long as she wishes. She knows she is becoming healthier, a fact that her mom verifies.

Andy. When I asked Andy how his exercises and activities impacted his ability to accomplish his transfer goal, he invariably said, "Practice makes me get better and faster, and I don't need help." He said that he did not value the other exercises because they made him tired, and took time and energy from his practice.

Jess. Jess also connected her exercises and activities with her overall goal to care for a baby at night. She was clear on her desire and expectations to become a wife and mother. Yet, sometimes she answered my question about the relevance of the exercises to her goal achievement with an impairment-based response: “My range of motion and strength will improve.” Sometimes Jess needed an additional prompt like, “Why is greater strength and range of motion important to you?” Jess could then respond with “So I can get out of bed to take care of my baby.”

Holly. When Holly was questioned about the relevance of her exercises to her mobility goal, she answered at the impairment level much like Jess. Later, Holly also responded that her exercises helped her get on and off her bed by herself, “without mom’s help.” She went further to state that gaining the ability to get into the tub by herself gave her the opportunity to shave her legs on her own, something she had never accomplished.

Toby. While Toby had the greatest communication challenges of all the participants, he and his mom always answered the questions about goal relevance in terms of the things Toby could do with his family, while mom and he remained healthy and safe. For example, I asked Toby why it was important to do the exercises and activities. His mom always stated, “Exercises make it easier for me to care for Toby and for us to do stuff together.” Toby acknowledged his agreement by answering yes or no, or by indicating something that his mom could do with him. For example, he would look at the door indicating his desire to go outside in his wheelchair to sit on the porch, one of his favorite things to do.

Summary of qualitative data. Qualitative data in the form of the previously-stated quotes and discussions suggest that the participants and their caregivers preferred the SD interventions, and found them to be valuable and relevant for achieving their respective mobility goals. Participants valued making informed choices, and they urged others to have higher and more realistic expectations for them. Participants recognized their need for ongoing supports, which matched pre-study findings on the *Supports Intensity Scale*; some participants learned to request these supports during the study. Participants understood and articulated how the PT exercises and activities related to their mobility goal when the therapist used the *SDLMI* to guide their self-determined learning during the SD interventions. Qualitative findings appeared to support the utility of the *SDLMI* within PT settings for young adults with severe and multiple disabilities in this study.

Chapter Four Summary

Quantitative evidence from this small-n study suggested that participants with severe and multiple developmental disabilities learned, maintained, and generalized mobility skills, regardless of the intervention applied. Visual analysis of participants' graphs revealed generally positive trends and greater level changes for the SD compared to the CD intervention. It was apparent that all of the participants learned from their experiences, or were affected by their previous therapy sessions, as none returned to their baseline performance level. Serial dependency was suspected and verified by the high autocorrelation factors noted in Table 4.1.

Post hoc analysis revealed that participants' overall mean mobility skills steps achieved were significantly greater during the SD intervention (*M* = 7.86, *SD* = 1.80), compared to their mean performance during the CD intervention (M = 6.93, *SD* = 1.89), *t*(4) = 3.42, *p* <.05 (.027). The resulting large effect size (*d* = 1.53) suggested that the SD intervention was more effective for enabling participants to gain motor skills, compared to the CD intervention.

Given the high autocorrelation factors, I calculated the Percent of Non-overlapping Data Points (PND) to determine effect size, a process growing in use for small-n studies. Andy and Carla again demonstrated a greater effect from the SD intervention than the CD intervention on mobility skill attainment (PND = 100%); Holly and Toby demonstrated almost questionably effective SD intervention (PND =50%); and Jess' PND revealed no effect from the SD intervention compared to the CD intervention. Overall PND scores suggest that the SD intervention was questionably effective, compared to the CD intervention in helping participants to gain motor skills. Visual and statistical analyses were comparable, overall favoring the SD intervention for discreet and global mobility goal attainment. Participants maintained their learned mobility skills at a higher level and generalized their mobility skills in a new setting as revealed by the relatively large effect sizes compared to baseline (d=2.34 and 1.51 respectively). Again, the autocorrelated data in such a small sample warrants caution when interpreting these seemingly encouraging results.

While qualitative data suggested that participants learned and used facets of the *SDLMI*, there was no clear association to the SD or the CD intervention. That is, there were no significant differences in prompts, self-initiated support requests, or adjustment topics offered by treatment condition. Participants appeared to self-evaluate fairly accurately from the beginning of the study, with no significant differences observed with either the SD or CD intervention.

CHAPTER FIVE

Introduction

This study investigated how well five young adults with severe and multiple developmental disabilities (SMDD) who participated in self-determined (SD) physical therapy interventions gained functional mobility skills, and used facets of the *Self-determination Learning Model of Instruction* (*SDLMI*) in the process, compared to when they participated in clinician-directed (CD) PT interventions. Notwithstanding the intervention applied (SD or CD), I also wanted to determine how well these participants maintained their newly learned motor skills in their familiar setting, and generalized the same skills in a new and less-familiar setting.

Chapter One introduced and defined the population of concern, individuals with severe and multiple developmental disabilities, and proposed using the *SDLMI* within physical therapy interventions for these individuals to support their motor skill development. Chapter One also listed the six research questions that I developed to examine the utility and effectiveness of using the *SDLMI* within physical therapy settings for individuals with severe and multiple developmental disabilities.

The extensive literature reviewed in Chapter Two situated the SMDD descriptor within relevant disablement models, described the *SDLMI* and its effectiveness with young adults with varying disabilities in vocational, educational, and community living settings, and provided professionally relevant evidence linking self-determination and physical therapy practices to support postsecondary transition planning processes for individuals with SMDD.

Chapter Three described the single case research methodology I used to compare the SD and CD physical therapy interventions that I applied in order to answer the six research questions. I implemented a multiple probe with alternating treatments design to determine the extent clinician-directed (CD) and participant self-directed (SD) physical therapy interventions effected motor skill performance and self-determined behaviors for five participants with SMDD across settings. I measured performance on six distinct variables that comprised each participant's identified motor goal: (a) number of motor skill steps accomplished, (b) frequency and type of therapist-directed prompts, (c) frequency of participant-driven support requests, (d) frequency of participant-offered adjustments to performance, (e) percent match between participants' and therapist's post-session evaluations, and (f) number of motor skill steps that were maintained in each participant's familiar setting and generalized to a less-familiar applied setting.

Chapter Four summarized the results related to those six research questions while concurrently prompting additional questions that I address in this chapter. In this chapter I discuss the significance of my findings relative to the six research questions, identify study limitations that impacted these findings, discuss social validity and value of small-n research in clinical practice, and suggest implications for future research.

Discussion

Physical therapists are in the business of helping people with disabilities gain or re-gain motor skills to improve meaningful function in relevant activities. We naturally want to know which, if any of our interventions result in measureable gains that make a difference to people. PTs are charged with providing the best practices to their clients while avoiding interventions that lack reasonable evidence, or those that cause harm. To that end, the five participants with severe and multiple developmental disabilities (SMDD) in this study gained preferred mobility skills in relevant environments, and were not harmed. I wanted to know if a client self-directed approach based on the *Self-determined Learning Model of Instruction* (*SDLMI)* would be as or more effective than a clinician-directed therapy approach at helping young adults with severe and multiple developmental disabilities gain mobility skills. Table 5.0 summarizes the relevant findings surrounding my six research questions, which I discuss next.

Table 5.0 Global Summary of Results

Mobility Skills Accomplished	Prompts	Self-initiated Supports	Adjust. Topics	Eval. Match	Skills Maintained and Generalized	Utility of the *SDLMI* (Qualitative)
SD ≥ CD intervention for gaining mobility skill steps Graphs: ✚ Statistical: ✚ Serial Dependency: ✚	Ø	Ø	Ø	Ø	✚ Main > General.	✚ choice ✚ relevant goals ✚ preferred SD over CD Ø Time/effort

Note: ✚ positive impact of SD compared to CD intervention; Ø no difference between SD and CD intervention; ≥ equal or greater impact; > greater impact.

Mobility Skill Steps Accomplished

Did the five participants in this study gain motor skills, and if so, which intervention approach (SD or CD) resulted in greater motor skill step accomplishment over time and settings? Regardless of the intervention applied (SD or CD), all of the participants gained discreet mobility skill steps toward their chosen mobility goal. Performance trends noted in Figures 4.0-4.7 suggest that the SD intervention was at least as effective as the CD intervention for Holly, Carla, and Jess, and significantly more effective for Andy and Toby. Carla, Holly, and Andy made steady mobility skill step gains beginning in baseline (less so for Jess and Toby), and continued this trend throughout the study's course, suggesting a practice and motor learning effect.

A Lag 1 autocorrelation analysis verified significant serial dependency for each participant. Serial dependency is a common finding in applied small-n research, and in fact, suggests that providing an opportunity to practice a motor skill, without any other exercises or interventions, can facilitate motor skill acquisition. Nevertheless, serial dependency threatened external validity by violating independence assumptions required for any inferential statistical analysis surrounding the specific intervention effects. Given the small sample size and significant autocorrelation results, I then conducted post hoc analysis of participants' mean scores across conditions (group means) in order to determine any intervention effects that were masked by serial dependency. Transforming participant data into grand means allowed analysis of trends and slopes (level changes) using *t* values, an approach that augments visual analysis of participants' data.

At the $p < .05$ level, mean mobility step gains for participants during the SD intervention were significantly higher compared to when they participated in the CD interventions. The standardized effect size of *d*=1.53, demonstrated greater effect from the SD intervention, though this interpretation should be viewed cautiously given the large confidence interval which suggests low precision and limited power to identify small and medium effects. Though visual analysis of graphs, and paired samples *t*-test suggested promising results for the SD intervention, typical constraints of single-case research (autocorrelation and small sample size) prevent reliable parametric analyses and demand caution when making definitive interpretations about specific SD and CD intervention effects. In light of the aforementioned results, I conducted one more effect size analysis, a more quantifiable method that is rising in popularity in single-case research.

Analyzing Percent of Non-overlapping Data (PND) provided a method for calculating effect sizes for motor skill steps accomplished during the SD and CD interventions. Participant-specific PND analysis in Figures 4.8-4.13 suggest that the SD intervention proved highly effective for Carla and Andy, somewhat effective for Holly and Toby, and ineffective for Jess compared to baseline performance. I also determined the median PND because outlier data points were present for Holly, Toby, and Jess, making the mean less reliable for interpretation. Median PND findings revealed a greater effect size for the SD intervention (but still only at the somewhat effective level) compared to the ineffective CD intervention.

Compared to baseline motor skill steps accomplished, the CD intervention was somewhat effective for Carla, but ineffective for the remaining participants. Comparing the interventions to baseline performance, the SD intervention appeared to be somewhat effective, and clearly more effective than the CD intervention, to produce overall mean gains in motor skill steps (Table 4.0 and Figure 4.7).

Compared to Holly, Andy, Carla, and to some extent, Toby, Jess had the most difficulty achieving her mobility goal. This was surprising at first knowing that her pre-study GMFCS, FIM, and SIS levels (Appendix B) were similar to Andy and Holly. I now suspect that Jess' inconclusive and varied motor skill step data was more a function of her chosen goal, one that was too broad and multi-faceted, and not comparable to the other participants' goals. Jess' discreet skill steps by themselves were actually separate goals. That is, Jess' entire mobility goal consisted of: (a) transferring from her bed to wheelchair, (b) picking up a baby, (c) feeding a baby, (d) diapering the baby, (e) returning the baby to bed, and then (f) returning herself to bed. Jess' complicated goal and task steps contributed to her varied and inconclusive performance. Nevertheless, she chose this all-encompassing goal, caring for a baby at night, because she wanted to learn these skills before she married and had a child.

Global mobility goal achievement. Goal Attainment Scaling (G.A.S.) painted a broader picture of each participant's motor skill achievement by assessing actual compared to expected goal performance. Visual analysis of each participant's graphed G.A.S. scores favored the SD intervention over the CD intervention for promoting global goal attainment. The magnitude and trends noted for participants' G.A.S. scores in Figures 4.14-4.18 are analogous to those found for mobility skill steps accomplished.

The evidence provided by both visual and quantitative analysis of participants' separate, aggregated, and global motor skill data is equivalent, and mutually supports the findings that all participants gained discreet motor skills, regardless of the intervention type. Furthermore, the graphed data in Figures 4.1-4.5 suggest that participants benefited from practice in previous sessions, regardless of the intervention provided, as they gained motor skills. Finally, some participants found the SD intervention more effective than the CD intervention for gaining motor skill steps. Andy stated that he liked having the ability to choose to “just practice” his transfer during the SD sessions, compared to having to do my chosen exercises during the CD sessions.

The *Self-determined Learning Model of Instruction (SDLMI)* played an integral role within the SD interventions. Facets of the *SDLMI* were distinctly promoted during the SD interventions. The impact of the SD intervention appeared promising, or at least as effective as CD interventions for enabling participants in this study achieve motor skills. Next, I will discuss facets of the *SDLMI* that were apparent during the interventions.

Frequency and Level of Prompts

Chapter Three described the available prompts given to participants that ranged from most intrusive (physical), less intrusive (touch), to least intrusive (verbal). Prompts were provided to the participant by the therapist as needed to ensure participant safety and attention to task. There were no appreciable differences in the number or type of prompts given between the SD and CD interventions across participants (see Table 4.3). Toby received the most of all three prompt types. His need for unsolicited prompts was indicative of his multiple system impairments, typical of his Gross Motor Function Classification System (GMFCS) level V status, Functional Independence Measure (FIM) level 1, and equated with the level of supports he demonstrated on the Supports Intensity Scale (SIS) prior to his beginning the study. Likewise, Carla required the fewest physical and touch prompts, but a large number of verbal prompts to keep her on task, reflecting her greater cognitive rather than physical impairments. Again, the type and frequency of prompts that Carla needed matched her pre-study status as GMFCS level I, FIM level 7I, and reflected the fewer supports needed on the SIS. Holly and Jess both required more physical, touch, and verbal prompts compared to Andy, who required surprisingly few prompts overall given his pre-study measures of function. Holly, Andy, and Jess all functioned at the GMFCS IV and FIM level 7I suggesting the need for physical prompts or support due to physical impairments. Holly also required greater verbal prompts due to her problem solving challenges.

Student-initiated Support Requests

The *SDLMI* promotes the ability of a person to self-evaluate and identify barriers that block progress on their plan, or to adjust their plan as they endeavor to successfully achieve a goal (Wehmeyer et al., 2000). Participants' pre-study assessments demonstrated the supports each needed to accomplish daily tasks, and presumed some level of ongoing support (Table 3.1). Yet, after evaluating their performance, did participants request specific supports to enhance, or ensure more success in subsequent sessions? Compared to all of the participants, Toby and his caregivers requested the fewest supports to enhance performance, thought in reality he required the most prompting and supports. Toby's extremely severe and multi-system impairments, especially in the communication domain, made this a most challenging task. For example, it took a long time to establish a consistent method of communication with Toby, and an objective way to measure his weight bearing in standing. Holly, Jess, and Andy requested supports equally during the SD and CD interventions compared to baseline, maintenance, or generalization phases. For Carla and Jess, the SD interventions proved to be more conducive for requesting supports, while Andy seemed to request supports more often during the CD intervention. Andy often protested during the CD interventions because he repeatedly stated his desire to just practice his transfer skill. Overall, there were no significant differences between the SD and CD interventions on participants' ability to request supports (see Table 4.5).

I was somewhat surprised that there were so few participant-initiated support requests. Yet, I was also at times aware of a respectful barrier that may have prevented participants and caregivers from questioning or requesting support during a session. One mom stated that she did not think it was proper to question the therapist. Toby's mom often stated that she was infrequently consulted about her son's needs and interventions when he was in school, especially when it was apparent that Toby could not reliably self-advocate. Holly's mom remarked that Holly rarely questioned anything, and often just "gave up" rather than problem solve through an issue. Yet Holly could request a support after she witnessed the therapist providing the support during an intervention. For example, during one session, I moved a pillow away to give Holly less interference during an exercise. In subsequent sessions, Holly threw all of her pillows off of her bed prior to completing the transfer.

At some point all of the participants intimated that evaluating their own progress toward a given goal while they were in school, or in their current living environment was rarely recognized or promoted. Participants stated that they were unfamiliar with the process of setting a goal, determining for if and when the goal was achieved, and taking action to ensure goal achievement. These are requisite skills for planning successful postsecondary experiences and sometimes require training. I next discuss the participants' ability to self-evaluate, a critical facet of the *SDLMI,* during the SD and CD interventions.

Percent Match Between Participant and Therapist Evaluations

Except for Toby, the participants overall self-evaluated at higher levels than I expected, regardless of the interventions (see Table 4.6). Even their baseline self-evaluation scores suggest that they each possessed a fair ability to self-evaluate from the beginning, and may also attest to the relative strength of their cognitive abilities compared to their physical impairments. Toby's lower self-evaluation scores may relate more to his communication challenges, rather than true ability to self-evaluate. It is clear that therapists may need to spend time determining most effective means of communication before their clients with severe and multiple developmental disabilities can benefit from self-determined therapy approaches.

Holly, Carla, Andy, and Jess accurately self-evaluated their performance as evidenced by the nearly 75% match with therapist's evaluation, regardless of the applied or absent intervention. The SD interventions resulted in only slightly higher evaluation match, and most of the participants demonstrated the same or higher level of self-evaluation accuracy during the generalization phase. The data suggests that at least four of the five participants self-evaluated fairly accurately, at least at middle ‘C’ if we equated this accuracy match with a letter grade in school. Notwithstanding the CD intervention’s low match score, participants appeared to improve their self-evaluation ability into the ‘B’ category, with over 80% match during maintenance and generalization. As Mithaug (2005) found, it is apparent that promoting self-evaluation skills can help to functionally enhance a person’s ability to make adjustments that can impact future performance. I next discuss the frequency of adjustment topics that participants suggested after evaluating their motor skill performance.

Frequency of Adjustment Topics

“Based on your performance today, what will you do differently next time”? Even though this was the last question the participants needed to answer on their evaluation, I also verbally asked the question to ensure a response. Again, the results are split with Holly and Carla suggesting more adjustment topics during their SD interventions, while Jess, Toby, and Andy suggested more adjustments during their CD interventions (Table 4.7). Carla suggested the greatest number of adjustment topics during her generalization phase, which makes intuitive sense. Carla originally learned to ride her bike using appropriate safety on the relatively deserted road outside her home. Her generalization sessions occurred on trails in a city park and on a city street, which prompted her frequent suggestions to make a stop, to walk her bike when the terrain was unstable, or to use a particular hand sign. Holly often suggested topics during the SD session that she observed or experienced during a CD intervention. She appeared to benefit from seeing or experiencing an activity at least once, before she adopted it as her own useful tool. She had difficulty coming up with ideas until she saw it once. Andy's adjustment topics during the CD session usually consisted of him saying, "I just want to practice next time; the exercises make me tired". Jess seemed to gain courage during the SD sessions so that during CD interventions she would ask for specific help like, "could I just practice diapering the baby"? In the end, it is unclear whether identifying and suggesting adjustment topics factored in to the participants' ability to initially achieve, later maintain, and finally to generalize their mobility skill steps into a new setting.

Mobility Skill Steps Maintained and Generalized

Only Holly, Andy, and Toby participated in both the maintenance and generalization phases of the study. Carla completed generalization without maintenance probes because her new applied setting was so geographically distant from her original setting. These three participants maintained a greater mean number of mobility skill steps than they achieved in any other condition, and generalized more skill steps in the new setting compared to baseline and the CD intervention. Maintenance and generalization data in Table 4.8 and Figure 4.19 clearly demonstrate that each participant made progress on his or her mobility goal, and some were able to maintain and generalize to a new setting.

Discussion summary. Considering the motor learning and autocorrelation discussion in Chapter Four, it is apparent and encouraging to note that all five participants initially learned a new and preferred mobility task in a familiar environment, regardless of intervention applied, but with slight advantage to the SD intervention. Four of the five participants who completed the entire study performed their learned mobility skills in the familiar environment without intervention, and three participants applied their newly learned mobility skills in an unfamiliar setting without intervention. These results are encouraging for physical therapists; but, what effect, if any, did the *Self-determined Learning Model of Instruction* have in the process?

Implications for Clinical Practice and Research

Small-n studies like this one embody simple methods for physical therapists to use to investigate the effectiveness of their interventions (Effgen & McEwen, 2007). Data derived from small-n studies like this one is meaningful even when only visual analysis of progress is considered. Newer methods for quantifying and augmenting visual analysis exist that strengthen the external validity of these studies, as demonstrated herein. This study demonstrated the value of small-n research to determine specific mobility goal outcomes for individuals with severe and multiple developmental disabilities. By using reliable methodology with iterative visual and quantitative data analysis to support the findings, results over time will have greater meaning and application. Collecting qualitative data in the form of our clinical notes further supports objective outcome measurements, and can steer the clinician toward alternative interventions that match the client's individual preferences and needs. Small-n research is ideally suited for measuring effects of customized treatments because therapy recipients serve as their own controls across time. Therapists can carefully control and manipulate intervention variables, as I did in this study, and analyze the outcome effects across time and settings. However, within this strength exists its biggest challenge for maintaining experimental rigor in terms of internal and external validity.

Study Challenges

The individually determined mobility goals and steps made for variability in target acquisition. That is, the participants worked on different goals, gained their mobility skill steps at varying rates, and required varied frequencies of intervention. Toby's difficult step analysis is testimony to the challenge that some steps provided for the participants, which suggests differences in step difficulty across the participants. The mobility goals and steps were not sufficiently comparable, and likely masked the observed differences between the SD and CD interventions.

Cognitive differences between the participants affected the reliability of the self-evaluation tool. Even though each participant's post-session evaluation was uniquely designed for their mobility goal, and the evaluation remained consistent across time and settings for each participant, the variability in cognitive abilities surrounding answering the evaluations was high. For example, there were times when Toby and Carla answered "yes" to almost all of his evaluation questions, with regard mostly to being finished than to evaluating his actual performance. Noting this during the session prompted me to re-ask the question in another way, again decreasing the validity of the evaluation tool.

Even though none of the participants were part of my existing therapy caseload, therapist as researcher introduced bias into the study. It is impossible to ignore the bias that exists when therapist and researcher are the same. Future studies should separate the researcher from the study implementation activities, specifically the interventions and assessments.

Internal Validity

Threats to internal validity in this multi-element study's design included instrumentation, measurement error, and interaction effects, primarily in terms of carry-over effects. Offering counterbalanced interventions and conducting no-treatment baseline probes throughout intervention helped to minimize the carryover effects. It is typical in small-n studies to observe learning effects, which remained strong in this study regardless of attempts to defeat.

Each participant's mobility goal and task steps were uniquely determined and defined, and each participant's target mobility goal encompassed ten measurable skill steps that comprised a unique measurement form. Although Holly, Andy, and Toby worked on a wheelchair transfer goal with similar task steps, these steps encompassed measurement criteria that matched their skill and support needs and were not identical to other participants' measurement criteria. Carla and Jess had distinctly different goals and task steps, bike riding and transfer with baby care, respectively. Inter-observer agreement (IOA) provided a measure of confidence that the target motor skills and task steps were clearly defined and remained clear throughout the course of the study (Table 3.15). IOA also ensured consistent measurement and data collection procedures so that changes in behaviors could not be attributed to measurement errors.

Fidelity of intervention was measured to ensure that the intervention distinctions remained intact. Although fidelity of intervention agreement was fairly high, there were a number of missed steps within each intervention procedure that were occasionally missed (Tables 3.17 and 3.18). It is highly likely that these missed steps contributed to the observed auto-correlated results. It is also possible that the insignificant findings surrounding the self-determination elements (self-initiated supports, self-evaluation, and adjustment topics) are attributable to insufficient distinction between the two interventions.

External validity

The multi-element design of this study allowed all participants to continue interventions without the need to withdraw to no-treatment baseline until generalization. However, this small-n design and variability in the participants, coupled with rampant serial dependency prevented valid comparison and parametric analysis needed for generalization. Utilizing the Percent of Non-overlapping Data in post-hoc analysis helped to diminish the effects of serial dependency in an effort to provide reliable effect determination, but no ability to generalize the findings. Replicating this small-n study to investigate the impact of the *SDLMI*, in addition to investigating its effect on motor skill development, will enhance generalizability of results over time for the physical therapy and special education professions.

Self-determined Physical Therapy Paradigm—Is it Worth the Effort?

PTs need to know if our interventions are effective in order to be reimbursed for treatments. Small-n studies like this one provide objective ways to measure progress. In this study, participants achieved most if not all of their identified mobility goals, and some made greater gains after participating in the SD intervention. Though the objective data revealed no particular benefits in terms of self-determination skills observed in either the SD or CD intervention, qualitative data and participant testimonials suggest that participants did learn and utilize self-determination skills. I believe the benefits for participants to learn and utilize self-determination skills within a physical therapy setting are well worth a PTs time and effort. By merely taking the time to mutually determine a goal, discuss progress toward the goal, enabling individuals to routinely self-evaluation progress toward their goals, and by acknowledging and reinforcing a person's ability to request supports or changes to a plan, physical therapists can help their clients to utilize self-determined approaches to achieve meaningful postsecondary work, education, or independent living goals.

Intervention Frequency and Duration.

When PTs consider implementing new programs or treatments, we always need to consider the relative cost of the intervention in terms of our time and benefit to the client. In this study, I found no significant difference in therapy session duration between the SD and CD interventions. Cost per treatment session is based on the average hourly rate that PTs earn when they work with individuals who have developmental disabilities in Oklahoma. The average hourly rate of pay for PTs is about $35 per hour, with a range from $25 to $51 per hour. Using the average of $35/hour, and breaking the cost down by minute, $35/60 = $.58/minute, Table 5.1 shows no significant difference between the SD and CD interventions on session length or cost.

Table 5.1

Average Duration (minutes) and Cost Per Session

Participant	SD	CD	SD Cost ($)	CD Cost ($)

Holly	45	41	26.00	24.00
Jess	40	47	23.00	27.00
Andy	50	53	29.00	31.00
Carla	57	54	33.00	31.00
Toby	48	46	28.00	27.00
Paired Sample Statistics based on Grand Means	*M* = 48 *SD* = 6.28	*M* = 48 *SD* = 5.36	*M* = $27.80 *SD* = 3.70	*M* = $28.00 *SD* = 3.00
	t(4) = .096, *p* = .928		*t*(4) = .167, *p* = .876	

If individuals with severe and multiple developmental disabilities learn to self-evaluate accurately and make changes in their plan to successfully achieve a new mobility skill, then implementing self-determined PT approaches seems worth the effort, and is likely to be reimbursable, especially if relevant mobility skills are achieved in the process.

PTs routinely choose a variety of modalities and treatments to help their clients gain motor goals, and hopefully these interventions have evidence backing their utility. Results from this study suggest that promoting a student-self-determined PT approach that utilized a model (*SDLMI*) with an established evidence base in educational, vocational, and minimally in related services, appears to be well worth the effort. At a minimum, participants gained relevant mobility goals at no higher cost than traditional clinician-directed interventions.

Recommendations for Future Research

The analysis from this study prompted a number of future research tracts. This study revealed that it is possible for individuals with severe and multiple disabilities to learn and practice relevant self-determination behaviors from the established *Self-determined Learning Model of Instruction.* Facilitating self-determined behaviors in these people did not disrupt or detract from their ability to achieve relevant and meaningful mobility skill steps, and it was no more costly to provide. During this study, individuals with severe and multiple developmental disabilities (SMDD) discussed and pursued personal goals that related to independent living, family and societal participation, and quality of life. These are qualities that embody the personal, societal, and environmental levels from the International Classification of Functioning, Disability and Health (ICF), as discussed in Chapter One.

Future research endeavors should investigate more systematic and efficient ways to implement and measure outcomes from a self-determined approach to intervention. Specific and quantifiable ways to teach self-determination skills within a therapy setting needs investigating. Choice making, planning, and self-evaluation are all critical features of the *SDLMI*, and relevant for individuals with SMDD who participate in physical therapy, or other aspects of life. Physical therapy, if provided within inclusive and relevant settings, provides a perfect venue for teaching self-determination skills to this vulnerable population, but further research on the impact of this approach in applied settings is needed.

Replicating this and similar small-n designs to test the effectiveness of self-determined intervention in physical therapy, and critically evaluating the resultant studies is the way to increase the evidence base within the physical therapy and self-determination bodies of knowledge. Additional research using small-n studies fits with the American Physical Therapy Association's revised research agenda (Goldstein, et al. 2011) to examine skill acquisition and motor development; examine the effectiveness and efficacy of interventions provided by therapists across relevant health domains; and examine the effect of interventions provided in combination with other behavioral interventions, such as the *SDLMI*.

The Rest of the Story…

Consider one last time the opening scenario of a young boy with cerebral palsy that opened this study: "I don't want to go to therapy any more - I just want to go home and play, like my friends. I've been doing this ALL—MY—LIFE, and going to therapy doesn't make me feel like a regular person" (Snow, 2006, p. 16). I suggested that this young boy exhibited strong self-determination in his efforts to control his life by choosing to *not* participate in physical therapy. I asked if he valued PT for achieving the things he wanted to do. The 'rest of the story' is informative.

This little boy, Benjamin Snow, is now 24 years old and about to graduate from college with a dual degree in political science and film/media studies. He arranges his schedule so that he can take things a little slower at college, takes online classes because they fit his learning style and energy level. He won a national competition by developing and submitting a short film on an issue he found important—the inaccurate onscreen portrayal of people with disabilities. Benjamin competed at the Sundance Film Festival, and later won an award at the Russia Film Festival in Moscow.

Benjamin's parents have always held high expectations for him. They helped him to learn that having a disability is not a barrier to success. Together, he and his parents came up with strategies that kept him totally included in his family, school, and community. Benjamin admits that he has had no formal physical therapy services since his frightful, yet brave exit at the age of six years. His mom states that if PTs had utilized self-determined approaches when her son was small, to recommend powered mobility, he might have developed even faster. Benjamin described therapy like this:

> Maybe they were doing that [therapy] from their perspective, and they were thinking they were doing what was right at the time, but to me it was about stretching and doing things that I didn't understand. It also seemed like it was important for them to tell me something like "the goal is so you can do this thing by this date." I think in a situation like that the goal becomes more important than the kid. But with all due respect, goals like that weren't important to me, because I didn't care about those things. I just wanted to be a kid like all my friends (B. Snow, personal communication, March 12, 2011).

Benjamin's PT focused on his limbs instead of his life. However, physical therapists are still occasionally part of his life. Benjamin does value physical therapists, and other related services providers because these are the professionals that help him obtain and maintain his assistive technology. Without this technology, he would not have independent mobility via a power wheelchair, succeed in college, and pursue his film making interests. He checks in with therapists when he requires interventions to keep living his "normal" life (B. Snow, personal communication, March 12, 2011).

Benjamin believes that he must be the one to determine the interventions that match and support his life goals and dreams. He is supported by his family, and sometimes by physical therapists, in these endeavors. Some would say that Benjamin achieved great things in spite of physical therapy. I believe we can help individuals with severe and multiple developmental disabilities like Benjamin achieve great things through self-determined physical therapy practices.

While it is up for review this year, the Declaration of Principle put forth by the World Confederation for Physical Therapy (WCPT) states: "The WCPT promotes the respect of the patients'/clients' dignity, integrity and *self-determination*" (WCPT, 2007, pg. 1). Physical therapists should take the WCPT's declaration to heart and investigate interventions that promote self-determination, and prevent learned helplessness. Therapists owe it to our patients/clients to provide interventions that promote integrity and self-determination just as we aim to improve mobility and function. Individuals with SMDD in this study wanted no less from their physical therapy programs, and achieved at least this much during the study.

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APPENDICES

APPENDIX A

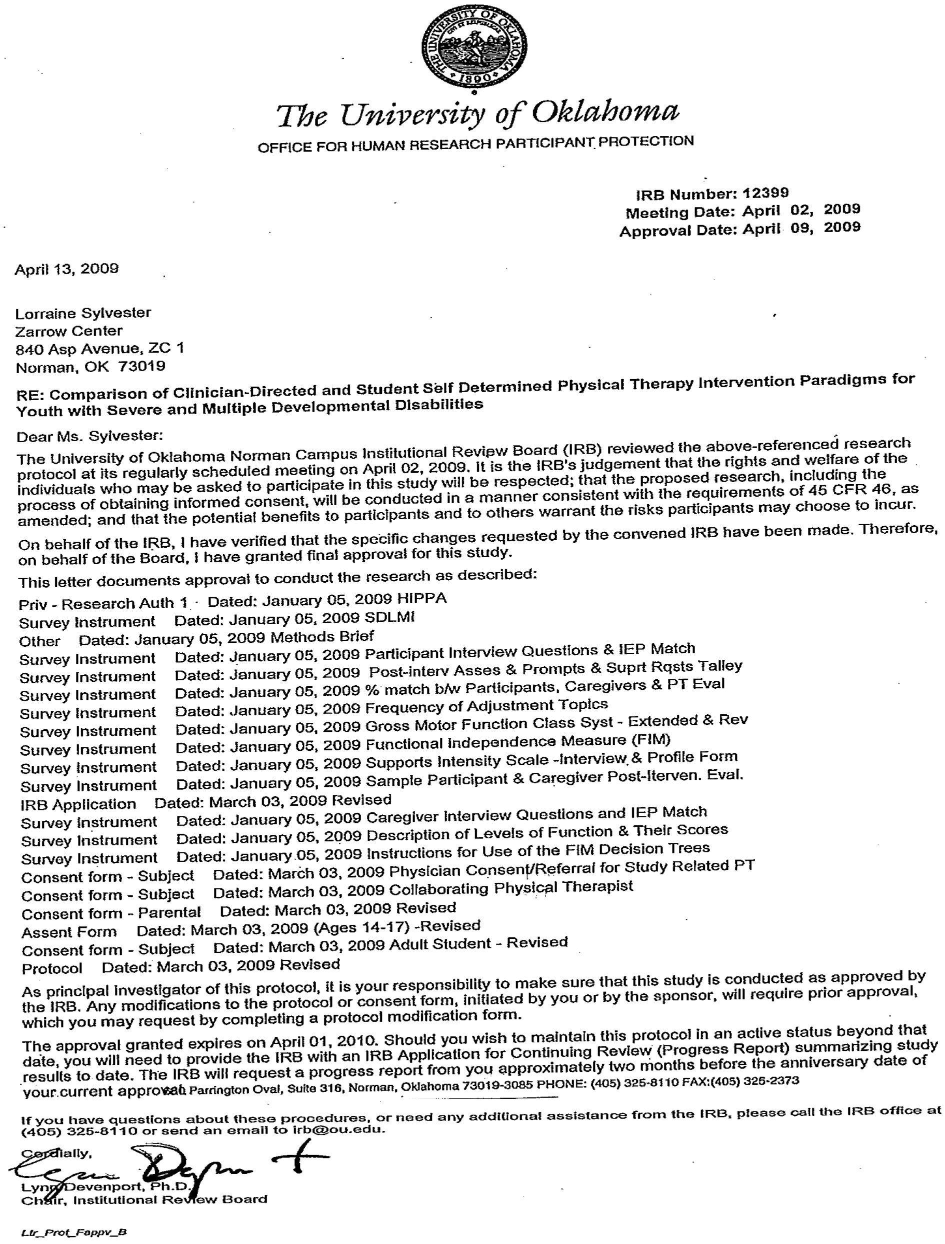
A1 University of Oklahoma Norman Campus Institutional Review Board Approval

A2 Authorization to Use or Disclose Protected Health Information for Research

A3 Consent Letters

- Student Assents
- Parent/Guardian Consent
- Adult Student (18 years of age and self-guardian) Consent
- Collaborating Physical Therapist Consent
- Physician Consent and Referral for Study-Related Physical Therapy Services

A1



The University of Oklahoma
OFFICE FOR HUMAN RESEARCH PARTICIPANT PROTECTION

IRB Number: 12399
Meeting Date: April 02, 2009
Approval Date: April 09, 2009

April 13, 2009

Lorraine Sylvester
Zarrow Center
840 Asp Avenue, ZC 1
Norman, OK 73019

RE: Comparison of Clinician-Directed and Student Self Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities

Dear Ms. Sylvester:

The University of Oklahoma Norman Campus Institutional Review Board (IRB) reviewed the above-referenced research protocol at its regularly scheduled meeting on April 02, 2009. It is the IRB's judgement that the rights and welfare of the individuals who may be asked to participate in this study will be respected; that the proposed research, including the process of obtaining informed consent, will be conducted in a manner consistent with the requirements of 45 CFR 46, as amended; and that the potential benefits to participants and to others warrant the risks participants may choose to incur.

On behalf of the IRB, I have verified that the specific changes requested by the convened IRB have been made. Therefore, on behalf of the Board, I have granted final approval for this study.

This letter documents approval to conduct the research as described:

Priv - Research Auth 1 Dated: January 05, 2009 HIPPA
Survey Instrument Dated: January 05, 2009 SDLMI
Other Dated: January 05, 2009 Methods Brief
Survey Instrument Dated: January 05, 2009 Participant Interview Questions & IEP Match
Survey Instrument Dated: January 05, 2009 Post-interv Asses & Prompts & Suprt Rqsts Talley
Survey Instrument Dated: January 05, 2009 % match b/w Participants, Caregivers & PT Eval
Survey Instrument Dated: January 05, 2009 Frequency of Adjustment Topics
Survey Instrument Dated: January 05, 2009 Gross Motor Function Class Syst - Extended & Rev
Survey Instrument Dated: January 05, 2009 Functional Independence Measure (FIM)
Survey Instrument Dated: January 05, 2009 Supports Intensity Scale -Interview & Profile Form
Survey Instrument Dated: January 05, 2009 Sample Participant & Caregiver Post-Iterven. Eval.
IRB Application Dated: March 03, 2009 Revised
Survey Instrument Dated: January 05, 2009 Caregiver Interview Questions and IEP Match
Survey Instrument Dated: January 05, 2009 Description of Levels of Function & Their Scores
Survey Instrument Dated: January 05, 2009 Instructions for Use of the FIM Decision Trees
Consent form - Subject Dated: March 03, 2009 Physician Consent/Referral for Study Related PT
Consent form - Subject Dated: March 03, 2009 Collaborating Physical Therapist
Consent form - Parental Dated: March 03, 2009 Revised
Assent Form Dated: March 03, 2009 (Ages 14-17) -Revised
Consent form - Subject Dated: March 03, 2009 Adult Student - Revised
Protocol Dated: March 03, 2009 Revised

As principal investigator of this protocol, it is your responsibility to make sure that this study is conducted as approved by the IRB. Any modifications to the protocol or consent form, initiated by you or by the sponsor, will require prior approval, which you may request by completing a protocol modification form.

The approval granted expires on April 01, 2010. Should you wish to maintain this protocol in an active status beyond that date, you will need to provide the IRB with an IRB Application for Continuing Review (Progress Report) summarizing study results to date. The IRB will request a progress report from you approximately two months before the anniversary date of your current approval.

Parrington Oval, Suite 316, Norman, Oklahoma 73019-3085 PHONE: (405) 325-8110 FAX:(405) 325-2373

If you have questions about these procedures, or need any additional assistance from the IRB, please call the IRB office at (405) 325-8110 or send an email to irb@ou.edu.

Cordially,

Lynn Devenport, Ph.D.
Chair, Institutional Review Board

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The University of Oklahoma®
OFFICE OF HUMAN RESEARCH PARTICIPANT PROTECTION - IRB

IRB Number: 12399
Approval Date: January 12, 2011

January 13, 2011

Lorraine Sylvester
Zarrow Center
338 Cate Center Drive, Room 190
Norman, OK 73019

RE: Comparison of Clinician-Directed and Student Self Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities

Dear Ms. Sylvester:

Thank you for completing and returning the IRB Application for Continuing Review (Progress Report) for the above-referenced protocol. You have indicated that this study is still active but closed to enrollment. The Institutional Review Board (IRB) Chair has reviewed and approved your Progress Report, and this memorandum is to extend protocol approval through January 11, 2012.

Please note that this approval does not include authorization to enroll additional participants. Reopening the study to new participant accrual will require prior approval from the IRB.

Please note that any modification to this protocol and/or consent form must be approved prior to its incorporation into study procedures. Submit amendment requests using the IRB Protocol Modification form which can be downloaded from the IRB web page.

Approximately two months prior to expiration of this approval, you will be contacted by IRB staff about procedures necessary to maintain this protocol in active status beyond the anniversary of the above-referenced approval date. If you have any questions about this protocol or if you need additional information, please do not hesitate to call the IRB office at (405) 325-8110 or send an email to irb@ou.edu.

Cordially,

Lynn Devenport, Ph.D.
Chair, Institutional Review Board

A2

UNIVERSITY OF OKLAHOMA – NORMAN CAMPUS
INSTITUTIONAL REVIEW BOARD

AUTHORIZATION TO USE or DISCLOSE PROTECTED HEALTH INFORMATION FOR RESEARCH

An additional Informed Consent Document
for Research Participation may also be required.

Title or Research Project: Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for YOuth with Severe and Multiple Developmental Disabilities

Principal Investigator: Lorraine Sylvester, PT, MS

IRB Number: 12399

Address: Zarrow Center for Learning Enrichment, 555 E. Constitution Street, SC Building 4, Suite 119, Norman, OK 73072-7820

Phone Number: 405-325-8951

If you decide to join this research project, University of Oklahoma (OU) researchers may use or share (disclose) information about you that is considered to be protected health information for their research. Protected health information will be called private information in this Authorization.

Private Information To be Used or Shared. Federal law requires that researchers get your permission (authorization) to use or share your private information. If you give permission, the researchers may use or share with the people identified in this Authorization any private information related to this research from your medical records and from any test results. Information, used or shared, may include all information relating to any tests, procedures, surveys, or interviews as outlined in the consent form, medical records and charts, name, address, telephone number, date of birth, race, and government-issued identification number.

Purposes for Using or Sharing Private Information. If you give permission, the researchers may use your private information to .

Other Use and Sharing of Private Information. If you give permission, the researchers may also use your private information to develop new procedures or

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commercial products. They may share your private information with the research sponsor, the OU Institutional Review Board, auditors and inspectors who check the research, and government agencies such as the Department of Health and Human Services (HHS). The researchers may also share your private information with .

Confidentiality. Although the research may report their findings in scientific journals or meetings, they will not identify you in their reports. The researchers will try to keep your information confidential, but confidentiality is not guaranteed. Any person or organization receiving the information based on this authorization could re-release the information to others and federal law would no longer protect it.

YOU MUST UNDERSTAND THAT YOUR PROTECTED HEALTH INFORMATION MAY INCLUDE INFORMATION REGARDING ANY CONDITIONS CONSIDERED AS A COMMUNICABLE OR VENEREAL DISEASE WHICH MAY INCLUDE, BUT ARE NOT LIMITED TO, DISEASES SUCH AS HEPATITIS, SYPHILIS, GONORRHEA, AND HUMAN IMMUNODEFICIENCY VIRUS ALSO KNOWN AS ACQUIRED IMMUNE DEFICIENCY SYNDROME (AIDS).

Voluntary Choice. The choice to give OU researchers permission to use or share your private information for their research is voluntary. It is completely up to you. No one can force you to give permission. However, you must give permission for OU researchers to use or share your private health information if you want to participate in the research and if you revoke your authorization, you can no longer participate in this study.

Refusing to give permission will not affect your ability to get routine treatment or health care from OU.

Revoking Permission. If you give OU researchers permission to use or share your private information, you have a right to revoke your permission whenever you want. However, revoking your permission will not apply to information that the researchers have already used, relied on, or shared.

End of Permission. Unless you revoke it, permission for OU researchers to use or share your private information for their research will . You may revoke your permission at any time by writing to:

Privacy Official
University of Oklahoma
1000 Stanton L. Young Blvd., STE 221,
Oklahoma City, OK 73117
If you have questions, call: (405) 271-2511

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Giving Permission. By signing this form, you give OU and OU's researchers led by Lorraine Sylvester, PT, MS, permission to share your private information for the research project called Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for YOuth with Severe and Multiple Developmental Disabilities.

Subject Name:

______________________________ ____________________

Signature of Subject Date
Or parent if Subject is a Child

Or

______________________________ ____________________

Signature of Legal Representative** Date

**If signed by a legal Representative of the Subject, provide a description of the relationship to the Subject and the Authority to Act as Legal Representative:

____

OU may ask you to produce evidence of your relationship.

A signed copy of this form must be given to the Subject or the Legal Representative at the time this signed form is provided to the researcher or his representative.

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OU-NC IRB

APPROVAL
APR 0 1 2010
EXPIRES

University of Oklahoma
Institutional Review Board
Informed Consent to Participate in a Research Study
Student Assent (14-17 years of age)

Project Title:	Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities
Principal Investigator:	Lorraine Sylvester, PT, MS
Department:	Educational Psychology, Zarrow Center for Learning Enrichment

You are being asked to volunteer for this research study because you have severe or multiple developmental disabilities, you currently receive or have received physical therapy services at school, at home, or in your community, you have or had an IEP in school, you are between 14 and 22 years old, and you are currently planning for your adult life after you graduate from high school. This study is being conducted at either your home, your school, or in another location you choose.

I will review as you read this form. Please ask any questions that you have before agreeing to take part in this study.

Purpose of the Research Study

The purpose of this study is:

To find out how well you can learn a mobility skill when you participate in two different styles of physical therapy; one style is directed by the therapist in all ways, and may be like what you do now in physical therapy. The other style is more directed by you, but with guidance from the therapist. I will use a program called the *Self-Determined Learning Model of Instruction* to help you understand and have more control over what happens in your physical therapy session. Does one sort of PT help you achieve your mobility skills better? Can you perform your mobility skill in your familiar environment and in a new setting after treatment is over? You will be helping me complete my doctoral dissertation research.

Number of Participants

There will be a total of five youth with disabilities like you and their caregivers participating in this study (total of 10), but you will work only with me.

Procedures

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

1) Interview: With your caregiver, you will talk with me at the beginning of the study, and again at the end of the study for at least 1 hour, but maybe 2 hours at the most. During these interviews we will review your IEP document if you have one to gather information to include age, disability category, and goals/objectives that relate to physical therapy and postsecondary transition planning, and help us identify relevant mobility skills that you want to pursue at home and in another setting you choose.

2) Allow me to video & audio record the interviews and intervention sessions: Video recording ensures accurate recording of your comments and goals, and it enables an independent observer to make sure that I do all study activities correctly.

3) Participate in pre-study tests: I conducted three mobility tests that will give a picture of your mobility skills and support needs prior to beginning the study. Some of the tests will be done as part of the interview in #1 above. You may recognize these tests from previous PT sessions, and they should take no more than 2 hours to complete (total for all three tests).

4) You will participate in daily physical therapy sessions. These sessions will be like what you experience (d) in school or in your community physical therapy. You will work on the mobility skill you choose before the study starts. I will provide different physical therapy methods that will help you achieve your mobility skill. One method, called clinician-directed (CD), is a standard and probably familiar PT method to help you achieve your mobility goal. I will determine all of the activities to do and their order in which we do them during the session. I will not talk much about what we do. The other method, called student-directed (SD) will help you understand and take more control of your PT session, allow you to choose physical therapy activities and the order you want to do them so you can achieve your mobility skill. In the SD sessions, I will help you understand how your mobility skill will be used in post-secondary life, and you will evaluate your own skill performance. Physical therapy sessions will occur daily, for no longer than 90 minutes per session, scheduled at times that are convenient for you. Initial therapy sessions will be provided in your home (or other familiar setting you choose). At the end of the study, you will choose a new (or less familiar) community setting where you will use the mobility skill you've been learning.

5) Complete a post-intervention evaluation at the end of each therapy session. You will tell me how well you think you accomplished your

mobility skills during each session. This evaluation should take you no more than 10 minutes to do. You can have help to understand the questions and to record your answers.

Length of Participation

Pre- and post-study interviews will last no longer than 2 hours. Pre-study assessments should take no more than 2 hours to complete. Physical therapy interventions will happen daily, for 90 minutes per session. You will be active for about 60 to 80 minutes during the PT session, and you will complete the self-evaluation in about 10 minutes at the end of each session. The entire study will take about two months to finish.

This study has the following risks:

You will not be harmed in any way by participating in this study. There are no greater risks than what you currently (or used to) experience in physical therapy.

Benefits of being in the study are

There are no known benefits for your participation in this study.

Alternate Procedures

None

Confidentiality

In published reports, there will be no information included that will make it possible to identify you without your permission. Research records will be stored securely and only approved researchers will have access to the records. Unless you specify otherwise, all data and video/audio recordings will be held for 1 year after the study is completed. At that time, all video recordings and data will be destroyed.

There are organizations that may inspect and/or copy your research records for quality assurance and data analysis. These organizations include U.S. Department of Education, Office of Special Education Programs, and the OU Institutional Review Board.

Compensation

At the end of each week of your participation in the study, you and your caregiver (as a team) will receive a $10.00 gift card for your time and participation in this study. If you choose to withdraw from the study mid-week, you will still receive a $10.00 gift card for that week if you participated at all.

Voluntary Nature of the Study

Participation in this study is voluntary. If you withdraw or say no to participation, you will not be punished or lose benefits or services unrelated to the study. If you decide to participate, you don't have to answer all questions, and you can stop at any time.

Waivers of Elements of Confidentiality

Your name will not be linked with anything you say unless you specifically agree to be identified. Please select all of the following options that apply:

_____ I consent to being quoted directly.
_____ I do not consent to being quoted directly.
_____ I give consent to quote my child directly.
_____ I do not give consent to quote my child directly.
_____ I consent to the use of video and audio recordings should study findings be presented or published.

Video with Audio Recording of Study Activities

To assist with accurate recording of your responses and to make sure that I provide intervention in the way that is planned, interviews will be video recorded. You have the right to refuse recording without penalty. Please select either/both of the following options if they apply.

I agree/assent to video recording of study activities. Yes No
(circle one)

I agree/assent to audio recording study activities. Yes No
(circle one)

Interview

I agree to talk with Lorraine Sylvester about my current mobility skills and needed supports and physical therapy programs as they relate to transition planning and adult outcome achievement. Yes No (circle one)

IEP Document Review

If I have a recent IEP, I agree to let Lorraine Sylvester review my IEP to get information about my education and PT programs, and to review my goals and transition planning activities as written. Yes No (circle one)

CONTACTS AND QUESTIONS

If you have concerns or complaints about the research, you can contact Lorraine Sylvester at 405-325-8951, or contact me by e-mail at lorraine.sylvester-1@ou.edu. Because I am a doctoral student, you may also contact my advisor, James E. Martin, PhD at 405-325-8951, or e-mail him at jemartin@ou.edu.

If you have any questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

Contact the researcher if you have questions or if you have experienced a research-related injury.

You will be given a copy of this information to keep for your records. If you are not given a copy of this consent form, please request one.

Statement of Assent

I have read the above information. I have asked questions and have received satisfactory answers. I consent to participate in the study.

____

Student Signature Date

SIGNATURE OF PERSON CONDUCTING ASSENT DISCUSSION

I have explained the study to ________________________(*print name of student here*) in language he/she can understand, and the child has agreed to be in the study. I have given a copy of this information to the participant to keep.

____ ________________

Signature of Person Conducting Assent Discussion Date

____

Name of Person Conducting Assent Discussion (*print*)

University of Oklahoma
Institutional Review Board
Informed Consent to Participate in a Research Study
Parent/Guardian Consent

Project Title:	Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities
Principal Investigator:	Lorraine Sylvester, PT, MS
Department:	Educational Psychology, Zarrow Center for Learning Enrichment

You and your child are being asked to volunteer for this research study because your child has severe or multiple developmental disabilities and currently receives (or has received) physical therapy services at school or in the community; your child had or has an IEP at school; your child is between 14 and 22 years of age; and you and your child are involved in planning for postsecondary transition to employment, education, or adult living situations. This study will be conducted in your home, your child's school, or another location that you choose.

Please read this form and ask any questions that you and your child may have before agreeing to take part in this study.

Purpose of the Research Study

The purpose of this study is to explore whether utilizing an established self-determination model, the *Self-Determined Learning Model of Instruction* during PT interventions will help your child gain functional mobility skills, compared to when your child participates in more typical clinician (PT) directed therapy sessions. I also want to see if your child can maintain newly learned mobility skills in a familiar setting, and perform these mobility skills in a new setting that you choose. This study is part of the requirements for my doctoral dissertation.

Number of Participants

There will be about five other youth with severe and multiple developmental disabilities, and their caregivers participating in this study (total of 10), but you and your child will work only with me.

Procedures

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

1) Interview: You and your child will talk with me at the beginning of the study, and again at the end of the study for at least 1 hour, but maybe 2 hours at the most. During these interviews we will review your child's IEP document (if you have one) to gather information including age, disability category, and goals/objectives that relate to physical therapy and postsecondary transition planning, and help us identify relevant mobility skills that you and your child want to pursue at home and in another setting you choose.

2) Allow video & audio recording the interviews and intervention sessions: Video recording ensures accurate recording of you and your child's comments and goals, and it enables an independent observer to ensure that I am collecting data correctly, and performing interventions as planned.

3) Participate in pre-study assessments: I conducted three mobility tests that will give a complete picture of your child's mobility skills and support needs prior to beginning the study. Some of the assessments will be accomplished as part of the interview in #1 above. These tests may be familiar from previous PT sessions and should take no more than 2 hours to complete (total for all three assessments).

4) You and your child will participate in daily physical therapy interventions. These sessions will be like what you experience (d) in school or in your community physical therapy. Your child will work on the mobility skill identified before the study starts. I will provide different physical therapy methods that will help your child achieve his/her mobility skill. One method, called clinician-directed (CD), is a standard method of providing physical therapy to help your child achieve his/her mobility goal. I will determine all of the activities to do and their order of implementation during the session. I will not talk much about the intervention. The other method, called student-directed (SD) will teach your child ways to direct the therapy session, to know what he/she wants or can do in physical therapy to achieve a mobility skill, identify ways to achieve the mobility skill, relate the mobility skill to something your child wants to do in post-secondary life, and evaluate his/her own performance on the skill. Your child will get to choose from a menu of activities and their order of implementation during the session. Physical therapy interventions will occur daily, for no longer than 90 minutes per session, scheduled at times that are convenient for you and your child. Initial therapy sessions will be provided in your home (or other familiar setting you and your child choose). At the end of this phase of the study, you and your child will choose a new (or less familiar) community setting where you will use the mobility skill you've been learning.

5) A post-intervention evaluation at the end of each therapy session. You and your child will complete an evaluation about the mobility skills he/she accomplished during that session. You will complete your evaluation about how you think your child completed the mobility skills. This post-intervention evaluation should take no more than 10 minutes to complete at the end of each session. Your child can receive help to record answers on the self-evaluation form.

Length of Participation

The pre- and post-study interviews will last no longer than 2 hours. Pre-study assessments should take no more than 2 hours to complete. Physical therapy interventions will happen daily, for 90 minutes per session. About 60 to 80 minutes will be active physical therapy intervention, with about 10 minutes at the end allowed for session evaluation. The entire study will take about two months to finish.

This study has the following risks:

Neither you nor your child will be harmed in any way by participating in this study. Risks involved by your participation are no greater than when your child participates (d) in physical therapy sessions at school or in your community.

Benefits of being in the study are

There are no known benefits to you or your child's participation in this study.

Injury

In case of injury or illness resulting from this study, emergency medical treatment is available. However, you or your insurance company may be expected to pay the usual charge from this treatment. The University of Oklahoma Norman Campus has set aside no funds to compensate you in the event of injury.

Confidentiality

In published reports, there will be no information included that will make it possible to identify you or your child without your permission. Research records will be stored securely and only approved researchers will have access to the records. Unless you specify otherwise, all data and video/audio recordings will be held for 1 year after the study is completed. At that time, all video recordings and data will be destroyed.

There are organizations that may inspect and/or copy your research records for quality assurance and data analysis. These organizations include U.S. Department of Education, Office of Special Education Programs, and the OU Institutional Review Board.

Compensation (Removed reference to free physical therapy.)

At the end of each week of you and your child's participation in the study, you and your child (as a team) will receive a $10.00 gift card for your time and participation in this study. If you or your child chooses to withdraw from the study mid-week, you will still receive a $10.00 gift card for that week if you participated at all.

Voluntary Nature of the Study

Participation in this study is voluntary. If you or your child withdraws or declines participation, neither you nor your child will be penalized or lose benefits or services unrelated to the study. If you or your child decides to participate, you and your child may decline to participate in physical therapy sessions or activities, decline to answer any assessment or questions, and you can choose to withdraw at any time.

Waivers of Elements of Confidentiality

Neither your name, nor your child's name will be linked with your responses unless you specifically agree to be identified. Please select all of the following options that apply.

_____ I consent to being quoted directly.

_____ I do not consent to being quoted directly.

_____ I give consent to quote my child directly.

_____ I do not give consent to quote my child directly.

_____ I consent to the use of video and audio recordings should study findings be presented or published.

_____ I consent to having my name reported with quoted material.

_____ I do not consent to having my name reported with quoted material.

Request for record information

If you approve, your child's confidential records will be used as data for this study. The records that will be used include your child's Individual Education Program, or IEP. These records will be used for the following purpose(s): to get needed demographic information and to review your child's PT programs, goals, and transition planning activities as written.

_____ I agree for my child's IEP records to be accessed and used for the purposes described above.

_____ I do not agree for my child's IEP records to be accessed for use as research data.

Audio Recording of Study Activities

To assist with accurate recording of participant responses, interviews and physical therapy sessions may be recorded on an audio recording device while video recording. You have the right to refuse to allow such recording without penalty. Please select one of the following options.

I consent to audio recording. ___ Yes ___ No.

Video Recording of Study Activities

To assist with accurate recording of your responses, interviews and physical therapy sessions may be recorded on a video recording device. You have the right to refuse to allow such recording. Please select one of the following options:

I consent to video recording. ___ Yes ___ No.

Physical Therapy Interventions

I agree to participate, and allow my child to participate in all physical therapy intervention sessions and related assessment activities.

Yes No (circle one)

Contacts and Questions

If you have concerns or complaints about the research, you can contact Lorraine Sylvester at 405-325-8951, or contact me by e-mail at lorraine.sylvester-1@ou.edu. Because I am a doctoral student, you may also contact my advisor, James E. Martin, PhD., at 405-325-8951 or e-mail him at jemartin@ou.edu.

If you have any questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

Contact the researcher if you have questions or if you have experienced a research-related injury.

You will be given a copy of this information to keep for your records. If

you are not given a copy of this consent form, please request one.

Statement of Consent

I have read the above information. I have asked questions and have received satisfactory answers. I consent and give my consent for my child to participate in the study.

Parent/Guardian Signature Date

University of Oklahoma
Institutional Review Board
Informed Consent to Participate in a Research Study
Adult Student (18 years of age and self-guardian)

Project Title:	Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities
Principal Investigator:	Lorraine Sylvester, PT, MS
Department:	Educational Psychology, Zarrow Center for Learning Enrichment

You are being asked to volunteer for this research study because you have severe or multiple developmental disabilities, you currently receive or have received physical therapy services at school, at home, or in your community, you have or had an IEP in school, you are between 14 and 22 years old, and you are currently planning for your adult life after you graduate from high school. This study is being conducted at either your home, your school, or in another location you choose, and one of your parents or guardians will be present.

Please read this form and ask any questions that you may have before agreeing to take part in this study.

Purpose of the Research Study
The purpose of this study is to find out how well you can learn a mobility skill when you participate in two different styles of physical therapy. One style is directed by the therapist in all ways, and may be like what you do now in physical therapy. The other style is more directed by you, but with guidance from the therapist. I will use a program called the *Self-Determined Learning Model of Instruction* to help you understand and have more control over what happens in your physical therapy session. Does one sort of PT help you achieve your mobility skills better? Can you perform your mobility skill in your familiar environment and in a new setting after treatment is over? You will be helping me complete my doctoral dissertation research.

Number of Participants
There will be a total of five youth with disabilities like you and their caregivers participating in this study (total of 10 people), but you will work only with me.

Procedures
If you agree to be in this study, you will be asked to do the following:

1) Interview: With your caregiver, you will talk with me at the beginning of the study, and again at the end of the study for at least 1 hour, but maybe 2 hours at the most. During these interviews we will review your IEP document if you have one to gather information to include age, disability category, and goals/objectives that relate to physical therapy and postsecondary transition planning, and help us identify relevant mobility skills that you want to pursue at home and in another setting you choose.

2) Allow me to video with audio recording the interviews and intervention sessions: Video recording ensures accurate recording of your comments and goals, and it enables an independent observer to make sure that I do all study activities correctly.

3) Participate in pre-study tests: I conducted three mobility tests that will give a picture of your mobility skills and support needs prior to beginning the study. Some of the tests will be done as part of the interview in #1 above. You may recognize these tests from previous PT sessions, and they should take no more than 2 hours to complete (total for all three tests).

4) You will participate in daily physical therapy sessions. These sessions will be like what you experience (d) in school or in your community physical therapy. You will work on the mobility skill you choose before the study starts. I will provide different physical therapy methods that will help you achieve your mobility skill. One method, called clinician-directed (CD), is a standard and probably familiar PT method to help you achieve your mobility goal. I will determine all of the activities to do and their order in which we do them during the session. I will not talk much about what we do. The other method, called student-directed (SD) will help you understand and take more control of your PT session, allow you to choose physical therapy activities and the order you want to do them so you can achieve your mobility skill. In the SD sessions, I will help you understand how your mobility skill will be used in post-secondary life, and you will evaluate your own skill performance. Physical therapy sessions will occur daily, for no longer than 90 minutes per session, scheduled at times that are convenient for you. Initial therapy sessions will be provided in your home (or other familiar setting you choose). At the end of the study, you will choose a new (or less familiar) community setting where you will use the mobility skill you've been learning.

5) Complete a post-intervention evaluation at the end of each therapy session. You will tell me how well you think you accomplished your mobility skills during each session. This evaluation should take you no more than 10 minutes to do. You can have help to understand the questions and to record your answers.

Length of Participation

Pre- and post-study interviews will last no longer than 2 hours. Pre-study assessments should take no more than 2 hours to complete. Physical therapy interventions will happen daily, for 90 minutes per session. You will be active for about 60 to 80 minutes during the PT session, and you will complete the self-evaluation in about 10 minutes at the end of each session. The entire study will take about two months to finish.

This study has the following risks:

You will not be harmed in any way by participating in these study activities. There are no greater risks than what you currently (or used to) experience in physical therapy.

Benefits of being in the study are

There are no known benefits of participation in this study.

Injury

In case of injury or illness resulting from this study, emergency medical treatment is available. However, you or your insurance company may be expected to pay the usual charge from this treatment. The University of Oklahoma Norman Campus has set aside no funds to compensate you in the event of injury.

Confidentiality

In published reports, there will be no information included that will make it possible to identify you without your permission. Research records will be stored securely and only approved researchers will have access to the records. Unless you specify otherwise, all data and video/audio recordings will be held for 1 year after the study is completed. At that time, all video recordings and data will be destroyed.

There are organizations that may inspect and/or copy your research records for quality assurance and data analysis. These organizations include the U.S. Department of Education, Office of Special Education Programs and the OU Institutional Review Board.

Compensation (removed reference to free physical therapy)

At the end of each week of your participation in the study, you and your caregiver (as a team) will receive a $10.00 gift card for your time and participation in this study. If you choose to withdraw from the study mid-week, you will still receive a $10.00 gift card for that week if you participated at all. (I removed reference to free physical therapy).

Voluntary Nature of the Study

Participation in this study is voluntary. If you withdraw or decline participation, you will not be penalized or lose benefits or services unrelated to the study. If you decide to participate, you may decline to answer any question and may choose to withdraw at any time.

Waivers of Elements of Confidentiality

Your name will not be linked with your responses unless you specifically agree to be identified. Please select one of the following options

_____ I consent to being quoted directly.

_____ I do not consent to being quoted directly.

_____ I consent to having my name reported with quoted material.

_____ I do not consent to having my name reported with quoted material

Request for record information

If you approve, your confidential records will be used as data for this study. The records that will be used include (your recent Individualized Education Program, or IEP). These records will be used for the following purpose(s): to get information about your education and PT programs, and to review your goals and transition planning activities as written.

_____ I agree for my IEP records to be accessed and used for the purposes described above.

_____ I do not agree for my IEP records to be accessed for use as research data.

Audio Recording of Study Activities

To assist with accurate recording of participant responses, interviews and interventions may be recorded on an audio recording device during video taping. You have the right to refuse to allow such recording without penalty. Please select one of the following options.

I consent to audio recording. ___ Yes ___ No.

Video Recording of Study Activities

To assist with accurate recording of your responses, interviews and therapy sessions may be recorded on a video recording device. You have the right to refuse to allow such recording. Please select one of the following options:

I consent to video recording. ___ Yes ___ No.

Interview

I agree to talk with Lorraine Sylvester about my current mobility skills and needed supports and physical therapy programs as they relate to transition planning and adult outcome achievement. Yes No (circle one)

Physical Therapy Interventions

I agree to participate, and allow my child to participate in all physical therapy intervention sessions and related assessment activities.

Yes No (circle one)

Contacts and Questions

If you have concerns or complaints about the research, you can contact the Principle Investigator, Lorraine Sylvester at 405-325-8951, or contact me by e-mail at lorraine.sylvester-1@ou.edu. Because I am a doctoral student, you may also contact my advisor, James E. Martin, PhD at 405-325-8951, or e-mail him at jemartin@ou.edu.

If you have any questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

Contact the researcher(s) if you have questions or if you have experienced a research-related injury.

If you have any questions about your rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

You will be given a copy of this information to keep for your records. If you are not given a copy of this consent form, please request one.

Statement of Consent

I have read the above information. I have asked questions and have received satisfactory answers. I consent to participate in the study.

Signature	Date

University of Oklahoma
Institutional Review Board
Informed Consent to Participate in a Research Study
Collaborating Physical Therapist

Project Title:	Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities
Principal Investigator:	Lorraine Sylvester, PT, MS
Department:	Educational Psychology, Zarrow Center for Learning Enrichment

NOTE: ***You, the collaborating physical therapist, are not being asked to participate in this study, only to be aware and consent to additional physical therapy services that I will provide for your patient, and to facilitate communication with your patient's referring physician. Your patient and his/her caregiver have read and signed consent forms allowing their participation in this study. All information below is the same information provided to your patient, his/her caregiver, and your patient's referring physician.***

Your patient and his/her caregiver are being asked to volunteer for this research study because your patient has severe or multiple developmental disabilities and currently receives (or has received) physical therapy services at school or in the community; your patient had or has an IEP at school; your patient is between 14 and 22 years of age; and your patient is involved in planning for postsecondary transition to employment, education, or adult living situations. This study will be conducted in your patient's home, school, or another location that your patient and his caregiver choose. If your patient currently receives physical therapy services by a licensed physical therapist, he or she has agreed to let me work with your patient too. Because your patient already has a physical therapist, I will not bill for any of my physical therapy services during this study. Your consent acknowledges that you will continue to see your patient as usual, and that I will also see your patient for physical therapy services. I will not bill for my additional physical therapy services during this study. You will help me to maintain contact with your patient's referring physician.

Please read this form and ask any questions that you may have before agreeing to your patient's participation in this study.

Purpose of the Research Study

The purpose of this study is to explore whether utilizing an established self-determination model, the *Self-Determined Learning Model of Instruction* during PT interventions will help your patient gain functional mobility skills, compared to when your patient participates in more typical clinician (PT) directed therapy sessions. I also want to see if your patient can maintain newly learned mobility skills in a familiar setting, and perform these mobility skills in a new setting that you choose. This study is part of the requirements for my doctoral dissertation.

Number of Participants

There will be about five other youth with severe and multiple developmental disabilities, and their caregivers participating in this study (total of 10), but your patient will work only with me.

Procedures

If you agree to let your patient be in this study, he/she will be asked to do the following:

1) Interview: Your patient and his caregiver will talk with me at the beginning of the study, and again at the end of the study for at least 1 hour, but maybe 2 hours at the most. During these interviews we will review your patient's IEP document (if he/she has one) to gather information including age, disability category, and goals/objectives that relate to physical therapy and postsecondary transition planning, and help us identify relevant mobility skills that your patient and his caregiver want to pursue at home and in another setting you choose.

2) Allow video & audio recording the interviews and intervention sessions: Video recording ensures accurate recording of your patient's comments and goals, and enables an independent observer to ensure that I am collecting data correctly, and performing interventions as planned.

3) Participate in pre-study assessments: I conducted three mobility tests that will give a complete picture of your patient's mobility skills and support needs prior to beginning the study. Some of the assessments will be accomplished as part of the interview in #1 above. These tests may be familiar from previous PT sessions and should take no more than 2 hours to complete (total for all three assessments).

4) Your patient and his/her caregiver will participate in daily physical therapy interventions. These sessions will be like what the patient experience (d) in school or in your community physical therapy. Your patient will work on the mobility skill identified before the study starts. I will provide different physical therapy methods that will help your patient achieve his/her mobility skill. One method, called clinician-directed (CD), is a standard method of providing physical therapy to help your patient achieve his/her mobility goal. I will determine all of

the activities to do and their order of implementation during the session. I will not talk much about the intervention. The other method, called student-directed (SD) will teach your patient ways to direct the therapy session, to know what he/she wants or can do in physical therapy to achieve a mobility skill, identify ways to achieve the mobility skill, relate the mobility skill to something your patient wants to do in post-secondary life, and evaluate his/her own performance on the skill. Your patient will get to choose from a menu of activities and their order of implementation during the session. Physical therapy interventions will occur daily, for no longer than 90 minutes per session, scheduled at times that are convenient for your patient. Initial therapy sessions will be provided in your patient's home (or other familiar setting your patient chooses). At the end of this phase of the study, your patient will choose a new (or less familiar) community setting where he/she will use the mobility skill they've been learning.

5) <u>A post-intervention evaluation</u> at the end of each therapy session. Your patient will complete an evaluation about the mobility skills he/she accomplished during that session. Your patient and his/her caregiver will complete an evaluation about how they think your patient completed the mobility skills. This post-intervention evaluation should take no more than 10 minutes to complete at the end of each session. Your patient can receive help to record answers on the self-evaluation form.

Length of Participation

The pre- and post-study interviews will last no longer than 2 hours. Pre-study assessments should take no more than 2 hours to complete. Physical therapy interventions will happen daily, for 90 minutes per session. About 60 to 80 minutes will be active physical therapy intervention, with about 10 minutes at the end allowed for session evaluation. The entire study will take about two months to finish.

This study has the following risks:

Your patient will not be harmed in any way by participating in this study. Risks involved in participation are no greater than when your patient participates (d) in physical therapy sessions at school or in your community.

Benefits of being in the study are

There are no known benefits to your patient's participation in this study.

Injury

In case of injury or illness resulting from this study, emergency medical treatment is available. However, your patient's insurance company may be expected to pay the usual charge from this treatment. The University of Oklahoma Norman Campus has set aside no funds to compensate you in the event of injury.

Confidentiality

In published reports, there will be no information included that will make it possible to identify you or your patient without your permission. Research records will be stored securely and only approved researchers will have access to the records. Unless your patient specifies otherwise, all data and video/audio recordings will be held for 1 year after the study is completed. At that time, all video recordings and data will be destroyed.

There are organizations that may inspect and/or copy these research records for quality assurance and data analysis. These organizations include U.S. Department of Education, Office of Special Education Programs, and the OU Institutional Review Board.

Compensation

At the end of each week of your patient's participation in the study, your patient and caregiver (as a team) will receive a $10.00 gift card for their time and participation in this study. If your patient chooses to withdraw from the study mid-week, he/she will still receive a $10.00 gift card for that week if he/she participated at all.

Voluntary Nature of the Study

Your patient's participation in this study is voluntary. If your patient withdraws or declines participation, your patient will not be penalized or lose benefits or services unrelated to the study. If your patient decides to participate, he/she may decline to participate in physical therapy sessions or activities, decline to answer any assessment or questions, and he/she can choose to withdraw at any time.

Waivers of Elements of Confidentiality

Neither your name, nor your patient's name will be linked with your patient's responses unless your patient specifically agrees to be identified. Your name will not be linked to your patient.

Request for record information

Your patient has agreed to allow me to review his/her Individual Education
Program
(IEP). I will not seek any other information from you for the study unless your
patient
needs me to seek for such information. I need no information from you.

Audio Recording of Study Activities

Your patient as agreed to allow me to audio record as I video record our interview and therapy sessions. I will not audio record you.

Video Recording of Study Activities

Your patient has agreed to allow me to video record our interview and therapy sessions. I will not video record you if you are present.

Physical Therapy Interventions

Your patient has agreed to participate in study-related physical therapy interventions. You may be present for study-related interventions, but you do not have to be present unless your patient requests your presence.

Contacts and Questions

If you have concerns or complaints about the research, you can contact Lorraine Sylvester at 405-325-8951, or contact me by e-mail at lorraine.sylvester-1@ou.edu. Because I am a doctoral student, you may also contact my advisor, James E. Martin, PhD., at 405-325-8951 or e-mail him at jemartin@ou.edu.

If you have any questions about your patient's rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

Your patient was instructed to contact the researcher if you have questions or if you have experienced a research-related injury.

You and your patient will be given a copy of this information to keep for your records. If you are not given a copy of this consent form, please request one.

Statement of Consent and Referral for Study-related Physical Therapy Services

I have read the above information. I have asked questions and have received satisfactory answers. I give my consent for my patient to participate in study-related physical therapy services. I am aware that I will continue to provide my patient with billable physical therapy services, and that the study-related physical therapist will not bill for her services.

I agree to maintain communication with my patient's referring physician to gain referral for study-related physical therapy interventions.

_______ Yes _____ No

Current Physical Therapist's Signature Date

Current Physical Therapist's Name (Print)

University of Oklahoma
Institutional Review Board
Informed Consent to Participate in a Research Study

Physician Consent/Referral for Study-Related Physical Therapy Services

Project Title:	Comparison of Clinician-Directed and Student-Self-Determined Physical Therapy Intervention Paradigms for Youth with Severe and Multiple Developmental Disabilities
Principal Investigator:	Lorraine Sylvester, PT, MS
Department:	Educational Psychology, Zarrow Center for Learning Enrichment

NOTE: ***You, the referring physician, are not being asked to participate in this study, only to be aware and consent to/refer for additional physical therapy services for your patient. Your patient and his/her caregiver have read and signed consent forms allowing their participation in this study. All information below is the same information provided to your patient, his/her caregiver, and his/her current physical therapist.***

Your patient and his/her caregiver are being asked to volunteer for this research study because your patient has severe or multiple developmental disabilities and currently receives (or has received) physical therapy services at school or in the community; your patient had or has an IEP at school; your patient is between 14 and 22 years of age; and your patient is involved in planning for postsecondary transition to employment, education, or adult living situations. This study will be conducted in your patient's home, school, or another location that your patient and his caregiver choose. If your patient currently receives physical therapy services by a licensed physical therapist, he or she has agreed to let me work with your patient too. Because your patient already has a physical therapist, I will not bill for any of my physical therapy services during this study. Your consent is your referral for me to see your patient for physical therapy services during this study.

Please read this form and ask any questions that you may have before agreeing to your patient's participation in this study.

Purpose of the Research Study

The purpose of this study is to explore whether utilizing an established self-determination model, the *Self-Determined Learning Model of Instruction* during PT interventions will help your patient gain functional mobility skills, compared to when your patient participates in more typical clinician (PT) directed therapy sessions. I also want to see if your patient can maintain newly learned mobility skills in a familiar setting, and perform these mobility skills in a new setting that you choose. This study is part of the requirements for my doctoral dissertation.

Number of Participants

There will be about five other youth with severe and multiple developmental disabilities, and their caregivers participating in this study (total of 10), but your patient will work only with me.

Procedures

If you agree to let your patient be in this study, he/she will be asked to do the following:

1) Interview: Your patient and his caregiver will talk with me at the beginning of the study, and again at the end of the study for at least 1 hour, but maybe 2 hours at the most. During these interviews we will review your patient's IEP document (if he/she has one) to gather information including age, disability category, and goals/objectives that relate to physical therapy and postsecondary transition planning, and help us identify relevant mobility skills that your patient and his caregiver want to pursue at home and in another setting you choose.

2) Allow video & audio recording the interviews and intervention sessions: Video recording ensures accurate recording of your patient's comments and goals, and enables an independent observer to ensure that I am collecting data correctly, and performing interventions as planned.

3) Participate in pre-study assessments: I conducted three mobility tests that will give a complete picture of your patient's mobility skills and support needs prior to beginning the study. Some of the assessments will be accomplished as part of the interview in #1 above. These tests may be familiar from previous PT sessions and should take no more than 2 hours to complete (total for all three assessments).

4) Your patient and his/her caregiver will participate in daily physical therapy interventions. These sessions will be like what the patient experience (d) in school or in your community physical therapy. Your patient will work on the mobility skill identified before the study starts. I will provide different physical therapy methods that will help your patient achieve his/her mobility skill. One method, called clinician-directed (CD), is a standard method of providing physical therapy to help your patient achieve his/her mobility goal. I will determine all of the activities to do and their order of implementation during the session. I will not talk much about the intervention. The other method, called student-directed (SD) will teach your patient ways to direct the therapy session, to know what he/she wants or can do in physical

therapy to achieve a mobility skill, identify ways to achieve the mobility skill, relate the mobility skill to something your patient wants to do in post-secondary life, and evaluate his/her own performance on the skill. Your patient will get to choose from a menu of activities and their order of implementation during the session. Physical therapy interventions will occur daily, for no longer than 90 minutes per session, scheduled at times that are convenient for your patient. Initial therapy sessions will be provided in your patient's home (or other familiar setting your patient chooses). At the end of this phase of the study, your patient will choose a new (or less familiar) community setting where he/she will use the mobility skill they've been learning.

5) A post-intervention evaluation at the end of each therapy session. Your patient will complete an evaluation about the mobility skills he/she accomplished during that session. Your patient and his/her caregiver will complete an evaluation about how they think your patient completed the mobility skills. This post-intervention evaluation should take no more than 10 minutes to complete at the end of each session. Your patient can receive help to record answers on the self-evaluation form.

Length of Participation

The pre- and post-study interviews will last no longer than 2 hours. Pre-study assessments should take no more than 2 hours to complete. Physical therapy interventions will happen daily, for 90 minutes per session. About 60 to 80 minutes will be active physical therapy intervention, with about 10 minutes at the end allowed for session evaluation. The entire study will take about two months to finish.

This study has the following risks:

Your patient will not be harmed in any way by participating in this study. Risks involved in participation are no greater than when your patient participates (d) in physical therapy sessions at school or in your community.

Benefits of being in the study are

There are no known benefits to your patient's participation in this study.

Injury

In case of injury or illness resulting from this study, emergency medical treatment is available. However, your patient's insurance company may be expected to pay the usual charge from this treatment. The University of Oklahoma Norman Campus has set aside no funds to compensate you in the event of injury.

Confidentiality

In published reports, there will be no information included that will make it possible to identify you or your patient without your permission. Research records will be stored securely and only approved researchers will have access to the records. Unless your patient specifies otherwise, all data and video/audio recordings will be held for 1 year after the study is completed. At that time, all video recordings and data will be destroyed.

There are organizations that may inspect and/or copy these research records for quality assurance and data analysis. These organizations include U.S. Department of Education, Office of Special Education Programs, and the OU Institutional Review Board.

Compensation

At the end of each week of your patient's participation in the study, your patient and caregiver (as a team) will receive a $10.00 gift card for their time and participation in this study. If your patient chooses to withdraw from the study mid-week, he/she will still receive a $10.00 gift card for that week if he/she participated at all.

Voluntary Nature of the Study

Your patient's participation in this study is voluntary. If your patient withdraws or declines participation, your patient will not be penalized or lose benefits or services unrelated to the study. If your patient decides to participate, he/she may decline to participate in physical therapy sessions or activities, decline to answer any assessment or questions, and he/she can choose to withdraw at any time.

Waivers of Elements of Confidentiality

Neither your name, nor your patient's name will be linked with your patient's responses unless your patient specifically agrees to be identified. Your name will not be linked to your patient except for standard medical referral for treatment only.

Request for record information

Your patient has agreed to allow me to review his/her Individual Education Program (IEP). I will not require any other information from you for the study unless your patient asks me to seek such information.

Audio Recording of Study Activities

Your patient as agreed to allow me to audio record as I video record our interview and therapy sessions.

Video Recording of Study Activities

Your patient has agreed to allow me to video record our interview and therapy sessions.

Physical Therapy Interventions

Your patient has agreed to participate in study-related physical therapy interventions.

Contacts and Questions

If you have concerns or complaints about the research, you can contact Lorraine Sylvester at 405-325-8951, or contact me by e-mail at lorraine.sylvester-1@ou.edu. Because I am a doctoral student, you may also contact my advisor, James E. Martin, PhD., at 405-325-8951 or e-mail him at jemartin@ou.edu.

If you have any questions about your patient's rights as a research participant, concerns, or complaints about the research and wish to talk to someone other than individuals on the research team or if you cannot reach the research team, you may contact the University of Oklahoma – Norman Campus Institutional Review Board (OU-NC IRB) at 405-325-8110 or irb@ou.edu.

Your patient was instructed to contact the researcher if you have questions or if you have experienced a research-related injury.

You and your patient will be given a copy of this information to keep for your records. If you are not given a copy of this consent form, please request one.

Statement of Consent and Referral for Study-related Physical Therapy Services

I have read the above information. I have asked questions and have received satisfactory answers. I give my consent and referral for my patient to participate in study-related physical therapy services. I am aware that my patient will continue to receive billable physical therapy services by his/her regular physical therapist, and that the study-related physical therapist will not bill for her services.

____

Physiclan's Name (Print) Date

____

Physician's Signature

APPENDIX B

Pre-Study Assessments

B1 Participant Interview Instructions, Questions, and Related IEP Documentation

B2 Caregiver Interview Instructions, Questions, and Related IEP Documentation

B3 Functional Independence Measure (FIM©) Check Sheet

B4 Gross Motor Function Classification System – Expanded & Revised
GMFCS – E & R

B5 Supports Intensity Scale (SIS)

B6 AIR Self-Determination Assessment

B1

Participant Interview Instructions, Questions, and Related IEP Documentation

Interview Questions	IEP Postsecondary Goals	IEP Strengths Limits	IEP Supports	Match IEP Yes No
What kind of job do you want after high school?				
What kind of mobility skills do you need in order to do the job you stated?				
What sort of education do you need in order to get and do the kind of work you want after high school?				
What kind of mobility skills do you need in order to get more education after high school?				
Where do you want to live after you graduate from high school?				
What kind of mobility skills do you need to live where you want (either your own, or your family's home)?				
What mobility skills do you have now and can do well on a job?				
What mobility skills are hard for you to do on a job?				
What mobility skills do you have now and can use to live independently / as you want to live?				
What is hard about living on your own/the way you want to live as an adult?				
What help do you need to live at home as you want as an adult?				
How do you take care of yourself now? Toileting Dressing Eating Medical Issues/Doctor Appointments/Medicine				
How do you get around at home, school, or in your community? Wheelchair mobility Transportation (personal or public)				

B2

Caregiver Interview Instructions, Questions, and Related IEP Documentation

Interview Questions	IEP Postsecondary Goals	IEP Strengths Limits	IEP Supports	Match IEP	
				Yes	No
What kind of job do you see your son/daughter doing after graduation?					
What kind of mobility skills does he/she need in order to do his/her preferred job?					
What sort of education does he/she need in order to get and do his/her preferred work after high school?					
What kind of mobility skills does he/she need in order to get more education?					
Where do you want to live after you graduate from high school?					
What kind of mobility skills does he/she need in order to live the way you think he/she should live?					
What mobility skills does he/she have now and can do well on a job?					
What mobility skills are hard for him/her to do on a job?					
What mobility skills does he/she have now and can use to live independently or as you want him/her to live?					
What makes it hard for him/her to live independently or the way you want him/her to live as an adult??					
What help does he/she need to live at home or as you want as an adult?					
How does your son/daughter you take care of him/herself now? Toileting Dressing Eating Medical Issues/Doctor Appointments/Medicine					
How does he/she get around at home, school, or in your community? Wheelchair mobility Transportation (personal or public)					

B3

FIM CHECKSHEET (I = independent; D = dependent; % of work done by participant)

Function Level⇒ ------------------ Activity⇓	**7 – I complete**	**6 – I modified**	**5 – D supervision**	**4 – D min contact; does 75% or more**	**3 – D mod assist; 50-74%**	**2 – D; complete max assist; 25-49%**	**1 – D Total assist, <25%**	**0 – Does not occur**
Eating								
Grooming								
Bathing								
Dressing-upper body								
Dressing-lower body								
Toileting								
Bladder Management-assistance								
Bladder Management-freq. of accidents								
Bowel Management-assistance								
Bowel Management-freq. of accidents								
Transfers: Bed, chair, wheelchair								
Transfers – toilet								
Transfers-tub								
Transfers-shower								
Locomotion – walk								
Locomotion – wheelchair								
Locomotion – stairs								
Comprehension (Auditory or Visual)								
Expression (Vocal or non-vocal)								
Social Interaction								
Problem Solving								
Memory								

B4

CanChild Centre for Childhood Disability Research
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GMFCS – E & R
Gross Motor Function Classification System
Expanded and Revised

GMFCS - E & R © **Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007**
CanChild Centre for Childhood Disability Research, McMaster University

GMFCS © **Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997**
CanChild Centre for Childhood Disability Research, McMaster University
(Reference: Dev Med Child Neurol 1997;39:214-223)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization's International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that **environmental** and **personal** factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the **child's or youth's present abilities and limitations in gross motor function**. Emphasis is on usual **performance** in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level I (i.e., can pull to stand and walk), would be classified in Level I. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child's/youth's current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to18 year age bands reflect the potential impact of environment factors (e.g., distances in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.

OPERATIONAL DEFINITIONS

Body support walker – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

Hand-held mobility device – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

Physical assistance – Another person manually assists the child/youth to move.

Powered mobility – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

Self-propels manual wheelchair – The child/youth actively uses arms and hands or feet to propel the wheels and move.

Transported – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

Walks – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

Wheeled mobility – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

GENERAL HEADINGS FOR EACH LEVEL

LEVEL I - Walks without Limitations

LEVEL II - Walks with Limitations

LEVEL III - Walks Using a Hand-Held Mobility Device

LEVEL IV - Self-Mobility with Limitations; May Use Powered Mobility

LEVEL V - Transported in a Manual Wheelchair

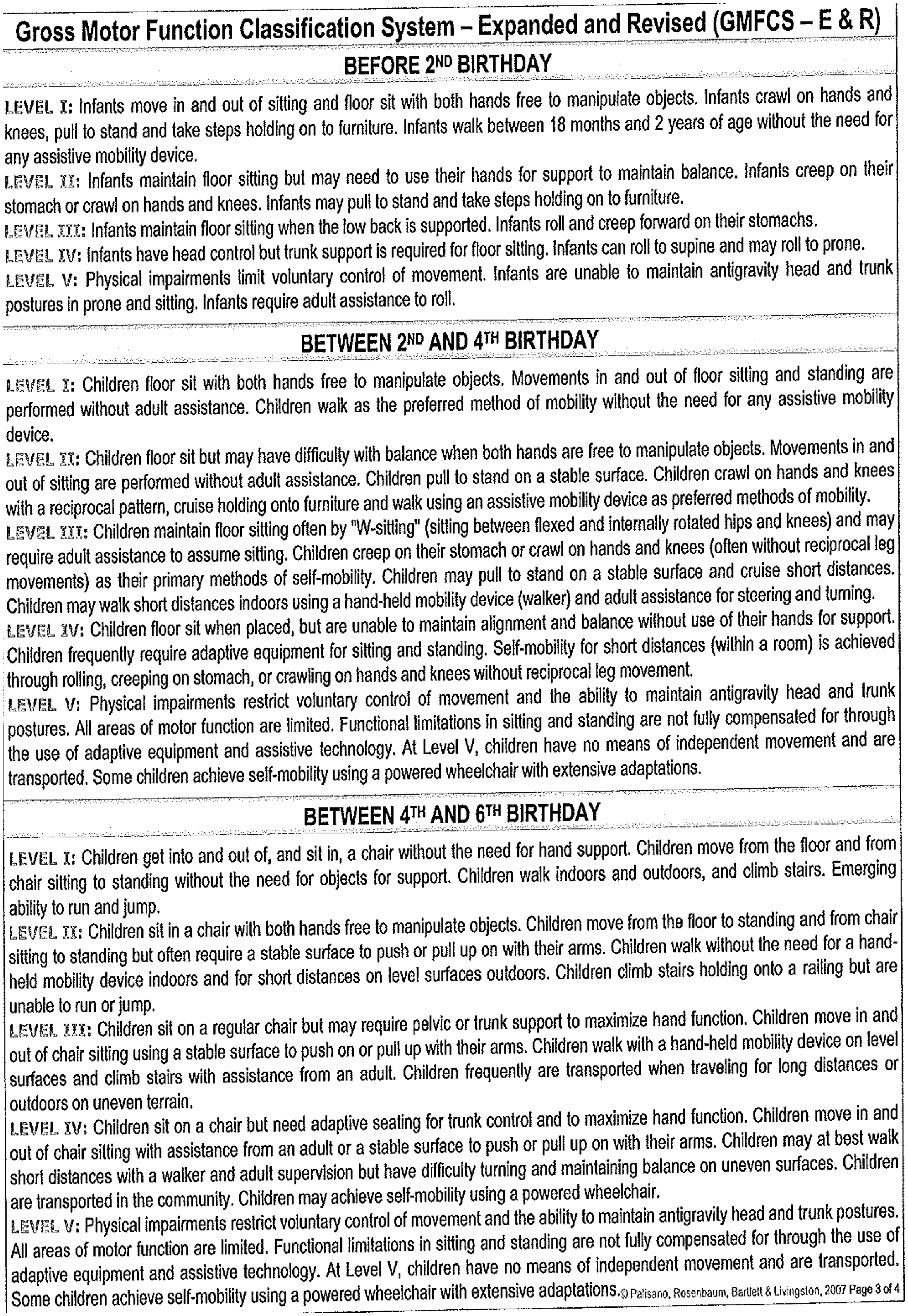
DISTINCTIONS BETWEEN LEVELS

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.



Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

BEFORE 2ND BIRTHDAY

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 4TH AND 6TH BIRTHDAY

LEVEL I: Children get into and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push on or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations. © Palisano, Rosenbaum, Bartlett & Livingston, 2007 Page 3 of 4

BETWEEN 6TH AND 12TH BIRTHDAY

Level I: Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

BETWEEN 12TH AND 18TH BIRTHDAY

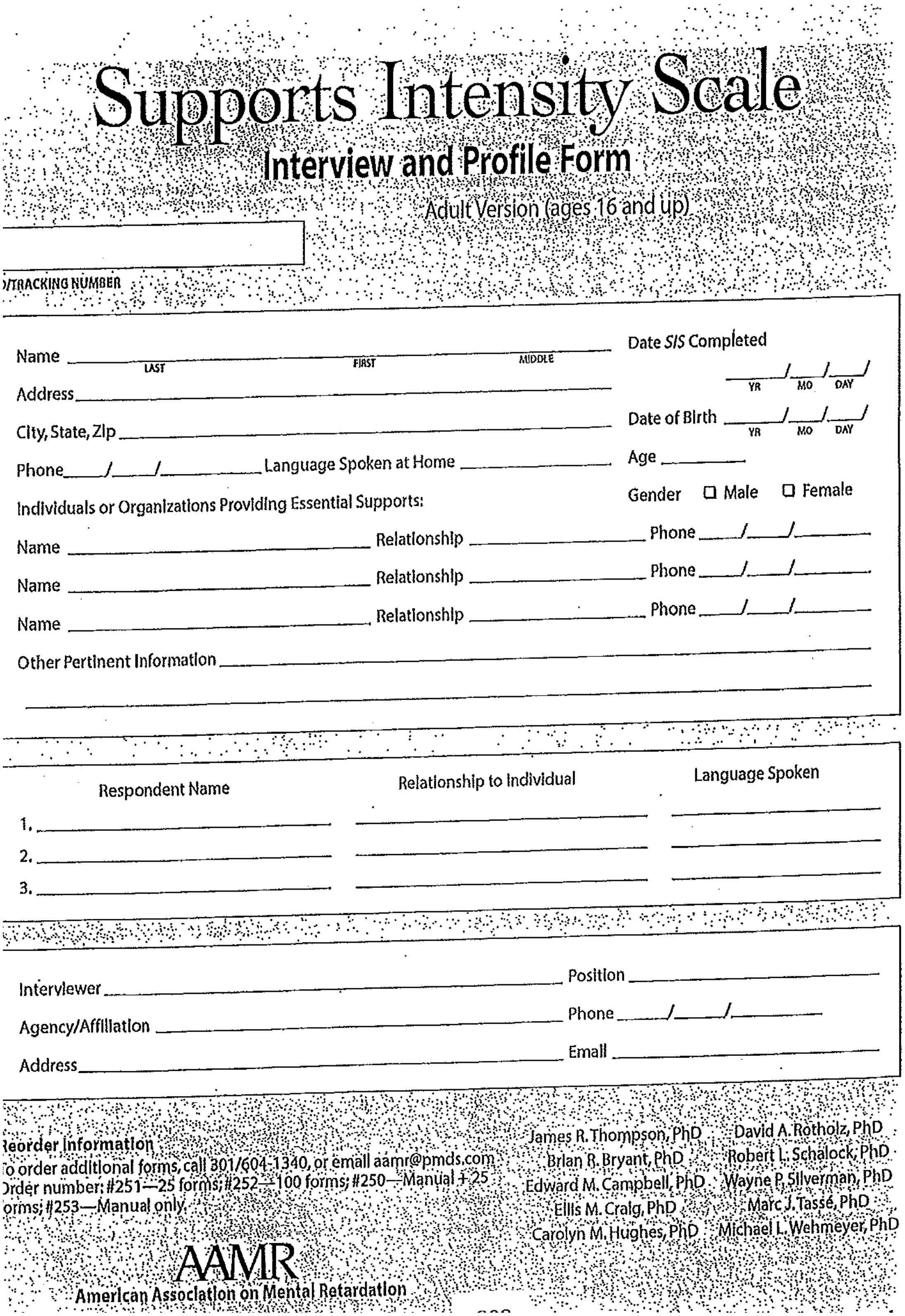
Level I: Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

Level II: Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a hand-held mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

Level III: Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

Level IV: Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

Level V: Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.



Supports Intensity Scale

Interview and Profile Form

Adult Version (ages 16 and up)

/TRACKING NUMBER

Name ____________ LAST ____________ FIRST ____________ MIDDLE

Address ____________

City, State, Zip ____________

Phone ____/____/____ Language Spoken at Home ____________

Date *SIS* Completed ____/____/____ YR MO DAY

Date of Birth ____/____/____ YR MO DAY

Age ____________

Gender ☐ Male ☐ Female

Individuals or Organizations Providing Essential Supports:

Name ____________ Relationship ____________ Phone ____/____/____

Name ____________ Relationship ____________ Phone ____/____/____

Name ____________ Relationship ____________ Phone ____/____/____

Other Pertinent Information ____________

	Respondent Name	Relationship to Individual	Language Spoken
1.			
2.			
3.			

Interviewer ____________ Position ____________

Agency/Affiliation ____________ Phone ____/____/____

Address ____________ Email ____________

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American Association on Mental Retardation

Section 1. Support Needs Scale

INSTRUCTIONS: Identify the Frequency, Daily Support Time, and Type of Support that is reported necessary for the person to b successful in the six activity domains (Parts A–F). **Circle the appropriate number (0–4) for each measurement** (i.e., Frequenc Daily Support Time, Type of Support). (See rating key below.) Add across each line item to obtain the Raw Scores. Sum the Raw Scores down to obtain the Total Raw Score for each Part.

1. This scale should be completed without regard to the services or supports currently provided or available.
2. Scores should reflect the supports that would be necessary for this person to be successful in each activity.
3. If an individual uses assistive technology, the person should be rated with said technology in place.
4. Complete ALL items, even if the person is not currently performing a listed activity.

Part A: Home Living Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Using the toilet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Taking care of clothes (includes laundering)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Preparing food	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4	
4. Eating food	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Housekeeping and cleaning	0	1	2	3	4	0	1	2	☒	☒	0	1	2	3	4	
6. Dressing	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Bathing and taking care of personal hygiene and grooming needs	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4	
8. Operating home appliances	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	

TOTAL Raw Score
Home Living Activities

Enter the Raw Score (max. = 92) on the *SIS Profile*, on page 8, Section 1A, Part A, Home Living Activities

RATING KEY

FREQUENCY:
How frequently is support needed for this activity?
0 = none or less than monthly
1 = at least once a month, but not once a week
2 = at least once a week, but not once a day
3 = at least once a day, but not once an hour
4 = hourly or more frequently

DAILY SUPPORT TIME:
On a typical day when support in this area is needed, how much time should be devoted?
0 = none
1 = less than 30 minutes
2 = 30 minutes to less than 2 hours
3 = 2 hours to less than 4 hours
4 = 4 hours or more

TYPE OF SUPPORT:
What kind of support should be provided?
0 = none
1 = monitoring
2 = verbal/gestural prompting
3 = partial physical assistance
4 = full physical assistance

Section 1. Support Needs Scale, continued

Circle the appropriate number (0–4) for each measurement. (See rating key.) Complete ALL items, even if the person i
not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a
Total Raw Score.

Part B: Community Living Activities	Frequency					Daily Support Time					Type of Support					Raw Score
1. Getting from place to place throughout the community (transportation)	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in recreation/leisure activities in the community settings	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Using public services in the community	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Going to visit friends and family	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Participating in preferred community activities (church, volunteer, etc.)	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
6. Shopping and purchasing goods and services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Interacting with community members	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Accessing public buildings and settings	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	

TOTAL Raw Score
Community Living Activities

Enter the Raw Score (max.= 91) on the *SIS* Profile, on page 8, Section 1A, Part B, Community Living Activities

Part C: Lifelong Learning Activities	Frequency					Daily Support Time					Type of Support (TS)					Raw Scores
1. Interacting with others in learning activities	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Participating in training/educational decisions	0	1	2	3	X	0	1	2	3	X	0	1	2	3	4	
3. Learning and using problem-solving strategies	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Using technology for learning	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Accessing training/educational settings	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Learning functional academics (reading signs, counting change, etc.)	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Learning health and physical education skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Learning self-determination skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
9. Learning self-management strategies	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	

TOTAL Raw Score
Lifelong Learning Activities

Enter the Raw Score (max.= 104) on the *SIS* Profile, on page 8, Section 1A, Part C, Lifelong Learning Activities

Section 1. Support Needs Scale, continued

Circle the appropriate number (0–4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part D: Employment Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Accessing/receiving job/task accommodations	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
2. Learning and using specific job skills	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
3. Interacting with co-workers	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
4. Interacting with supervisors/coaches	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
5. Completing work-related tasks with acceptable speed	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
6. Completing work-related tasks with acceptable quality	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
7. Changing job assignments	0	1	2	X	X	0	1	2	3	4	0	1	2	3	4	
8. Seeking information and assistance from an employer	0	1	2	3	X	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Employment Activities																

Enter the Raw Score (max. = 87) on the *SIS* Profile, on page 8, Section 1A, Part D, Employment Activities

Part E: Health and Safety Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Taking medications	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
2. Avoiding health and safety hazards	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
3. Obtaining health care services	0	1	2	3	4	0	1	2	X	X	0	1	2	3	4	
4. Ambulating and moving about	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
5. Learning how to access emergency services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Maintaining a nutritious diet	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Maintaining physical health and fitness	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Maintaining emotional well-being	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
TOTAL Raw Score Health and Safety Activities																

Enter the Raw Score (max. = 94) on the *SIS* Profile, on page 8, Section 1A, Part E, Health and Safety Activities

RATING KEY

FREQUENCY: How frequently is support needed for this activity?

0 = none or less than monthly
1 = at least once a month, but not once a week
2 = at least once a week, but not once a day
3 = at least once a day, but not once an hour
4 = hourly or more frequently

DAILY SUPPORT TIME: On a typical day when support in this area is needed, how much time should be devoted?

0 = none
1 = less than 30 minutes
2 = 30 minutes to less than 2 hours
3 = 2 hours to less than 4 hours
4 = 4 hours or more

TYPE OF SUPPORT: What kind of support should be provided?

0 = none
1 = monitoring
2 = verbal/gestural prompting
3 = partial physical assistance
4 = full physical assistance

Section 1. Support Needs Scale, continued

Circle the appropriate number (0-4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Add the Raw Scores down to get a Total Raw Score.

Part F: Social Activities	Frequency					Daily Support Time					Type of Support					Raw Scores
1. Socializing within the household	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4	
2. Participating in recreation/leisure activities with others	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4	
3. Socializing outside the household	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
4. Making and keeping friends	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4	
5. Communicating with others about personal needs	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
6. Using appropriate social skills	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
7. Engaging in loving and intimate relationships	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	
8. Engaging in volunteer work	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4	

TOTAL Raw Score Social Activities ______

Enter the Raw Score (max. = 93) on the *SIS* Profile, on page 8, Section 1A, Part F, Social Activities

Section 2. Supplemental Protection and Advocacy Scale

Circle the appropriate number (0-4) for each measurement. (See rating key.) Complete ALL items, even if the person is not currently performing a listed activity. Add the scores across to get a Raw Score. Rank the Raw Scores from highest to lowest (1 = highest). Enter the four highest ranked activities (1-4) and their scores on the *SIS* Profile.

Protection and Advocacy Activities	Frequency					Daily Support Time					Type of Support					Raw Scores	Rank Raw Scores from highest to lowest
1. Advocating for self	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4		
2. Managing money and personal finances	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
3. Protecting self from exploitation	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
4. Exercising legal responsibilities	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
5. Belonging to and participating in self-advocacy/support organizations	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
6. Obtaining legal services	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
7. Making choices and decisions	0	1	2	3	4	0	1	2	3	4	0	1	2	3	4		
8. Advocating for others	0	1	2	3	☒	0	1	2	3	4	0	1	2	3	4		

List the four Protection and Advocacy Activities with the highest Raw Score (from highest to lowest) on the *SIS* Profile, on page 8, Section 2.

Section 3. Exceptional Medical and Behavioral Support Needs

Circle the appropriate number to indicate how much support is needed for each of the items below. Subtotal the circled 1's and 2's. Total the subtotals. (See rating key.) Complete ALL items.

Section 3A: Medical Supports Needed	No Support Needed	Some Support Needed	Extensive Support Needed
Respiratory care			
1. Inhalation or oxygen therapy	0	1	2
2. Postural drainage	0	1	2
3. Chest PT	0	1	2
4. Suctioning	0	1	2
Feeding assistance			
5. Oral stimulation or jaw positioning	0	1	2
6. Tube feeding (e.g., nasogastric)	0	1	2
7. Parenteral feeding (e.g., IV)	0	1	2
Skin care			
8. Turning or positioning	0	1	2
9. Dressing of open wound(s)	0	1	2
Other exceptional medical care			
10. Protection from infectious diseases due to immune system impairment	0	1	2
11. Seizure management	0	1	2
12. Dialysis	0	1	2
13. Ostomy care	0	1	2
14. Lifting and/or transferring	0	1	2
15. Therapy services	0	1	2
16. Other(s)—Specify: ____________	0	1	2
Subtotal of 1's and 2's			

Total (Add Subtotal of 1's and 2's) ______

Enter Total on the *SIS* Profile, on page 8, Section 3A: Support Considerations Based on Exceptional Medical and Behavioral Support Needs, *Medical*

Section 3. Exceptional Medical and Behavioral Support Needs, continued

Circle the appropriate number to indicate how much support is needed for each of the items below. (See rating key.) Complete ALL items.

Section 3B: Behavioral Supports Needed	No Support Needed	Some Support Needed	Extensive Support Needed
Externally directed destructiveness			
1. Prevention of assaults or injuries to others	0	1	2
2. Prevention of property destruction (e.g., fire setting, breaking furniture)	0	1	2
3. Prevention of stealing	0	1	2
Self-directed destructiveness			
4. Prevention of self-injury	0	1	2
5. Prevention of pica (ingestion of inedible substances)	0	1	2
6. Prevention of suicide attempts	0	1	2
Sexual			
7. Prevention of sexual aggression	0	1	2
8. Prevention of nonaggressive but inappropriate behavior (e.g., exposes self in public, exhibitionism, inappropriate touching or gesturing)	0	1	2
Other			
9. Prevention of tantrums or emotional outbursts	0	1	2
10. Prevention of wandering	0	1	2
11. Prevention of substance abuse	0	1	2
12. Maintenance of mental health treatments	0	1	2
13. Prevention of other serious behavior problem(s) Specify:____________________	0	1	2
Subtotal of 1's and 2's			
Total (Add Subtotal of 1's and 2's)			

Enter Total on the *SIS Profile*, on page 8, Section 3B: Support Considerations Based on Exceptional Medical and Behavioral Support Needs, *Behavioral*

RATING KEY

0 = no support needed

1 = some support needed (i.e., providing monitoring and/or occasional assistance)

2 = extensive support needed (i.e., providing regular assistance to manage the medical condition or behavior)

Supports Intensity Scale (SIS) Scoring Form & Profil

ID/TRACKING NUMBER ______

Name ______

Date SIS Completed ___/___/___
YR MO DAY

Name of Interviewer ______

Section 1A: Support Needs Ratings

1. Enter the Raw Scores for parts A–F from pages 2–5.
2. Enter the Standard Scores and Percentiles using Appendix 6.2.
3. Enter the *SIS* Support Needs Index using Appendix 6.3.

Activities Subscales	Total Raw Scores (From pages 2–5)	Standard Scores (See Appendix 6.2)	Subscale Percentiles (See Appendix 6.2)
A. Home Living			
B. Community Living			
C. Lifelong Learning			
D. Employment			
E. Health & Safety			
F. Social			
Standard Scores TOTAL (sum)			
SIS SUPPORT NEEDS INDEX (Composite Standard Score) (See Appendix 6.3)			
Percentile of Support Needs Index (See Appendix 6.3)			

Section 1B: Support Needs Profile

Circle the Standard Score for each Activities Subscale and the *SIS* Support Needs Index. Then connect the subscale circles to form a graph.

Percentile	A. Home Living	B. Community Living	C. Lifelong Learning	D. Employment	E. Health & Safety	F. Social	*SIS* Support Needs Index	Percentile
99	17–20	17–20	17–20	17–20	17–20	17–20	> 131	99
	15–16	15–16	15–16	15–16	15–16	15–16	124–131	
90	14	14	14	14	14	14	120–123	90
	13	13	13	13	13	13	116–119	
80							113–115	80
	12	12	12	12	12	12	110–112	
70							108–109	70
							106–107	
60	11	11	11	11	11	11	105	60
							102–104	
50	10	10	10	10	10	10	100–101	50
							98–99	
40	9	9	9	9	9	9	97	40
							94–96	
30							92–93	30
	8	8	8	8	8	8	90–91	
20							88–89	20
	7	7	7	7	7	7	85–87	
10	6	6	6	6	6	6	82–84	10
	5	5	5	5	5	5	75–81	
1	1–4	1–4	1–4	1–4	1–4	1–4	< 74	1

Section 2: Support Considerations Based on Protection and Advocacy Scores

List the 4 highest ranked Protection and Advocacy Activities from page 5.

Activity	Raw Score
1. ______	______
2. ______	______
3. ______	______
4. ______	______

Section 3: Support Considerations Based on Exceptional Medical and Behavioral Support Needs

A. MEDICAL		
1. Enter the number of Total points from page 6.		
2. Is this Total larger than 5?	Yes	No
3. Is at least one "2" circled for Medical Supports Needed on page 6?	Yes	No
B. BEHAVIORAL		
1. Enter the number of Total points from page 7.		
2. Is this Total larger than 5?	Yes	No
3. Is at least one "2" circled for Behavioral Supports Needed on page 7?	Yes	No

If "yes" has been circled on any of the questions above, it is highly likely that this individual has greater support needs than others with a similar *SIS* Support Needs Index.

B5

AIR Self-Determination Scale©
EDUCATOR FORM

Student's Name ______________________________ Date __________

Date of Birth (or age) ______________ Grade ________ ☐ Female ☐ Male

Educator's Name ______________________________

School Name ______________________________

HOW TO FILL OUT THIS FORM

Each page of this form lists characteristics and behaviors that indicate the degree to which your student demonstrates traits of self-determination and the degree to which the people influencing your student provides opportunities that foster self-determination. For each item, select the appropriate rating code based on what you have observed about your student. An example is provided to illustrate each characteristic. Feel free to write in a different example that supports your rating for your student.

Here is an example of how you should mark your answers.

EXAMPLE QUESTION:

Student checks for errors after completing a project.

EXAMPLE ANSWER:

Check the box of the rating code which tells what your student is most like:
(Check **ONLY ONE** box per question).

1 **Never**..............................student **never** checks for errors.

2 **Almost Never**..................student **almost never** checks for errors.

3 **Sometimes**......................student **sometimes** checks for errors.

4 **Almost Always**................student **almost always** checks for errors.

5 **Always**.............................student **always** checks for errors.

©The *AIR Self-Determination Scale* was developed by the American Institute for Research (AIR), in collaboration with Teachers College, Columbia University, with funding from the U. S. Department of Education, Office of Special Education Programs (OSEP), under cooperative agreement H023J200005.

KNOWLEDGE of Self-Determination Behaviors

1. Student knows own abilities and limitations. *Example:* James can identify his personal strengths and talents, such as his musical ability as well as areas in which he needs improvement, like his below average math problem-solving skills.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
2. Student knows how to set expectations and goals that satisfy own interests and needs. *Example:* Lee wants to attend college and knows that to get good grades, she needs to work hard on her assignments and complete them on time.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
				Knowledge Total: Items 1+2	
3. Student knows how to make choices, decisions, and plans to meet own goals and expectations. *Example:* When making plans to meet her goals, Lynn knows how to identify various strategies, weigh the pros and cons, and follow through.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
4. Student knows how to take actions to complete own plans successfully. *Example:* Kenneth knows how to follow through on a scheduled plan to complete his work accurately and on time.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
				Knowledge Total: Items 3+4	
5. Student knows how to evaluate results of actions to determine what was effective. *Example:* Germaine knows what questions to ask to find out how well she is doing.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
6. Student knows how to change actions or plans to meet goals and satisfy needs and wants. *Example:* Jose understands that to get an A in math, he may need to study one hour every night; if that doesn't work he may have to work two hours every night; and if that doesn't work he may have to learn to study more effectively.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
				Knowledge Total: Items 5+6	

Please go on to the next page⇒

ABILITY to Perform Self-Determination Behaviors

1. Student expresses own interests, needs, and abilities. *Example:* Sarah communicates her athletic interest and talent in conversations, written journals, or participation in sports activities.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. Student sets expectations and goals that will satisfy own interests needs, and wants. *Example:* Loving to spend time drawing and doing art, Daniel sets the goal of finding art classes that he can take after school once a week.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
				Ability Total: Items 1+2	
3. Student knows how to make choices, decisions, and plans to meet own goals and expectations. *Example:* Anna weighed the pros and cons of doing three types of history projects, chose to write a research report, outlined the report, and made a schedule for completing the report on time.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. Student initiates actions on own choices and plans. *Example:* Ming begins work right away each time he gets an assignment or is asked by someone to help with a project.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
				Ability Total: Items 3+4	
5. Student gathers information on results of actions. *Example:* After completing her work, Theresa checks it for errors and asks others to look it over and make suggestions.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. Student changes own actions or plans to satisfy expectations and goals, if necessary. *Example:* Ricardo tries different approaches to solve problems and to complete tasks that are difficult for him.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
				Ability Total: Items 5+6	

Please go on to the next page⇒

PERCEPTION of Knowledge and Ability to Perform Self-Determination Behaviors

1. Student feels free to express own needs, interests, and abilities, even when facing opposition from others. *Example:* Fran defends her needs and interests to anyone who questions them.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. Student feels free to set own goals and expectations, even if they are different from the expectations others have for the student. *Example:* Trevor does not feel constrained by others' opinions in setting goals and expectations for himself.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
				Perception Total: Items 1+2	☐
3. Student feels free to make own choices, decisions, and plans to meet own goals and expectations. *Example:* Corine often considers her parents' suggestions when making choices and plans, but the final plans taken to meet her goals are her own.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. Student feels confident about being able to successfully complete own plans. *Example:* When Nicholas schedules his own activities, he is confident he can complete them accurately and on time.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
				Perception Total: Items 3+4	☐
5. Student is confident about using feedback to evaluate results of own work. *Example:* Amanda is confident that she will be able to benefit from the feedback she receives from her parents, teachers, and peers.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. Student changes plans again and again to meet a goal without getting discouraged. *Example:* Levar is motivated to work on a project as long as it takes, using whatever approaches are necessary, to get it right.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
				Perception Total: Items 5+6	☐

Please go on to the next page⇒

OPPORTUNITY To Perform Self-Determination Behaviors AT SCHOOL

1. Student has opportunities at school to explore, express, and feel good about own needs, interests, and abilities. *Example:* Christine's teachers encourage her to talk about her athletic interests and abilities and about what sports activities she wants to do.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
2. Student has opportunities at school to identify goals and expectations that will meet his or her needs, interests, and abilities; to set these goals; and to feel good about them. *Example:* Troy's teachers let him know that he is responsible for setting his own goals to get his needs and wants met.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
	Opportunity at School Total: Items 1+2				☐

3. Student has opportunities at school to learn about making choices and plans, to make them, and to feel good about them. *Example:* Shebra's teachers allow her to make her own choices and plans for school assignments, family chores, and leisure activities.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
4. Student has opportunities at school to initiate actions to meet expectations and goals. *Example:* Manuel's teachers tell him that he is responsible for scheduling study time and for handing in assignments on time.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
	Opportunity at School Total: Items 3+4				☐

5. Student has opportunities at school to get results of actions taken to meet own plans. *Example:* Michelle's teachers are available to give feedback on projects whenever she needs it.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
6. Student has opportunities at school to change actions and plans to satisfy own expectations. *Example:* Laurent's teacher encouraged him to take his time and to revise his work as often as necessary to satisfy his own expectations.	Never **1**	Almost Never **2**	Sometimes **3**	Almost Always **4**	Always **5**
	Opportunity at School Total: Items 5+6				☐

Please go on to the next page⇒

OPPORTUNITY To Perform Self-Determination Behaviors AT HOME

1. Student has opportunities at home to explore, express, and feel good about own needs, interests, and abilities. *Example:* Maria's parents encourage her to talk about her athletic interests and abilities and about what sports activities she wants to do.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. Student has opportunities at home to identify goals and expectations that will meet his or her needs, interests, and abilities; to set these goals; and to feel good about them. *Example:* Roberto's parents let him know that he is responsible for setting his own goals to get his needs and wants met.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
		Opportunity at Home Total: Items 1+2			
3. Student has opportunities at home to learn about making choices and plans, to make them, and to feel good about them. *Example:* Kelly's parents allow her to make her own choices and plans for school assignments, family chores, and leisure activities.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. Student has opportunities at home to initiate actions to meet expectations and goals. *Example:* Anthony's parents tell him that he is responsible for scheduling study time and for handing in assignments on time.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
		Opportunity at Home Total: Items 3+4			
5. Student has opportunities at home to get results of actions taken to meet own plans. *Example:* Thuy's parents are available to give feedback on projects whenever she needs it.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. Student has opportunities at home to change actions and plans to satisfy own expectations. *Example:* Stacy's parents encourage him to take his time and to revise his work as often as necessary to satisfy his own expectations.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
		Opportunity at Home Total: Items 5+6			

Please go on to the next page⇒

PLEASE WRITE YOUR ANSWERS TO THE FOLLOWING QUESTIONS IN THE SPACES BELOW.

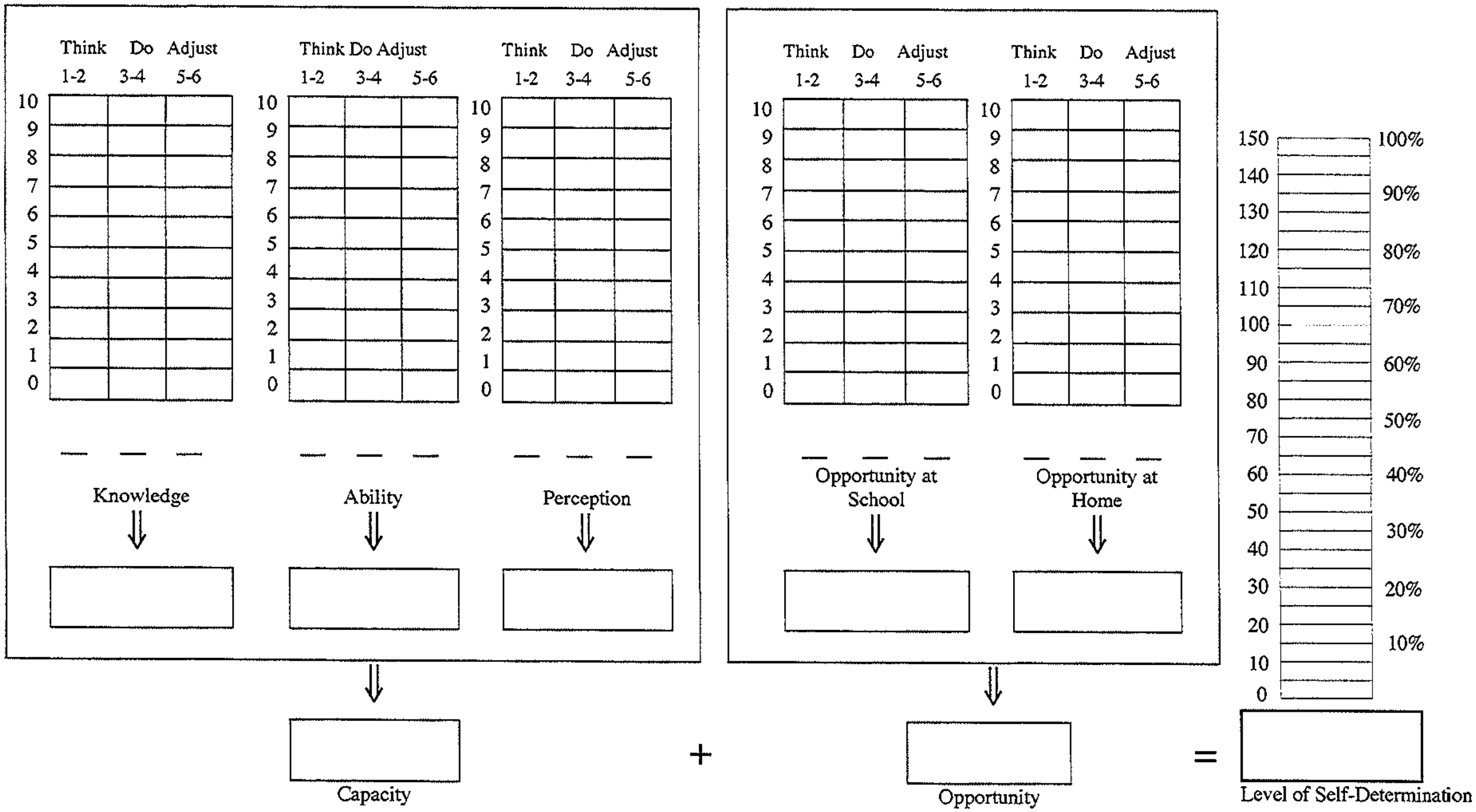
Give an example of a goal the student is working on.

What is the student doing to reach this goal?

How is the student doing in reaching this goal?

Thank you.

The AIR Self-Determination Profile
Educator Form



(Write sum in box and mark in column)

Student Name________________________ Date__________

APPENDIX C

Participant's Post-Session Evaluations

C1 Andy's Evaluation, G.A.S., and Therapist's Benchmark Tally Sheet

C2 Jess' Evaluation, G.A.S., and Benchmark Tally Sheet

C3 Holly's Evaluation, G.A.S. and Benchmark Tally Sheet

C4 Toby's Evaluation, G.A.S. and Benchmark Tally Sheet

C5 Carla's Evaluation, G.A.S. and Benchmark Tally Sheet

C1

Therapist's Post-Intervention Evaluation 07 (ANDY): Session ____________Date___

General Mobility Skill Self-evaluation Questions	**YES**	**NO**
1. Did AB achieve his whole transfer goal (w/c to couch to w/c) today independently, but with staff supervision, in 5 minutes or less, and requesting help when he needed it?	Yes	No
2. Did AB achieve some steps of his transfer goal today?	Yes	No
3. Did the therapist help AB by only holding his hands (not supporting other parts of his body)?	Yes	No
4. Did the therapist have to support AB's body more than by just holding his hands to help him get on the couch or back into his wheelchair?	Yes	No
5. Did the therapist give AB just verbal help (talk to him), but no physical help?	Yes	No

Discreet Mobility Skill Task-specific Self-evaluation Questions	**YES**	**NO**
1. Did AB propel his wheelchair up to the couch at the appropriate angle and distance, turns off the power, and prepare his chair for transfer to the couch, asking assistance as needed?	Yes	No
2. Did AB scoot forward in his wheelchair, angling feet/legs toward the couch and reach for the support (bar/device/person)?	Yes	No
3. Did AB reach for and hold support (chair, bar, etc.) as he stood with good balance to pivot toward the couch?	Yes	No
4. Did AB sit on the couch, and reposition himself as needed, all within 2 minutes of pulling his chair up to the couch?	Yes	No
5. Did AB sit up (lean forward on the couch), stabilize feet on floor/footplate, and reaches for support bar/chair?	Yes	No
6. Did AB pull himself to a stable standing position from the couch while supporting self on armrest of wheelchair (or bar)?	Yes	No
7. Did AB pivot and sit down in his wheelchair, adjusting his position and seat belt (requesting staff assist as needed for seat belt)?	Yes	No
8. Did AB request assistance to flip up or flip down his footplate as needed during the transfer	Yes	No
9. Did AB request assistance to re-position his wheelchair, body, or feet as needed if he determines either is not quite right before completing the transfer from the couch to the wheelchair?	Yes	No

---

10. Did AB complete the couch to chair transfer in 3 minutes or less? Yes No

---

Self-initiated support requests (no prompting):

Adjustment topics (prompted): What would you change or do differently next time?

07 - GOAL ATTAINMENT SCALING FOR TRANSFER from WC to Couch

Check whether or not scale has been mutually negotiated between participant and therapist.	*Yes____ No_____*	**SCORE**
Goal Attainment Levels	**Goal: AB will safely and independently (with supervision) move from his wheelchair to his couch, and back to his wheelchair. (3 consecutive times)**	
Most unfavorable outcome thought likely (-2)	AB requires maximum assist/total lift by 1 staff person onto couch, and back to wheelchair (Staff does >75% of the move), 15 minutes or more, and AB doesn't ask for help.	
Less than expected success achieved (-1)	AB requires moderate assist of 1 staff person (50-75%) to move from wheelchair to couch to wheelchair, in 10 – 15 minutes, no request for help.	
Expected level of success (0)	AB transfers to his couch from wheelchair with 1 staff holding onto his hands only (<25% help from staff), or a support bar, but requires 50%-75% help from staff to return to his wheelchair from couch, in 8-10 min, no request for help.	
More than expected success (+1)	AB transfers from his couch, and back to wheelchair (<25% help from staff) in 8 minutes, and requests help with re-positioning or safety getting back in chair.	
Best anticipated success (+2)	AB transfers from his wheelchair, to couch, and back to his wheelchair with staff standing by to supervise and ensure safety (no touch), in 8 minutes or less, and AB asks for help as needed.	

Therapist's Benchmark Evaluation on Dependent Measure: ***Transfer from Wheelchair to Couch, and back to Wheelchair in 8 minutes or less. – 07 (ANDY)***

Transfer Benchmark	**Achieved** **Yes**	**No**	**Assistance Level (Prompts)** **I L V T P**		**Self-initiated supports (tally)**	
1. AB propels his wheelchair up to the couch at the appropriate angle and distance, turns off the power, and prepares his chair for transfer to the couch.						
2. AB scoots forward in his wheelchair, angling feet/legs toward the couch and reaches for the support (bar/device/person).						
3. AB reaches for and holds support (chair, bar, etc.) as he stands with good balance to pivot toward the couch.						
4. AB sits on the couch, and repositions himself as needed, all within 2 minutes of pulling his chair up to the couch.						
5. AB sits up (leans forward on the couch), stabilizes feet on floor/footplate, and reaches for support bar/chair.						
6. Did AB pull himself to a stable standing position from the couch while supporting self on armrest of wheelchair (or bar)?						
7. Did AB pivot and sit down in his wheelchair, adjusting his position and seat belt (requesting staff assist as needed for seat belt)?						
8. Did AB request assistance to flip up or flip down his footplate as needed during the transfer						
9. Did AB request assistance to re-position his wheelchair, body, or feet as needed if he determines either is not quite right before completing the transfer from the couch to the wheelchair?						
10. Did AB complete the couch to chair transfer in 3 minutes or less?						
Total Mobility Steps Accomplished: Pre: Post:			I = V = T = P=	I = V = T = P =	Total # self-initiated support requests:	

Note: I = independent, L = look, V = verbal, T = touch with 1 body part, P = physical help with two or more body parts.

C2

05. THERAPIST Post-Intervention Evaluation: __JESS_________ Date:

General Mobility Skill Self-evaluation Questions (Independence is assumed unless otherwise stated)	**YES**	**NO**
1. Did JF achieve her whole transfer/baby care goal today independently and within the designated time limits?	Yes	No
2. Did JF achieve some steps of her transfer/baby care goal today?	Yes	No
3. Did the therapist help JF with just a touch (just using one hand or foot)?	Yes	No
4. Did the therapist give JF verbal help (talk to JF) during her goal?	Yes	No
5. Did the therapist give JF physical help beyond a touch (have to use most of her body to lift, support or help JF with her transfer / baby care goal?	Yes	No

Discreet Mobility Skill Task-specific Self-evaluation Questions (Independence is assumed unless otherwise stated)	**YES**	**NO**
1. From her bed, did JF move herself into sitting in preparation for transfer into Her wheelchair (sit up, put her get legs over the side of the bed and feet on the floor, and maintain her balance before standing up?	Yes	No
2. Did JF pull up on wheelchair, transfer bar, or other support to standing with stability and pivot toward her wheelchair for safe sitting?	Yes	No
3. Did JF re-position herself for stability, adjust safety belt, before moving toward the crib?	Yes	No
4. From the baby's first cry, did JF safely get out of bed and over to the baby within 3 minutes?	Yes	No
5. Did JF safely pick up the baby (doll), supporting head and limbs, and comfort it in her lap?	Yes	No
6. Did JF get the bottle, feed the baby, and then burp the baby?	Yes	No
7. Did JF put the baby back into the crib safely (supporting head and extremities) ensuring baby is OK?	Yes	No
8. Did JF wheel back to her bed and get safely from the wheelchair into the bed using supports (bar) as needed to roll into bed, or to pivot transfer?	Yes	No
9. Did JF get back into bed within 3 minutes after putting the baby back into the crib?	Yes	No
10. Did JF safely reposition and cover herself in the bed as needed?	Yes	No

What would JF do differently next time to make JF more successful with her goal? Make it easier? Safer?

JF - GOAL ATTAINMENT SCALING FOR Transfer and Baby Care

Check whether or not scale has been mutually negotiated between participant and therapist.	*Yes____* *No_____*
Goal Attainment Levels	**Goal: Transfer from WC to Bed to WC**
Most unfavorable outcome thought likely (-2)	JF required physical and verbal assist with all transfers and baby care skills to include picking up baby, diapering, feeding, and putting baby back in bassinet.
Less than expected success achieved (-1)	JF required physical assist at legs and upper body for transfer, and for baby and diaper placement.
Expected level of success (0)	JF required physical assist (more than touch) at legs to transfer from wheelchair, and touch cues for baby care.
More than expected success (+1)	JF required touch assist only at legs for transfer or baby care.
Best anticipated success (+2)	JF accomplished all of transfer and baby skill with visual observation only.

Therapist's Benchmark Evaluation on Dependent Measure: ***JF: Bed/wheelchair/bed transfer with baby care. JESS***

Transfer Benchmark	**Achieved**		**Assistance Level (Prompts)**		**Self-initiated supports**	
	Yes	**No**				
1. From her bed, did JF move herself into sitting in preparation for transfer into Her wheelchair (sit up, put her get legs over the side of the bed and feet on the floor, and maintain her balance before standing up?						
2. Did JF pull up on wheelchair, transfer bar, or other support to standing with stability and pivot toward her wheelchair for safe sitting?						
3. Did JF re-position herself for stability, adjust safety belt, before moving toward the crib?						
4. From the baby's first cry, did JF safely get out of bed and over to the baby within 3 minutes?						
5. Did JF safely pick up the baby (doll), supporting head and limbs, and comfort it in her lap?						
6. Did JF get the bottle, feed the baby, and then burp the baby?						
7. Did JF put the baby back into the crib safely (supporting head and extremities) ensuring baby is OK?						
8. Did JF wheel back to her bed and get safely from the wheelchair into the bed using supports (bar) as needed to roll into bed, or to pivot transfer?						
9. Did JF get back into bed within 3 minutes after putting the baby back into the crib?						
10. Did JF safely reposition and cover herself in the bed as needed?						
% Mobility skills accomplished			I = V = T = P =	I = V = T = P =	Total # self-initiated support requests:	

Note: I = independent, L = look, V = verbal, T = touch with 1 body part, P = physical help with two or more body parts.

Therapist's Post-Intervention Evaluation for HW __HOLLY__________Date___

General Mobility Skill Self-evaluation Questions	**YES**	**NO**
1. Did HW achieve her whole transfer goal today independently?	Yes	No
2. Did HW achieve some of her transfer steps today?	Yes	No
3. Did the therapist help HW with just a touch (just using one hand or foot)?	Yes	No
4. Did the therapist give HW verbal help (talk to you)?	Yes	No
5. Did the therapist give HW physical help beyond a touch (have to use most of her body to lift, support or help HW)?	Yes	No

Discreet Mobility Skill Task-specific Self-evaluation Questions	**YES**	**NO**
1. Did HW prepare for transfer by removing obstacles (move right armrest out of the way), make sure her wheelchair is turned off before starting the transfer, and remove her pelvic belt?	Yes	No
2. Did HW push up from the wheelchair to scoot onto her bed, keeping her trunk balanced and stable and legs safely in line with her body?	Yes	No
3. Did HW lift one leg, or both legs onto her wheelchair seat from the legrests using leg strap, or pant legs, or her legs themselves, and keep them in line with her body (not twisted), keeping her trunk balanced as you moved onto the bed?	Yes	No
4. Did HW continue to push up with her arms to position herself on the bed, keeping her trunk balanced and stable, and keeping her legs safely positioned on the wheelchair?	Yes	No
5. Once HW was fully and safely on her bed, did she pull her legs all the way onto the bed safely (one-at-a-time, or together), and settle herself in bed?	Yes	No
6. Did HW sit up and reposition her body and legs in preparation for return to her wheelchair?	Yes	No
7. Did HW lift her legs from the bed and place them on the wheelchair seat (singly or together, may use strap)?	Yes	No
8. Did HW scoot her body by pushing up with her arms toward her wheelchair?	Yes	No
9. Did HW alternately re-position her legs on the wheelchair seat and/or legrests while scooting her bottom into her wheelchair?	Yes	No
10. Did HW finish the transfer by ensuring that her body and legs were safely aligned in her wheelchair, right armrest secured down, and pelvic belt re-attached?	Yes	No

Self-initiated support requests (no prompting):
Adjustment topics (prompted): What would you change or do differently next time?

Therapist's Benchmark Evaluation on Dependent Measure: ***Transfer from Wheelchair to bed, and back to Wheelchair - HOLLY***

Transfer Benchmark	**Achieved** **Yes No**	**Assistance Level (Prompts)** **I L V T P**	**Self-initiated supports (tally)**
1. HW prepares for transfer by removing obstacles (moves her right armrest out of the way), makes sure her wheelchair is turned off before starting the transfer, and removes her pelvic belt.			
2. HW pushes up from the wheelchair to scoot onto her bed, keeping stable and balanced trunk and legs safely in line with body.			
3. HW lifts one leg, or both legs onto her wheelchair seat from the legrests using leg strap, or pant legs, or her legs themselves, and keep them in line with her body (not twisted), keeping her trunk balanced as she moves onto the bed?			
4. HW continues pushups with her arms to position herself on the bed, maintaining balanced and stable trunk and keeping legs safely positioned on the wheelchair.			
5. Once she is fully and safely on the bed, HW pulls her legs all the way onto the bed safely (one-at-a-time, or together), and settles herself in bed. (*May use strap).*			
6. HW sits up and repositions her body and legs in preparation to return to her wheelchair.			
7. HW lifts her legs from the bed and places them on the wheelchair seat (singly or together, may use strap).			
8. HW scoots her body by pushing up with her arms toward her wheelchair.			
9. HW alternately re-positions her legs on the wheelchair seat and/or legrests while scooting her bottom into her wheelchair.			
10. HW finishes transfer by ensuring her that her body and legs are safely aligned in her wheelchair, right armrest is secured down, and pelvic belt is re-attached.			
% Mobility skills accomplished:		I = V = T = P =	Total # self-initiated support requests:

C4

THERAPIST'S Post-Intervention Evaluation for TP __TOBY_______________Date_______

General Mobility Skill Self-evaluation Questions	**YES**	**NO**
1. Did TP achieve his whole transfer goal today independently?	Yes	No
2. Did TP achieve some of his transfer steps today?	Yes	No
3. Did the caregiver/therapist help TP with just a touch (just using one hand or foot)?	Yes	No
4. Did the therapist/caregiver give TP verbal help (talk to you) while giving touch support?	Yes	No
5. Did the therapist/caregiver give TP physical help beyond a touch (have to use most of her body to lift, support or help TP) while also giving verbal cues?	Yes	No

Discreet Mobility Skill Task-specific Self-evaluation Questions	**YES**	**NO**
1. Did TP assist caregiver to sit up on the edge of his couch by showing he is ready to get up (TP looks at his wheelchair, or indicates yes with eyes or switch), and by keeping his head in midline (not extended back). Caregiver then assists TP to sit up on the couch?	Yes	No
2. Did TP lean forward keeping feet on the floor and arms on caregiver in preparation for standing (caregiver supports TP 25% or less at trunk – two hands)?	Yes	No
3. On the count of 3 (1- 2 – 3- stand) did TP stand taking at least 50% of his weight through his legs (may use floor footplates, or stool)?	Yes	No
4. Did TP maintains at least 50% weight through his legs and arms stay supported on caregiver as caregiver pivoted him toward his wheelchair until his backside/legs touches wheelchair?	Yes	No
5. Did TP maintain "strong legs and arms" (50% self-support) and "head in the middle" as he bent at the waist to sit down in his wheelchair?	Yes	No
6. Did TP assist with re-positioning in his wheelchair by keeping his head in midline (not extended back), and indicate his comfort level in the wheelchair using his eyes or his switch (yes, I'm comfortable or no, something's not right yet)?	Yes	No
7. Did TP indicate it time to get out of his wheelchair and back onto his couch using his eyes (gaze at couch), or answer using switch device?	Yes	No
8. Did TP assist with transfer back to couch by bringing his head forward, supporting at least 25% of his weight through his legs/feet, and arms supported on caregiver?	Yes	No
9. On the count of 3 (1 – 2 – 3 – stand) did TP stand taking at least 50% of his weight through his legs (may use footplates, floor, or stool)?	Yes	No
10. Did TP maintain strong legs and arms (50% self-support) and keep his head in midline as bent at the waist to sit back down on the couch, in upright position and not falling over?	Yes	No

What would you change or do differently next time?

TP - GOAL ATTAINMENT SCALING FOR WHEELCHAIR/COUCH TRANSFER

Check whether or not scale has been mutually negotiated between participant and therapist.	*Yes____X No_____*
Goal Attainment Levels	**Goal: TP will transfer from his couch, to his wheelchair, and back to upright sitting on his couch by: Supporting at least 50% of his weight through his legs and arms on the wheelchair/helper; staying up during pivot with head in midline; sitting down when back of legs touches the couch/chair; staying upright in sitting on the couch.**
Most unfavorable outcome thought likely (-2)	TP does not communicate transfer readiness, and requires maximum support (100%) by helper or mechanical lift to keep head in midline, stand, pivot, and sit down.
Less than expected success achieved (-1)	TP communicates with direct eye gaze or switch, and keeps head in midline, but otherwise requires 100% support of caregiver for all transfer movements.
Expected level of success (0)	TP communicates consistently with eye gaze/switch, keeps head in midline, and takes 10% weight through legs during the stand/pivot transfer.
More than expected success (+1)	TP communicates consistently with eye gaze/switch, keeps head in midline, and supports at least 25% of his weight through his legs and arms with caregiver helping 75%.
Best anticipated success (+2)	TP communicates consistently with eye gaze/switch, keeps head in midline, and supports at least 50% of his weight through his legs and arms with caregiver helping 50% or less.

Therapist's Benchmark Evaluation on Dependent Measure: ***Transfer Goal – 02 TOBY's Tally Sheet***

Transfer Benchmark	**Achieved** **Yes No**	**Assistance Level (Prompts)** **I L V T P**	**Self-initiated supports (tally)**
1. TP assists caregiver to sit up on the edge of his couch by showing he is ready to get up (TP looks at his wheelchair, or indicates yes with eyes or switch), and by keeping his head in midline (not extended back). Caregiver then assists TP to sit up on the couch.			
2. TP leans forward keeping feet on the floor and arms on caregiver in preparation for standing (caregiver supports TP 25% or less at trunk – two hands).			
3. On the count of 3 (1- 2 – 3- stand) TP will stand taking at least 50% of his weight through his legs. (may use floor footpates, or stool).			
4. TP maintains at least 50% weight through his legs and arms stay supported on caregiver as caregiver pivots him toward his wheelchair until his backside/legs touches wheelchair.			
5. TP maintains "strong legs and arms" (50% self-support) and "head in the middle" as he bends at the waist to sit down in his wheelchair.			
6. TP assists with re-positioning in his wheelchair by keeping his head in midline (not extended back), and indicates his comfort level in the wheelchair using his eyes or his switch (yes, I'm comfortable or no, something's not right yet).			
7. TP indicates it is time to get out of his wheelchair and back onto his couch using his eyes (gaze at couch), or answer using switch device.			
8. TP assists with transfer back to couch by bringing his head forward, supporting at least 25% of his weight through his legs/feet, and arms supported on caregiver.			

9. On the count of 3 (1 – 2 – 3 – stand) TP stands taking at least 50% of his weight through his legs (may use footplates, floor, or stool).			
10. TP maintains strong legs and arms (50% self-support) and keeps his head in midline as bends at the waist to sit back down on the couch, in upright position and not falling over.			
% Mobility skills accomplished:		T = P = I = V =	Total # self-initiated support requests:
% Mobility skills accomplished:		T = P = I = V =	Total # self-initiated support requests:

Note: I = independent, L = look, V = verbal, T = touch with 1 body part, P = physical help with two or more body parts.

C5

Therapist's Post-Intervention Evaluation for C.H. _______CARLA **Circle**

General Mobility Skill Self-evaluation Questions	**YES orNO**
1. Did C.H. achieve her whole cycling goal today (prepare for riding, ride the designated distance safely and with appropriate hand signals, ride back to garage, and put away bike and helmet, with visual observation only)?	Yes No
2. Did C.H. achieve some of her cycling skills today?	Yes No
3. Did the therapist help C.H. with just a touch (just using one hand or foot)?	Yes No
4. Did the therapist give C.H. verbal help (just talk to you)?	Yes No
5. Did the therapist give C.H. physical help beyond a touch (have to use most of her body to support or help you)?	Yes No

Discreet Mobility Skill Task-specific Self-evaluation Questions	**YES or NO**
1. Did C.H. prepare for cycling by opening the garage door, taking out her trike, putting on her helmet, and getting on the trike?	Yes No
2. Did C.H. ride from the garage and over the yard to the driveway without stopping or hitting an obstacle, and without constantly braking? (*some verbal cues to avoid obstacles, stay in 1st gear, etc. OK)*	Yes No
3. Did C.H. ride down the driveway using her brakes as needed to slow speed and stop at the end of the driveway to look for traffic before moving onto the road? (*Verbal cues only to use brakes, or to keep pedaling, and to stop to check traffic before getting on the road)*	Yes No
4. Did C.H. ride on the right side of the road toward the western designated mailbox? (*Verbal cues only to stay out of the middle of the street and to watch for cars)*.	Yes No
5. Did C.H. signal with her left hand to turn around, and check traffic before turning back east? (*verbal cues to stay out of the middle of the street and to watch for cars).*	Yes No
6. Did C.H. ride on the right side of the road toward the eastern designated mailbox? (*verbal cues to stay out of the middle of the street and to watch for cars).*	Yes No
7. Did C.H. signal left turn around to head back down the street to her driveway?	Yes No
8. Did C.H. signal left turn before turning onto her driveway?	Yes No
9. Did C.H. ride back over her driveway and yard back to her garage?	Yes No
10. Did C.H. end the ride by putting away her trike and safety helmet, and closing the garage door?	Yes No

Adjustment Topics

Based on your performance today, what will you do differently during the next session toward achieving your cycling goal?

C.H. - GOAL ATTAINMENT SCALING FOR CYCLING ___________

Check whether or not scale has been mutually negotiated between participant and therapist.	*Yes_X___ No_____*	
Goal Attainment Levels	**Goal 1: Riding Adult Trike**	**Score**
Most unfavorable outcome thought likely (-2)	C.H. doesn't ride the trike. *(Therapist did not provide opportunity to ride the Trike.)*	
Less than expected success achieved (-1)	C.H. requires constant verbal assistance with all of the cycling skill tasks, plus physical assistance with at least 5 out of 10 cycling tasks.	
Expected level of success (0)	C.H. cycles with verbal assistance for only steps 5-10	
More than expected success (+1)	C.H. cycles with verbal cues only for steps 2-6	
Best anticipated success (+2)	C.H. cycles completing all steps with visual observation and encouragement only (no verbal cues for direction)	

Therapist's Benchmark Evaluation on Dependent Measure: Cycling with only Visual Observation CH) ***CARLA' Tally Sheet***

Cycling Benchmark	**Achieved** **Yes No**	**Assistance Level (Prompts)** **I L V T P**	**Self-initiated supports (tally)**
1. CH prepares for cycling by opening the garage door, taking out her bike, putting on helmet, and gets on the bike.			
2. CH rides from the garage and over the yard to the driveway without stopping or hitting an obstacle, and without constantly braking?			
3. CH rides down the driveway using brakes as needed to slow speed, stop at the end of the driveway to look for traffic, and signal before moving onto the road? *(V cues*)			
4. CH rides on the right side of the road? (*V cues only)*			
5. CH signals with her left hand to turn around, checking traffic. *(V cues only)*			
6. CH rides on the right side of the road heading in the opposite direction. *(V cues only)*			
7. CH checks traffic and signals turn around to head to driveway.			
8. CH signals before turning into her driveway.			
9. CH rides up driveway and yard back to garage.			
10. CH ends the ride by putting away her bike and helmet, and closes the garage door.			
% Mobility skills accomplished:		I = 2 V = 9 T = 4 P = 1	Total # self-initiated support requests:

Note: I = independent, L = look, V = verbal, T = touch with 1 body part, P = physical help with two or more body parts.

APPENDIX D

Baseline (also Maintenance and Generalization) Sample Script

Clinician-Directed Intervention Sample Script

Student-Directed Intervention Sample Script

Baseline Sample Script

"Today we will work on your goal to safely and independently transfer from your wheelchair to your living room couch, and these are the steps you will perform in order to reach your goal. Now show me how you get from your wheelchair to sitting on your couch, and I will write down all the steps you complete. I will make sure that you will be safe and I won't get hurt." With his best effort, John went onto complete his wheelchair-to-couch transfer, without therapist intervention unless he was in danger, until he achieved to criterion, 30 minutes elapsed, or John indicated he was finished. Once John finished his wheelchair-to-couch transfer, I said "Great! You completed your wheelchair-to-couch transfer. Now you will take about ten minutes to answer some questions about how well you did today. Your caregiver will answer questions about your performance too. You can just circle or answer 'yes' or 'no'." "Now, John, based on your progress today, what would you change the next time you work on your wheelchair-to-couch transfer?" "Now, John, you can take a five-minute break to do something else for a bit, and then we will do your wheelchair-to-couch transfer again."

Clinician-Directed Session Sample Script

"Today is Lorrie's PT session. That means that I will tell you what mobility goal to work on, what exercises and activities to do, and the order in which we will do them. We will work for about 30 minutes on different exercises and activities." "John, show me how you perform your mobility skill before we start the exercises." The participant and caregiver complete the post intervention evaluation for the first time during the session. I continue working with the participant on exercises and re-check performance on the mobility skill tasks throughout the session. "Okay! We are finished with the exercises. Now, you will answer some questions about what we did today, and tell me what you would change during the next session." The therapist again evaluates the participant's mobility skill steps accomplished and all other dependent measures. The participant and caregiver complete the post intervention evaluation.

Student-directed Session Sample Script

"This is your PT session. We'll call it John's session. That means that you will choose the mobility skill you want to work on, what exercises and activities to do, and the order in which we will do them." "If you want to change, add, or stop an activity, we will do so." First, I want to see how you do your mobility skill before we do any exercises, and I want you to answer some questions about your performance." "We may evaluate your progress at least one more time before today's session ends."

"So, John, what mobility goal do you want to work on?" John picks wheelchair-to-couch transfer because he wants to do his homework on the couch and he likes sitting on the couch to visit with his friends. "John, show me how you get on the couch now." John attempts the movement from his wheelchair to his couch. "I see you can push your wheelchair over to the couch on your own, and you get your seat belt unbuckled, and brakes locked." "What needs to happen for you to get all the way onto the couch?" John might or might not give suggestions like getting out of the chair, reaching for the couch, etc. "That's right John, you need to get closer to the couch, lift yourself up, and then twist over to the couch, while your feet are on the floor. These are all steps that we can work on today. Where do you want to start?" John tries to slide across his chair to the couch, but gets caught on his wheelchair tire. “John, it looks like you are stuck. What can you do to fix it?” “John, how do you get your bottom off of your wheelchair when you do wheelchair push ups? Yes, that’s it. Let’s try that!” We continue working on the transfer skill, using other exercises that John knows to help him achieve each component skill. “John, is it helpful to keep your feet down on the floor before you lift up? Is it helpful for me to put one hand on your knees as you get ready to lift out of the chair?”

“John, we are almost finished for this session. Let’s talk a minute together with mom to see how getting on the couch worked for you today.” To John and caregiver: “Is getting on the couch still something you want to do? Do we need to change anything to make it easier for you to do next time?” Mom might answer that it seemed helpful to place one hand on John’s knees in order to keep his feet one the floor; or telling John to “lift and twist” seemed to work to get his bottom over to the couch.

“John, during these last few minutes, you and mom need to complete this evaluation about how you did today”. John and mom complete their respective evaluations. “John, what do you want to change or do differently next time we meet?” “Okay, we are finished for now.”

APPENDIX E

Fidelity of Intervention Check Sheets

Baseline Procedural Steps (also Maintenance and Generalization)

Clinician-Directed Procedural Steps

Student-Directed Procedural Steps

Baseline *procedural steps – Fidelity Check Sheet*

Step	Procedural Step	Yes	No	NA	Comment
1	Review mobility goal and skill tasks (mutually decided previously) with participant and caregiver.				
2	Describe measures that I will observe and write down during the therapy segments (skill steps, help needed, etc.).				
3	Instruct participant to do the mobility goal, and remind participant that therapist will not give direction or help unless safety issues arise.				
4	Therapist gives no direction or help (verbal or physical) unless safety concerns arise.				
5	Therapist records dependent measures including mobility steps, assist needed, participant's request for help (minimum of two times, up to 5 times)				
6	Participant & caregiver complete self- and caregiver evaluation while therapist completes her evaluation: do a minimum of 2 but up to 5 times during the session.				
7	With therapist prompt, participant & caregiver suggests adjustments, or what he/she would do differently next time.				
8	After break to do evaluations, have the participant repeat the mobility goal as above.				

Clinician-Directed *Procedural Steps – Fidelity Check Sheet*

Step	Procedural Step	Yes	No	NA	Comment
1	Therapist states: "This is my therapy session. I will be in charge and choose all activities and the order we do them today".				
2	Review mobility goal, skill tasks, and menu of treatment activities (previously mutually decided) with participant and caregiver.				
3	Describe measures that I will observe and write down during the therapy segments (skill steps, help needed, etc.).				
4	Participant does initial mobility goal performance (with little or no therapist direction unless safety is an issue).				
5	Therapist chooses activities and exercises, instructs participant and directs intervention activities without explanation (about 30 minutes of intervention activities).				
6	If participant objects to an activity or wants to stop, therapist continues on, cajoles participant to continue, and does not deviate from her plan.				
7	Therapist directs participant to perform the mobility goal again without any other explanation (OK to acknowledge completion of session, and "good job"; "we're done now").				
8	Therapist records dependent measures including mobility steps, assist needed, participant's request for help.				
9	Therapist provides needed direction and support for participant & caregiver as they complete self- and caregiver post-intervention evaluation while therapist completes her evaluation.				
10	With therapist prompt, participant & caregiver suggests adjustments, or what he/she would do differently next time.				

Student-Directed *Procedural Steps – Fidelity Check Sheet*

Step	Procedural Step	Yes	No	NA	Note
1	Therapist states: "This is your therapy session. You will be in charge and choose all activities and the order we do them today".				
2	Review mobility goal, skill tasks, and menu of treatment activities (previously mutually decided) with participant and caregiver.				
3	Participant chooses activities and exercises from the previously established menu.				
4	Therapist describes measures she will observe and write down during the therapy segments (skill steps, help needed, etc.).				
5	Therapist asks: *"What's the goal you'll work on today?"* Participant does initial mobility goal performance (with little or no therapist direction unless safety is an issue). [SDLMI-Phase 1, Question #1)				
6	Participant performs their chosen mobility goal before intervention commences (with little or no therapist direction unless safety is an issue).				
7	Therapist asks: *"How did that go for you? What parts do you need to work on (or what do you need to learn or do) in order to achieve your goal"?* [SDLMI-Phase 1, Questions 2,3,4)				
8	Participant and therapist work on previously participant-chosen activities and exercises. Therapist follows participant's lead relative to order of activities, omission or addition of activities, changes, or ceasing activity altogether (at least 30 minutes of intervention activities). [SDLMI-Phase 2, Take Action – What's my plan?]				
9	While working on activities, therapist converses with participant about the relevance of the exercise to the participant's chosen mobility goal. Discuss relevance to post-secondary goal; i.e., *"improving cycling increases fitness and stamina so I can hold a job".* [SDLMI-Phase 2, Take Action, Question 5]				
10	If participant wants to stop, change the activity, or do something different, therapist agrees, but asks why the change or stop, and when we will start again. We re-assess the goal and move on with the changes. [SDLMI Phase 2, Take Action, Questions 6, 7, 8; Phase 3: Adjust Goal or plan, Questions 9-12]				

11	After about 30 minutes of exercises, therapist says: *"We've finished the exercises. It's time to do your mobility goal again"*. We discuss mobility goal again, relate it to postsecondary goals and disability-related impairments. [SDLMI-Phase 3: Adjust plan –What have I learned, Questions 9-12]				
12	Participant completes mobility goal again while therapist records dependent measures including mobility steps accomplished, assist needed, participant's requests for help or changes. [SDLMI-Phase 1, Questions1-3 again]				
13	With needed direction or support, participant & caregiver complete self- and caregiver post-intervention evaluation while therapist completes her evaluation. [SDLMI-Phase 3: Adjust plan –What have I learned, Questions 9-12]				
14	With therapist prompt, participant & caregiver suggests adjustments, or what he/she would do differently next time and how it will help her achieve her goal. [SDLMI-Phase 3: Adjust plan –What have I learned; do I know what I want to learn next? Questions 9-12]				

APPENDIX F

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