Disability Experiences of Childhood Therapy: Recollections and Recommendations for

Pediatric Therapy

BY

FAYE WEINSTEIN
B.S., Northwestern University Medical School, 1972
M.M.Sc., Emory University, 1983

THESIS

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Defense Committee:
        Carol Gill, Chair and Advisor
        Tamar Heller
        Demetra John, Physical Therapy

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LIST OF ABBREVIATIONS

APTA   American Physical Therapy Association

AT   Assistive Technology, equipment

CAPE   Children's Assessment of Participation and Enjoyment

CPN   Critical Physiotherapy Network

DS   Disability Studies

ICF   International Classification of Function

ICF-CY   International Classification of Function – Children and Youth's version

OT   Occupational Therapy, Occupational therapist

PAC   Preferences for Activities of Children

PE   Physical Education

PT   Physical Therapy, physical therapist

PPTs   Pediatric physical therapists

SoP   Section on Pediatrics, APTA

UIC   University of Illinois at Chicago

US   United States

WHO   World Health Organization

SUMMARY

This study retrospectively explored childhood PT experiences of eleven Disability Studies scholars with lifelong physical disabilities to: gain the developmental perspective of therapy, the effects of those experiences over time, and inform better pediatric PT practice and education. Eleven disability studies scholars participated in email interviews, or on the telephone as accommodation for access, about their childhood and teen physical therapy experiences. Demographic, physical therapy setting type and location information was also collected.

Results were organized into six major themes: characteristics of positive and negative physical therapy experiences; PT in the family context; values conveyed through therapy; the quality of relationships with therapists; lasting developmental impact of therapy, including the development of disability identity and scholar perspectives; participant recommendations for current and future pediatric PT practice and educational programs; and implications for PTs working with adults with lifelong, very early onset, physical disabilities. Within those themes, there were 22 subthemes described.

Member checking revealed that findings were relatable to more than the majority of the participants. Discussion related to themes; contributions to the literature; intersections with participant characteristics; limitations of the study; and recommendations for future research and application of the study's findings.

I. INTRODUCTION

People, women, who had more power than I did, took me in to their space, they took some of my clothes off, touched me in ways that were painful, and I felt that I had no choice in it. To me it's a form of sexual assault even though it was completely asexual. It's the power and domination that is part of the abuse…It's important for professionals to understand and acknowledge the power differential that exists between themselves and the children with disabilities they are supposed to be serving . . . . I hope professionals will recognize that the very nature of their role is an oppressor because of the massive power differential between themselves and the children they work with, or should I say 'work on.'

Excerpt from "The Stairs Don't Go Anywhere" (Giancreco, 1996)

"The Stairs Don't Go Anywhere," is the title of Giancreco's (1996) retrospective interview with disability self-advocate Norm Kunc and his perception as a disabled child[1] of a seemingly absurd therapy activity on a practice staircase typically found in a physical therapy department. Reading Giancreco almost immediately changed my perspective on therapy and later my scholarship as a Disability Studies (DS) student. Now, it inspires my thesis.

What was novel about Giancreco's interview then, and even now, is that it gave voice to disabled children, as a particularly vulnerable and difficult to document group in a most common, but vulnerable, situation: therapy. When I first read this interview, I had been practicing pediatric physical therapy for several decades, as well as studying disability studies for several years. As a disability studies scholar, I was familiar with the critique of physical therapists as oppressors, but it previously was difficult to comprehend completely. This

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[1] In this thesis, whereas the dominant "politically correct" terminology in the United States is "people with disabilities" which indicates that the person is more important than the impairment, I will use "disabled people" to denote the social, political and economic barriers in the environment that disable people (Oliver, 1990). However, as Magasi (2008), an OT and DS scholar, suggested, usage of both terms indicates a respect of both perspectives that I will follow in the remainder of my thesis.

interview, not only coming from a child's perspective, but also the fact that a child ascribed meaning to therapy and physical therapy activities intensified its impact on me. It disturbed me to realize my potential for what some disability scholars have termed professional "oppression" of the very children that I was "supposed to be serving" and that these therapy experiences had a negative effect into adulthood.

Reading Giancreco (1996) made clear that in my practice and that of my colleagues, we had failed to recognize the power and privilege of adults and non-disabled individuals in relationships between adult and child, professional and parent, or professional and disabled child. I became uneasy with my interactions, which, at that time, or at some time in the future, a child with whom I am working might experience as overly intrusive.

As an example, I became very aware of the child's perspective during my treatment of a child with spina bifida who was approximately 18 months old. The child had seen an out-of-town therapy specialist with a reputation for hastening the ability to walk in children who typically have delays in their walking. The child's therapist's instructions for a home exercise program were to impose the entire adult's force against the child's body (and the child's will) to "increase their strength through resistance in coming to stand" by towering over the child, by having the child "push up against the adult." In fact, the physical therapist had designed the activity to be a physical power struggle in the name of therapy. When I asked the child's parent the question: "Would you do this same activity to the child's non-disabled sibling or twin?" because the activity was so clearly (physically) oppressive in design, I was surprised when the parent answered, "Yes, if it was asked of me—or would 'help' them." This, to me, was a complete submission of judgment to the professional, which reproduced the power

relationships critiqued in works of disability studies scholars (Marks, 1999). I am concerned about "breaking" the child's sense of agency and motivation to move or to succeed with this kind of treatment. I can no longer either do these things myself, or ask others to do so, whether they are parents or students or other professionals.

Next, Giancreco's interview changed my perspective on the literature by increasing my awareness of two critical gaps in the discourse. First was a lack of voice from children with disabilities; Giancreco's interview with Kunc remains a rarity in both the health professional and disability studies fields, which have done little yet to document the experiences of disabled children in physical therapy. The second was a lack of any bridging of the chasm between disability studies, particularly scholarship rooted in the social model of disability, and physical therapy.

The "hope" to which Kunc refers in the quote above also prompts an invitation to address these gaps in the discourse. As for the lack of children's views, the most apparent solution is to gather these perspectives either by directly questioning children about their experience of physical therapy or, as in Giancreco's narrative, to ask adults to reflect retrospectively on their childhood experiences. My hope is that exploring disabled children's experiences in therapy, rehabilitation, and/or physical activity (hereafter referred to only as "therapy") will help inform better pediatric therapy practice and will broaden the reach of disability studies scholarship into rehabilitation.

II. LITERATURE REVIEW

A.   **Introduction**

This review will introduce the medical and social models of disability and explain how differently the field of Disability Studies views disability from more traditional disciplines. Because the World Health Organization's (WHO) International Classification of Function (ICF) (2001) has become the framework for disability and health and is used by the physical therapy field as a contemporary framework for disability, I will explain the ICF and components, followed by the physical and occupational therapy perspectives on the ICF, social model, and disability studies. Next, the way in which disabled children's voices, experiences, and thus their identity have been muted historically is explained. Finally, I discuss the few available studies of childhood that include experiences from disabled adults in physical therapy, rehabilitation in general, and in physical activity.

B.   **The Medical Model of Disability, the Social Model's Critique, and the Rise of Disability Studies**

1.   **The medical model of disability**

In what was termed the "medical model" by disability scholars and activists, pathology or impairment is viewed as residing within an individual, and needs fixing, intervention, or curing from medical or health professionals. Professionals in educational, medical, and health systems, and eventually the public, considered that disability was a deficit, or deviation from the Gold Standard of "normalcy." The cure or "fix" for impairments may come at great cost, seemingly at times without regard to intrusion into family life or one's childhood (Marks, 1999; Oliver, 1990). In the medical model of disability, medical and health

disciplines have dominant power over disabled people, including professional knowledge over

the experience of living with a disability (Magasi, 2008). The professional control and stigma

that people with disabilities experience from the dominant power of science and medicine

throughout society is "medicalization."

2.   **The social model of disability**

In contrast to the medical model of disability, the social model constructs

disability socially as a product of the environment and cultural and political phenomena

(Oliver, 1990). The social model of disability distinguishes between individuals and their

impairment, and thus externalizes disability to the barriers in society and the environment that

disable them as a (minority) group. Disability activists conceptualized the social model of

disability in response to disadvantages that disabled people experience, which in turn lead to

their isolation and exclusion from participation in various aspects of society. Impairment is

viewed as an aspect of diversity and a single aspect of human experience, instead of a

diagnostic category (Ferguson & Nusbaum, 2012; Hubbard, 2004). Disability is not a natural

consequence of impairment, but rather results from an environment in which the resources do

not adequately account for difference (Marks, 1999). Within this model, disability is not a

problem within the individual –it is a social issue (Ferguson & Nusbaum, 2012), and includes

the social conditions which further disable people with impairments (Wendell, 2001).

Proponents of the social model of disability reject the charity model of viewing people with

disabilities and, instead, work toward social justice for all, including people with disabilities

(Longmore, 2003). Therefore, their focus is on universal rights, opportunities and access to

participation in society, and away from the privilege and power of non-disabled people

(Linton, 1998). As a social phenomenon, access applies to more than just physical architecture, but to every aspect of society (universal design) (Charlton, 1988). In addition, in the social model of disability, there is less emphasis on health and mobility than in rehabilitation (against an ideal or normative model without sickness and disability), and instead more of a focus on environmental adjustments.

Liz Crow (1996), a disability activist interested in disability scholarship, described the impact of first learning of social model thinking because her feelings matched her personal experience. In her personal narrative, she referred to her life "before" and "after" what she described as a transformative experience to *social model thinking*. As a person with a disability, Crow initially felt relieved with the realization that the barriers to her independence or function did not originate from *her body,* but rather stemmed primarily from the social, attitudinal, and physical environments.

However, the social change (inclusion, elimination of barriers to participation) called for in the social model of disability philosophy could not solely solve all the issues of discrimination and disadvantage that Crow and people with disability experienced. As one of the first people to call for revision of the social model, she asserted that, in response to the medical model's focus on decreasing, preventing, or overcoming impairment effects, the social model had excluded people whose impairments were an essential part of their lived experience of disability. Crow argued that missing from the experience of disabled persons were *differences* in how their bodies worked, those meanings to the individual, as well as the disabling social treatment of persons with different bodies (or minds). These three aspects of impairments further divided the disability community. Crow specifically noted pain, fatigue, depression and

chronic illness as disabling impairments, which required recognition and expansion of the social model. Later, Shakespeare and Watson (2002) agreed on the need for a social model of impairments, and added considerations of the potential impact of impairments on personal identity and psychological well-being. Winance (2006) further elaborated on how the impairment of pain affects not only the individual, but also on how the individual is able to relate with others: thus affecting agency and interaction with the social environment.

3. **<u>Disability studies</u>**

Disability Studies is the interdisciplinary and multidisciplinary academic field of scholarship that grew out of the social model and the disability rights movement in response to the medicalization of disability. In Disability Studies, the disability community and the academy enrich and balance each other to inform the field. The disability community contributes experiences and perspectives, while the academy contributes rigor through examination of policies and structures that disempower people with body and mind differences (Longmore, 2003). The DS field examines the intersection of disability and impairment with culture, history, policies and structures. Disability Studies seeks to replace the historical disempowerment of people with disability, stigma, and exclusion (from the medical model) with pride, and education of society and professional disciplines in a different paradigm on disability (Linton, 1998). Disability Studies challenges the structural and institutional, pedagogical and attitudinal barriers to equal and just inclusion and participation for people with disabilities in their stand-alone, separate curricula, as well as infusing professional and other (including general undergraduate) curricula with disability studies. However, although Disability Studies is an

interdisciplinary field, there is scant literature exchanged between disability studies and physical therapy (Maitland et al., 2012; Raman & Levi, 2002; Roush & Sharby, 2011).

C.   **Reframing therapy practices with the disability studies lens**

Within the health related fields, there is little literature that has attempted to reframe practice to incorporate a DS perspective. Disability activists, scholars, and theorists have promoted the social model of disability, and the field of disability studies has grown. However, although health related fields have made some steps towards incorporating the social model of disability and DS into practice and training, the health disciplines have not truly adopted the social model of disability. Within that literature, the WHO is central and tied to disability studies.

The World Health Organization's ICF (2001) was intended to be a "value-neutral," universal communication and classification of function/disability and health. The ICF is a standard from which researchers, policy makers, economists, and clinicians can universally share and compare information and interventions on health and disability. As the professional physical therapy organization, the American Physical Therapy Association (APTA), officially endorsed and adopted the ICF framework of disability and health for professional education and practice (APTA, 2008), it is important to include an overview of it for this research.

The ICF is a biopsychophysical model of disability and health, in which both coexist and are on a continuum. Like the social model, the ICF considers disability a part of the universal human experience. The ICF is also an interactional ecological model which, again like the social model, emphasizes the interactions of people with the environment, and reflects the complexity of disability.

The ICF framework does shift the focus away from a solely medical model of disability "fixing" or "curing" an individual's impairment (replaced by a value neutral "function and structure" dimension of the ICF). "Barriers" and "facilitators" or "constraints" and "supports" exist within each of the contexts, and may be physical, psychological, and/or personal. As in the social model, the ICF instead focuses practice *towards eliminating barriers* to independence, control, and participation in the social, political, attitudinal, and physical contexts or environments.

Because of the neutrality of the terms, some refer to the ICF as an "enablement framework" (Goldstein et al., 2004), and others feel that the ICF "integrated the social and medical models", which are hybridized in rehabilitation models (Raman & Levi, 2003, p. 796). Still others criticize the ICF because in fact it remains a functional-limitation model, in which the opposites of the neutral value components are "limitations", e.g., activity and participation, and activity and participation limitations (Hubbard, 2004). Participation is the ultimate desired outcome of the interactions between all of the other ICF components, and as in the social model of disability, there is to be equality in participation with others in each of the "contexts" that are important to the disabled individual.

The ICF-CY (WHO, 2004) is the Children and Youth's Version of the ICF in which activities and contexts are specific to developing infants, children, and youth. For example, the ICF-CY environmental contexts include school, home and family; activities; and people, including adults and peers in each of the social environments that change with age and development. The "ICF" will represent both the ICF and ICF-CY in this literature review, as the ICF-CY is an elaboration of ICF that relates to children as does the thesis.

Although the disability community gave input into the development of the ICF and its precursors, the individual and the health condition are essential components of the ICF. This is in contrast to the social model of disability and disability studies, where there is less focus on the individual, and more on disabled people as a collective group. Health is also considered by some an ableist standard, in which the opposite is a negative concept.

Disability activists were successful in insuring the inclusion of the subjective voice and experience of *individuals* with disability, both important to DS and the social model of disability, as essential additions to the ICF model from previous iterations (Ueda & Okawa, 2003). The "health condition" and the "body structure and function" (impairment) in the ICF relate to Crow's (1996) and other disability activists' additions to the social model of disability with both the subjective voice and the environmental influences on the impairment. Similarly, the ICF also makes a distinction between disability and impairment, and both result from interactions with personal and environmental contexts.

1. **The physical therapy perspective**

Although APTA adopted the ICF as current theoretical framework of disability, there has been some difficulty and subsequent delay in embracing the ICF and the concepts of DS into physical therapy practice. Roush and Sharby (2011) believe that, in part, physical therapists' ableist attitudes of "discrimination in favor of able-bodied" are responsible for some of the delay in ability to work outside of the medical model. Other researchers agree that ableist attitudes demonstrate the pervasiveness of the medical model on physical therapists and other health professionals (Papadimitriou, 2001). These researchers also point to the need

to change the attitudinal environment towards disability, as advocated by disability studies

scholars.

Physical therapists have admitted the tension of bridging the social and medical models

in physical therapy practice (Raman & Levi, 2002; Roush & Sharby, 2011). To Roush and Sharby

(2011) it is a "paradox" of intervention: to work simultaneously at decreasing individual

impairments, while externalizing disability to the environment and celebrating it as a part of

diversity. Earlier, Raman and Levi (2002) felt that therapists should be able to connect the two

models by shifting their focus from the individual's problems towards improving quality of life

for people with disabilities throughout their lives.

The social model of disability had preceded findings of a disablement framework in

analysis of physical therapy practice documents in the United States. The APTA defined

disability as the limitation or inability of an individual to function in specific *roles,* based on

expected social *norms* (at that time) within a context, and limited to the *"immediate"* social and

physical environments (Raman & Levi, 2003, p. 796). In 2008, with the ICF endorsement, APTA

slated corresponding language and conceptual changes in all professional organizational

documents to follow. It was not until 2014 that one of the documents that Raman and Levi

originally analyzed (APTA's 2003 *Guide to Practice)*, was updated to reflect ICF language in the

Guide to Physical Therapist Practice 3.0, and is now an online version (APTA, 2014). Other

documents now have expanded beyond the individual to include the *ethical* responsibility to

global health, to social justice including rights and participation (APTA Code of Ethics, APTA).

However, the key documents for education continue to be based upon "A Normative Model of

Professional Education" (APTA, 2004), and "A Normative Model of Physical Therapist Assistant

Education" (APTA, 2007), which are resources for PT and Physical Therapist Assistant educators respectively, and remain as the name indicates, "normatively based".

Papadimitriou (2007), as a non-therapist disability studies scholar, demonstrates a notable exception in the literature by describing how physical therapists share power in the "privileged" knowledge of expectations of progress in collaborative therapy "work with" adult rehabilitation patients in the clinical setting. However, that is one of the few (qualitative) articles to demonstrate that kind of exchange between the two disciplines.

Whereas Kunc (Giancreco, 1996) was relating to rehabilitation or PT in a clinic setting within the medical model as a child, many pediatric therapy practices had also already moved out of the medical settings into the multiple settings in which children with disabilities "live, learn, and play" (later ICF-CY, 2004 language for home, school, and community). However, in some ways, pediatric therapists simply took the medical model into these settings and the philosophy with it. According to Davis and Watson (2001), "professional culture" practices (health related and special education, etc.) were a subsequent replay of the domination/decreased power/medicalization. For example, assessments focus on deficits, impairments, and individual differences from the norm, extended to qualify for, and receive ongoing services in schools. In contrast to adult therapists discussed above, pediatric physical therapists inherently focus on current as well as future issues for children with disabilities as they age and develop. Pediatric therapists work to promote participation both individually and as a group, in comprehensive programs, which address multiple areas of the ICF, and are similar to rehabilitation models. Physical therapists also work in assistive technology and rehabilitation models in roles of evaluating physical environments, providing, modifying equipment, which is

more within the social model of disability, in that they adapt the environment and eliminate barriers to function and to participation.

With the advent of the social model of disability and the ICF (WHO, 2001, 2004), pediatric physical therapists now promote healthy functioning and address the attitudinal, structural, institutional, and other social factors that are barriers or facilitators to maximal participation (Carey & Long, 2012). Pediatric physical therapists strive to provide activities and participation, and opportunities for participation that are "available to and/or expected of peers in the same context" (Coster quoted in Goldstein et al., 2004, p. 115). These pediatric physical therapy roles encompass the concepts of equal opportunities and full participation in the community as does disability studies (Block, 2004) and the ICF. In the recently revised mission statement of the APTA "transforming society by optimizing movement to improve the human experience" (APTA, 2013), there is no mention of addressing impairment or disability. With more focus on society and the human experience, the new APTA mission would appear to be more in line with the social model of disability. However, the new mission can also be interpreted from the social model perspective as devaluing (diversity in) the way people move, and thus sounding "disingenuous, and almost eugenic" (Gill, 2014). In other words, by proposing to "fix" all of society, by "fixing" movement, the mission still seems to reflect a medical model perspective which, again negates differences. Furthermore, the mission seems to omit goals for participation and inclusion that are not only key tenets of the social model, but also central to the ICF, which also was adopted by the APTA.

There are nascent efforts that have begun to bring DS into physical therapy and rehabilitation practices internationally through the online Critical Physiotherapy Network (CPN,

criticalphysio.net). CPN is comprised of "critically-informed academics, clinicians, practitioners, researchers and students" who are "challenging physiotherapy practice and thinking" by "critically reflecting on the profession's past, present and future". A proportionately small number of the physical therapist researchers in this organization are from the US.

2. **Occupational therapy perspective**

Occupational therapists (OTs) have discussed disability, disability studies, and the OT critique of the ICF. According to Kielhofner (2005), OTs have intentionally distanced themselves from traditional rehabilitation practices that oppress disabled people, distract from disability identity, and are the primary criticisms of health professionals from DS professionals. Occupational therapy has developed its own disciplinary concepts and parallel practices. For example, Kielhofner (2005) developed the practice Model of Human Occupation. The central concept of "occupation," is defined as "the ordinary and familiar things that people do every day", that are essential to "development, health and life, health and life satisfaction" (Hemmingsson & Jonsson, 2005, p. 572). Occupation also includes autonomy, self-actualization, and meaningful relationships to the individual. Now, OTs strive to provide resources and support disability identity as the social change part of their practice. Kielhofner (2005) also reflected on the shift in focus from clients' "conformity" (or lack thereof in some cases) with therapy, to more self-advocacy and self-determination, whereby disabled people have a voice. This type of shift, of including the voice of disabled people regarding therapy and truly adding a DS perspective, is part of this study's intent in promoting the participants' retrospection and reflection. In addition, the study addresses the recommendations of Magasi (2008), an OT and DS scholar, who advocates medical and allied health professionals use

criticisms of the medical model as opportunities for reflection and growth towards the disability community, and their medicalized power to update practices for responsiveness and relevancy and to empower people with disabilities.

Hemmingsson and Jonsson (2005), occupational therapists, joined others (Ueda & Okawa, 2003) in their criticism of the ICF, in that the subjective voice of experience was a missing element, and that "participation" in the ICF is observed (and often tested) by professionals who are "outsiders" or non-disabled people. Additionally, adults assess participation of children, who may also cast an additional, incorrect bias on participation. Thus, if, and how meaningful the interaction of participation (or part of the participation) and "occupation" (play or school for children) is to children is unknown without, in this case, the child's subjective experience.

Kramer, Olsen, Mermelstein, Balcells, and Liljenquist, (2012) did study what participation actually means to children and youth with disabilities themselves. Kramer's group (2012) found that disabled children and youth considered the essential meaning of participation as being truly engaged and included in activities together with their peers. In fact, it has been primarily (Canadian) pediatric occupational therapists, with only a few physical therapists, who have developed the few assessments at the participation level of the ICF to capture children's voices either via self-evaluations/reports or subjective components (Section on Pediatrics, APTA, 2012). For example, Kramer, Smith, and Kielhofner (2009) and King et al., (2004) have developed and studied children's self-report measures of participation. King et al.'s (2004) Children's Assessment of Participation and Enjoyment (CAPE) and the Preferences

for Activities of Children (PAC) assess children's participation in non-school recreation and

leisure activities, and include participation in physical activities.

3. **Other health professionals**

In a 2008 article, Murphy, Carbone, and the American Academy of Pediatricians

Council on Children with Disabilities reached out to other health professionals and families to

advocate for more opportunities for safe physical activity, sports and recreation participation.

They pointed out children's rights to participation in society and in PE despite existing barriers,

especially those of attitudes. These American pediatricians exemplified unique leadership in the

literature in collaboration and partnering with others for participation and physical activity.

As demonstrated in the literature from rehabilitation science/allied health perspectives,

DS has been more accepted in the literature, and probably in practice by disciplines *other than*

physical therapists—especially OTs and nurses. This lack of incorporation of the social model by

PTs and the medical profession, when compared with the other disciplines as described above,

has recently even been noted by Michael Oliver, the "father of the social model" in a blog post

on the Critical Physical Therapy Network (CPN, Nicholls, 2015).

D. **Disabled Children, Their Voice, Identity and Status**

According to some DS scholars, disabled children experience the greatest amount of

hegemony within their relationships, the greatest amount of governing, and the least amount

of independence and control over their own lives (Davis & Watson, 2000; Watson et al., 1999).

That is, children with disabilities have less power than professionals, non-disabled and disabled

adults, as well as their non-disabled peers. This hegemony occurs within each of the disabled

child's everyday environments within the corresponding professional system (e.g., educational,

family, and health/medical). These "close" primary environments are characterized by the presence of additional adults who work in their "professional cultures" (Holt, 2004), and who infringe upon the child's privacy with adult surveillance, even to the extent of their play with their peers (Davis & Watson, 2001). For example, disability is played out for disabled children in school, where not only do physical barriers restrict movement and interactions with peers, but children are also limited by geography or classroom structure. Extra adults assist, and the regulated locations in the school and classroom often reflect hegemony of ability, or disablist expectations for children with mind and body differences (Holt, 2004).

Health and medical professionals have felt justified in using their power and privilege in the objectifying "medical gaze", e.g., by undressing children for therapy, or in front of other physicians to demonstrate a different or atypical structure (Foucault, cited in Marks, 1999, p. 73). The experiences are "humiliating", and a violation of privacy and confidentiality (Blumberg, 1990; Marks, 1999; Wilson, 2005). According to Olkin (1997), the medical gaze is also an example of violations of the human rights of disabled children. Other disabled children's human rights relevant to therapy experiences include "having control of one's own body", "to live in a barrier free and tolerant physical and social environment." Olkin also has charted tasks for therapists and families to address each of her human rights. Children with disabilities feel challenged in each of these rights by some professionals in the medical model of disability.

Reactions from others at personal and institutional levels, or the psycho-emotional "barriers to being," that children with both learning and physical disabilities experience, may also affect the development of identity, self-confidence, and self-worth (Connors & Stalker, 2001). Thomas' (1999) concept of "psychoemotional disablism" discussed by both Connors and

Stalker (2001) and Watson (2012), that disabled children additionally experience from people who have direct day-to-day contact with children, is superimposed on the general disablism which disabled people experience from society. Other aspects of disabled children's identity, including "to be a child," "having a positive identity which incorporates the disability," and "not being treated as 'normal' but different, as a part of diversity," are human rights (Olkin, 1997), which are also challenged from professionals.

Further, Watson (2012) argued that disabled children and their experiences differ from those of disabled adults, in that children are not a collective as are adults. And, although generally supportive of the social model of disability, he argued that children's social experiences vary related to the interaction of the children's type of impairment (e.g., congenital or acquired, progressive, mental, intellectual, or physical), the outcomes, and differing needs. Exploring both the impairment and the social disability also parallels the ICF's framework of interaction between the (social) environment and the impairment.

In fact, the lives and experience of disabled children are so unique that scholars recently proposed an entirely new field of study to not only expand the fields of both disability studies and childhood studies, but also as a separate discipline to explore the uniqueness of disabled children's experiences (Curran & Runswick-Cole, 2014). "Disabled children's childhood studies" seeks the perspectives of disabled children regarding aspects of their lives that are not compared as a binary or "other" with children without disabilities. Rather, Curran and Runswick-Cole's proposed area of research probes within the systems and structures and personal (e.g., embodiment) and social differences that are a part of childhood experiences for disabled children. This study fits into this new area of research.

E.   **<u>Disabled Children in Therapy</u>**

One way of better creating more of a balance of power between health professionals and the clients they serve is by eliciting disability narratives or the voiced perspectives of disabled individuals for research, education, and practice (Franits, 2005; Kielhofner, 2005; Roush & Sharby, 2011). Disability narratives also expand the subjective voice in the ICF and are a way to broaden knowledge of the experience of disabled people.

Aside from Giancreco's interview with Kunc and a number of polio narratives, there has been little documentation of children's voices related to their experiences in therapy. A literature search of databases revealed, among other childhood experiences, polio narratives from adult survivors in the United States (Wilson, 2005); a personal narrative from an Icelandic physically disabled activist who is not a polio survivor (Haraldsdottir, 2013); two Scandinavian studies with adults with cerebral palsy that included retrospective childhood memories (Jahnsen, Villien, Aamoot, Stanghelle, & Holm, 2003; Sandstrom, Samuelsson, & Oberg, 2009); studies directly with physically disabled children from Australia (Bricher & Darbyshire, 2004); from Canada with children with cerebral palsy about walking in therapy (Gibson & Teachman, 2012); and finally, with American physically disabled children related to participation and physical activity at school (Taub & Greer, 2006). I noted nationalities and disciplines here to point out the contrast between origination from the US and other countries, and the few from the US, which may indicate another lag in the mindset and disabilities studies research. These studies will be reviewed in the next section.

1.   **<u>Disability therapy narratives</u>**

Survivors with polio had many shared experiences in therapy and rehabilitation that reflected the social aspects and the medicalization of disability that are similar to the experiences of other physically disabled people today. Among the polio experiences there are often some sections regarding their therapy because of the heavy focus on rehabilitation and physical therapy in polio treatment. The polio experiences varied, as some children with polio had temporary impairments, while others had residual impairments and grew into adulthood with lifelong, significant disabilities.

When retelling the childhood experiences with polio, there were descriptions of wet, smelly hot packs made of woolen army blankets, followed by painful stretching, and some therapists who were forceful, and insensitive to the amount of children's pain (Wilson, 2005). Others were highly motivated by their therapists to succeed in their rehabilitation. As told in the narratives, the therapists and nurses who were in charge of respirators/iron lungs seemed to wield their medicalized power over the disabled children with polio, which frightened children who were dependent on the machines for breathing. For some people, the recurrence of the impairments and increased disability with the onset of Post-Polio Syndrome, brought back the emotional trauma of the pain, struggle, and rehabilitation experiences from their childhoods that they might have buried for decades. Although recovering from the physical disability, the emotional effects of the medicalization remained.

Documenting therapy experiences from polio survivors is important because of the distinct historical era that essentially ended in the United States with the cure for polio. These survivors are aging, and the potential of their stories may be lost.

In a collection of papers in the area of "disabled children's childhood studies," a female DS scholar recalled her PT among other parts of her childhood (Haraldsdottir, 2013). Physically painful experiences made her so fearful of attending physical therapy as a child, that she developed strong avoidance behaviors, including not speaking when she was uncomfortable with any professionals where there were normalizing activities and a deficit focus. Those behaviors were then medically "diagnosed", when she was really only trying to refuse the activity.

2. **Disability therapy, and therapy and physical activity experiences**

In this section, I review studies of both childhood experiences of physical therapy, and physical therapy and physical activity that researchers have done first, with children with disabilities directly, and second, with physically disabled adults retrospectively. The retrospective studies, like aspects of therapy experiences that had carryover into Kunc's (Giancreco, 1990) adult life in the introductory quote of this thesis, have also examined the effects into adulthood.

Australian nurses interviewed children and youth growing up with a disability regarding the "relative powerlessness" and inability to be heard in their own health care decisions, including therapy, and their experiences with the tension between the medical and social models (discussed earlier) (Bricher & Darbyshire, 2004/5). Assistive technology, therapy, and remedial surgery, which health professionals routinely imposed upon children and young people have both personal and social interpretations (Bricher & Darbyshire, 2004/5). What may have been best practices for the professional, may not have considered the feelings, concerns, or effects which the young people experienced from them.

Further, powerful therapists' attitudes demanded compliance with therapy to not only progress in therapy goals, but also to prevent what physical therapists presented as "scary consequences of non-compliance" (Bricher & Darbyshire, 2004/5). Differences between tiny gains in therapy goals and what the youth often experienced as "not useful" were often along philosophical lines; i.e., professionals in the medical model of disability vs. youth reflecting a social model of disability (Bricher & Darbyshire, 2004/5). The authors emphasized considering the social, emotional, and physical impact on a disabled young person as superseding the all-out investment of time, energy, and emotions.

Physical therapists have been among the last professionals in the literature to critically analyze their rehabilitation practices for disabled children and the traditional assumptions underpinning them (Gibson et al., 2009). They called for more research to seek children's perspectives directly regarding their experiences in physical therapy, and for professional reconsideration of practices.

While others have included walking as part of their research, Canadian "physiotherapists" looked specifically at how experiences of children with cerebral palsy, along with their parents, were influenced by the universal goal of walking in physical therapy (Gibson & Teachman, 2012). The critical researchers found that therapy practices reiterate the social value of walking and disability. Walking therapies exemplify the priority for "normalcy", ableist values and attitudes that children subsequently internalize as a part of their identity.

Scandinavian researchers coupled physical activity with physical therapy, when studying adults with cerebral palsy regarding their childhood experiences (Jahnsen et al., 2003; Sandstrom et al., 2009), which is the reason for my inclusion of physical activity experiences in

the study. Physical activity is a wider definition of bodily movement that skeletal muscles produce and includes not only exercise (as often in therapy), but also sport, fitness, recreation, and play for all children. Physical activity is important to this study because it is an activity which participation has become a goal of therapy (in the ICF framework) for physical therapists and other health related disciplines today. However, professionals also address barriers to participation in physical activity that disabled adults and children face.

Swedish researchers interviewed, and Norwegian rehabilitation researchers surveyed, adults with cerebral palsy about physical therapy and physical activity experiences throughout their life, to determine the personal and environmental "prerequisite" factors that influence them (Sandstrom et al., 2009); and how childhood physical therapy and physical activity impacted their physical therapy and physical activity in adulthood (Jahnsen et al., 2003). Related to their childhood, Sandstrom et al. (2009) found that enjoyable activities included a focus away from their deficits and physical "training" per se; activities done with others, and that children's understanding the purpose of their therapy and/or meaningful goals were important. Like Sandstrom et al. (2009), Jahnsen et al.'s (2003) findings included the importance of fun and playful group activities as motivation for physical therapy. Activities where children learned about the long-term health implications and their personal responsibility for their health, translated into adults participating in physical activity they enjoyed (Jahnsen et al., 2009).

On the other hand, respondents in all of the above studies also reported negative and (unintended) psycho-emotional effects, e.g., feeling psychologically "traumatized" and deficient, as well as an effect on their body image (Giancreco, 1995; Jahnsen et al., 2003).

Respondents also disliked the deficit focus on their body (Sandstrom et al., 2009) and its differences, especially with surgeries, rehabilitation and assistive technology (Bricher & Darbyshire, 2004/5). Pain and fatigue were also reported during childhood PT activities.

3.   **Disability Physical Activity and Participation**

Physically disabled children also related their experiences related to lack of participation in physical activity during recess or gym (Taub & Greer, 2006). The children experienced apprehension of teasing, bullying, exclusion, and decreased expectations of their abilities from both their peers and adults/teachers. However, by participating in physical activities, the children in the study felt that they had increased not only their own and others' perceptions of competence, but also their identity as first a child, rather than as "the disabled or different child." Like Kunc, who counteracted deficient feelings from his therapists with his own attitude of disability as diversity of human experience (Giancreco, 1995), these children expressed important sentiments. Children's feelings of competence were contesting the socially constructed decreased expectations of competency and identity (Davis & Watson, 2001). These therapy, physical activity, and gym experiences exemplify important ones in disabled children's process of identity development, which Connors and Stalker (2001) also discussed along with feelings related to body image.

III. PROBLEM STATEMENT, RESEARCH QUESTIONS, AND GUIDING CONCEPTUALIZATIONS

A. **Problem Statement**

Disability studies scholars seek to transform the practices, attitudes, assumptions, and biases of "ableism" in society from the dominant, medicalized power of professionals operating from the medical model, to a social model of disability. However, a philosophical and pragmatic gap remains between disability studies and the health professions (as also noted by Magasi, 2008), and in particular, physical therapy. A further result is a divide or lack of intersection in the literature and acknowledgement of the other perspective in practice in both fields of physical therapy and disability studies.

Traditional practices of health and medical professionals have left some people with disabilities with untold childhood memories that affected their adulthood, identity, self-confidence, and self-worth. Physical therapy may not have been as responsive to the criticism or history of professional dominance, as have some of the other health professions, nor as accepting of the social model of disability, and now of the ICF. There also seems to be a decreased awareness of the power differential between therapists and their clients. Perhaps this is due in part to the missing voice of experiences of disabled people, among which there is even less documentation from the perspective of disability studies. In addition, relatively little scholarship exists that has reconceived therapy as anything other than an arm of the medical model of disability.

This study seeks to extend the literatures between DS and the disability community on the one hand, and physical and other rehabilitation therapists on the other, by foregrounding childhood experiences of therapy. While there is now a greater emphasis in research than

before on obtaining information directly from children in general, the literature regarding the impact of therapy on disabled children is limited. Even with the addition of retrospective studies from adults with disabilities, recent research emphasizes the physical impact, rather than the psychosocial aspects of childhood therapy experiences. The study aims at eliciting the meaning of therapy, including the subjective and social experience of impairment from those therapeutic interactions, and impact, if any, into adulthood. Finally, there have been few studies examining those childhood therapy experiences longitudinally, and none from both the personal and a disabilities studies perspectives. My participants, as DS scholars, apply that conceptual lens to their personal experiences of therapy through childhood and, in some cases, into adulthood. In this way, the study informs a more sensitive, complete perspective with which to approach disabled children, their families, and the practice of pediatric physical therapy.

B.   **Research Questions**

In order to explore childhood therapy experiences of disabled adults and the impact on their lives, and in attempts at addressing some of the aforementioned gaps in the literature and pediatric therapy practice, this study posed the following questions:

- Through the intellectual lens of disability studies, how would adults with lifelong physical disabilities describe their childhood experiences in physical therapy, physical activity, and/or rehabilitation?

- How did those experiences affect them developmentally?

- What are the implications of those reflections and how might their perspectives inform pediatric physical therapy practice?

C.	**<u>Situating, Theoretical/Conceptual Framework Perspective as a Researcher</u>**

My personal and professional experiences and conceptual frameworks are interrelated and somewhat indistinct. Like informants in the proposed study who have life-long physical disabilities, my mother also had a lifelong physical disability from polio. She often spoke of her PT, so that I have been familiar with disability and physical therapy from a young age. It was not until close to the time of her death that I heard of some of her experiences with power differentials from professionals. My professional work as a PT has been extensive with a developmental age span perspective: infants to adults with physical disabilities. Because of the span of my professional experience, I can offer an historical perspective to the interactions between children and therapist. My initial disciplinary training was strongly from the medical model of disability. I worked in clinics, rehabilitation centers, and hospitals, before becoming more community-oriented and working in both inclusive and self-contained classrooms and schools and homes, and community organizations in various venues of movement, e.g. aquatics. In the adapted aquatic community, however, I integrated the therapy with recreation or non-medical traditions, especially with Red Cross' Adapted Aquatic's motto of "Focus on Ability" (American Red Cross, 1976).

Coming from a medical model of disability tradition, as a DS student, I had a transformative experience to the social model of disability, which the Giancreco (1996) interview reinforced from a disabled child's perspective when I felt so strongly about both child and disability rights. Thus, both my participants and I have a DS background, with human rights, social justice towards equal participation, and social model of disability conceptual frameworks. I am an "insider" with my participants in that I too have both non-apparent disabilities and

inconsistent physical impairments, and have also experienced the dominant medicalized power differential as a patient. Insider/outsider issues with my participants in the study are complicated in various ways regarding professional background, academic standings, and other situations. Additionally, I am a Caucasian woman.

A.   <u>**Research Approach and Rationale for Use**</u>

This study used qualitative inquiry via email interviews. The research is broadly

phenomenological in terms of retrospectively documenting peoples' subjective experiences,

thoughts, and feelings in their own words, from their own points of view (Patton, 2002; Taylor

& Bogdan, 1984). In addition, it is broadly phenomenological related to the exploration of the

social meaning that my participants have attached to their experiences of therapy and

professional interactions (Taylor & Bogdan, 1984). To my knowledge, this is the first time that

these unique dual personal and academic participant perspectives have been explored

systematically with respect to physical therapy. Because disabled children have had their voices

regarding their therapy marginalized and silenced, or not even questioned for decades, this is

the appropriate approach to elicit those voices, as advocated by the ICF and disability studies.

In order to understand and analyze the social phenomena of childhood disability

therapy experiences, I used a modified grounded theory approach. Rather than having

numerous rounds of iterative sampling, I modified the classic grounded theory approach by

using one round of purposeful sampling with participants who have had both the personal

experience of the phenomenon of interest, and expertise in discussing and analyzing disability

phenomena. Rather than producing a theory, I explored the theoretical importance of the

participants' stories and responses to the questions.

B.   **<u>Data Collection</u>**

I used semi-structured open-ended questions in email interviews in order to obtain

details about participants' childhood therapy experiences (Franits, 2005). Open-ended

questions allow for the greatest amount of response, and thus the richest data from the

participants (Patton, 2002).

An interview guide was used in order to provide structure and consistency to the

interviews (See Appendix A). The guide included questions, possible probes (re-iterating the

participants' statement in attempts at retrieving further details) (Owens, 2007), and if needed

allowed for follow-up questions that might have occurred for clarification or elaboration of

details. Interview questions were derived from the literature. The interview guide was pilot

tested with three volunteer scholars in DS who had experienced physical therapy as children.

Using their feedback about the interview questions, the guide was revised to state the

questions in the most clear, unambiguous way.

Interviews were conducted primarily by secure, encrypted email, but telephone

interviews were an available accommodation for access. Both email and telephone interviews

allow greater accessibility related to geography and disability than do face-to-face interviews,

as well as other benefits of increased interviewee control, convenience, and ability to self-edit

and self-express (Egan, Chenoweth, & McAuliffe, 2006; Franits, 2005; & Novick, 2008). Further,

email interviews were a means of broadening access to individuals underrepresented in

research due to language or impairments of fatigue, personal care needs (Ison, 2009), in

preparation for potential participants with significant physical disabilities since early childhood.

Because of professional written experience that is a part of their scholarship as DS scholars,

email interviews were deemed optimal to obtain the richest data possible. However, I also acknowledged that for some scholar participants, face-to-face interviews might have been easier. The efficiency of written transcripts for prompt coding and analysis, and broader access to potential participants from email interviews was a personal benefit to me as researcher.

Telephone interviews lasted 45 to 60 minutes, and were audio taped and transcribed word-for-word. As needed, I contacted participants for clarification with follow-up questions that also served as member checking.

C.   **Research Sampling and Informants' Characteristics**

Twelve participants were enrolled in the study, but one did not complete the interview process resulting in a sample of 11. All were recruited through purposive sampling, which refers to intentionally recruiting a sample to provide the richest data relevant to the key research questions (Patton, 2002). I used purposive sampling in order to have participants with a unique combination of shared experiences in phenomena of interest (i.e., therapy as a child), and who are in a position to be thoughtful (i.e., DS scholarship) to compound the most informationally rich responses from both of the areas (Patton, 2002). I also used snowball sampling strategy in order to request further "experts" who may not have seen initial recruitment materials, or who were recommendations from other participants or consultants/key informants. Furthermore, my selection of Disabilities Studies scholars as a key informant sample of adults with lifelong disabilities provided yet an additional layer of thought, theory, and social model thinking, beyond that of other adults with similar experiences as children. This has particular importance to my study, as part of the purpose of my study is to inform and bridge social model thinking with what has been termed "impairment-based" (Gill, 2013), personal communication, or

therapy services. However, as previously stated, the current goal of many physical therapists has progressed towards intervention aimed at participation within the ICF. Thus, eligibility criteria included: DS graduate students, graduates, faculty, and other scholars who have had childhood experiences in therapy; are people who have been physically disabled since early childhood (5 years old and younger); are at least 21 years old; able to communicate either by email or, as an accommodation for accessibility, verbally on the telephone in order to answer interview questions; and willingness to discuss their childhood experiences.

Within the group of eligible volunteers, I used a sampling strategy to select participants and to provide diversity in details within my phenomenon of interest (participants' childhood therapy experiences) (Patton, 2002; Sandelowski, 1995). For example, not only demographics (current age, type of impairment, gender), but also other characteristics of the therapy received (e.g., the location and type) were variables that may have expanded the description and meaning of the participants' experiences. Although I am protecting the anonymity of study participants and not focusing on a medicalized impairment, some identification of this variable is important. Some researchers have argued the value of examining environment- impairment interactions as participants' experiences may differ based upon either the disability or the impairment (Crow, 1996; Shakespeare & Watson, 2002; Watson, 2012). Therefore, I gathered some personal demographic data, e.g., the impairment (congenital or acquired early in childhood, age of onset, etc.).

I sampled adults who had become physically disabled before age five, rather than children, to participate in discussion of their childhood experiences for several reasons. Connors and Stalker (2007) asserted that children might not have adequate language to describe the

desired experiences that related to more of a social model of disability, whereas scholars will have both academic and personal experience. I, like other researchers (Jahnsen et al., 2003; Sandstrom et al., 2009) who also used retrospective studies with disabled adults, wanted to gain the longitudinal perspective of childhood therapy and physical activity experiences, and possible impact into adulthood. In retrospective studies, participants can also evaluate the meaning of their experiences and their social interactions (in this case, of their childhood) (Taylor & Bogdan, 1984). The disadvantage of retrospective interviews is recall bias in which the respondent may not recall events accurately or may have altered memory of the events, or portray them in such a way to be socially accepted. However, this risk was minimized by the fact that study participants are scholars whose academic roles are to critically analyze DS issues. In addition, the research questions and the interview questions were designed to provide a framework for participant recall which may also diminish recall bias. Also, the important perspective is how participants had perceived their experience.

Sample size is a topic of discussion for qualitative research vs. quantitative research to assure maximal trustworthiness (Coyne, 1997). Some researchers state the importance of saturation of data, or collection until no further new findings emerge, or informational redundancy (Patton, 2002; Sandelowski, 1995). According to Sandelowski (1995), the sampling strategy noted above (purposeful, with maximal variation) is also an appropriate way for me as an individual researcher with limited resources on a project such as my thesis to limit my sample, but yield "credible and analytically … significant findings" (p. 182).

D.   **Recruitment Procedures**

I recruited participants with lifelong physical disabilities by:

•   Sending study announcements with requests for posting to national disability-related organizations, networks, and listservs; other DS graduate programs listservs in order to preserve the anonymity of program affiliations of participants, and contribute to the diversity of opinions and geographic locations; and

•   Sending direct emails to personal contacts with a description of the study and request for participants.

Seventeen potential participants responded who self-selected, and were screened based upon pre-defined eligibility criteria and additional sampling criteria (demographics, type of therapy, impairment, and disability, etc.), either by telephone or using encrypted web tools, which participants accessed through a link which I provided. Five people did not meet the eligibility criteria.

E.   **Ethics and Consent Process**

Study procedures to protect the rights of participants as human subjects' received approval (Research Protocol # 2014-0500) by the UIC Institutional Review Board (Appendix B). After the potential participant completed the eligibility screening, the Research Information Sheet and an opportunity to ask questions was attached to the email with the first interview question. Participants indicated their consent to participate in the study by answering the interview questions.

The consent covered participation in the study; applicable audio recording and the transcription of phone interviews; and possible follow-up contacts for further clarification or

member checking. Participants were informed that they could choose the extent to which they answer or not answer all of the questions and to withdraw from the study at any time during the process. Minimal risks and benefits were stated. Efforts to safeguard confidentiality included: having the emails encrypted with HTTPS; one computer, locked with passwords, on which the emails, transcriptions, and sound files of recorded interviews were located; removal of emails off the computer as soon as possible and storage of de-identified information; separate storage of identifying information: and storage on a password-protected, encrypted file, computer, and drive. The only people who had knowledge of the participants were myself and my research advisor, Dr. Carol Gill. Only de-identified information was given to a graduate of the program for a peer audit for triangulation of themes or coding.

F. **Research Procedures/Activities**

As the Principal Investigator, I:

• Emailed the interview questions to the participants, scheduled and conducted telephone interviews for those individuals who requested them as accommodation for access;

• Used two digital recorders with a speaker telephone – one as a back-up, to minimize the risk of loss of data during any (accommodated) telephone interviews;

• Followed up with probes, or additional questions for clarification;

• At completion of interviews and collection of all data, de-identified each of the responses;

• Wrote additional field notes as soon as possible after each interview;

• Made a word-for-word transcript from the audiotape of any telephone interviews; and

- Removed emails out of email client as soon as possible and transferred to a Word Document for thematic coding.

G.   **Analysis – Thematic Analysis and Modified Grounded Theory**

My analysis of the study included several phases (Hanson, Balmer, & Giardino, 2011; Patton, 2002). I did each of the following:

- Read and re-read the emails and transcripts to develop immersion into the data;

- Identified possible passages/quotes relevant to the research question;

- After each interview, read emails or transcripts for constant comparison;

- Wrote a one-page summary of the interview including interview notes/memos;

- Coded the first interview and continued to add codes with successive interviews (Coding in qualitative research is a method of categorizing, classifying, or summarizing words or phrases in the data.);

- Chunked or clustered codes into themes and grouped themes into theme families that were based upon analysis of patterns (similarities, differences, attributes) and relationships between/across recurrent codes to determine what part of the codes go together and which do not (Patton, 2002; Saldana, 2009);

- Examined all the data that has been coded to see if I had covered all the themes suggested by the data, and no new, non-redundant themes emerge, or "data saturation";

- Reflected and reviewed the data to examine patterns in the themes, connections with each other and the meanings to the participants; and

- Reflected on personal issues and journaled reflections.

All thematic data analysis was done by hand, rather than by using coding software.

H.   **<u>Enhancing Rigor and Trustworthiness</u>**

I used several strategies to strengthen the study's rigor and trustworthiness, as well as manage the bias.

•   Piloted my interview guide with three volunteers in order to obtain feedback regarding clarity of questions, etc., and incorporated each of their suggestions into the next successive pilot interview, and into the final iteration of the guide.

•   Used reflexivity and [bracketing] to journal my reflections to acknowledge my awareness of ableist biases which I was attempting to lay aside (Papadimitriou, 2001), and wrote memos regarding my biases, feelings or responses to the interviews, and the research process itself, for separate analysis. I considered my reflections in successive interviews, and in the development of the themes and subthemes, as well as in my discussion, where I have summarized some of the issues. With the reflections, I was able to also see the developmental progression in my research.

•   Received peer audits: My advisor was the primary auditor of the study, with whom I discussed analysis of all themes until we agreed on the titles, and their placement. In consultation with my advisor, I selected a graduate of this program who is familiar with qualitative research techniques as a second peer auditor. The second auditor was given two de-identified transcripts that I had coded and subsequently developed themes and subthemes, to audit. The audit involved reviewing how I arrived at my findings from the raw data; feedback on the coding, analysis, and interpretations of themes and subthemes that I pulled from the transcript; and my management of any personal biases within those transcripts. This audit was used to confirm the themes gleaned from the audited transcripts.

- Conducted member-checking with my participants by emailing a summary of my themes and subthemes regarding their agreement with my interpretations of their interview data. Seven of the 11 participants responded, all very positively, that they could relate to the findings. A summary of the comments may be found in the Discussion Chapter of my thesis.

- Managed data with a paper trail which can be peer audited. I have transcripts and one-page summaries of all interviews; the audit results from my auditor of two de-identified transcripts; journal of reflections; the email I sent out with the summarized themes for the member- checking, and collected comments.

V. RESULTS

Email Interviews were conducted with eight participants, and four telephone interviews were conducted with people who had requested them for accommodation for access. Eleven of the initial 12 participants completed the interview.

In order to preserve anonymity, and particularly because participants are known and recognized members of the disability community, demographics are stated in the aggregate, and not in relation to each other. There were 4 who identified as men, and 7 who identified as women. There were 2 people each in their twenties, fifties, and sixties; none in their forties, and five in their thirties. Ages ranged from 26 to 67. Eight people identified as Caucasian, 1 as Latino, and 2 as Asian. Four participants were current or former faculty, 6 were current graduate students, and 1 was a PhD graduate of a DS program. Graduate students were in social sciences and education, as well as in disability studies. Three people had acquired illnesses or disabilities before they were 5 years old. The other 8 participants were born with their physical disability: 3 had congenital orthopedic conditions; and 5 had cerebral palsy.

Participants received therapy in various settings: hospitals as in-patients and out-patients, and in military hospitals (a less common kind of hospital); therapy centers not associated with hospitals; public, private, and residential schools; and home. At home, participants received therapy from their parents, from therapists, and did home programs themselves (with the exception of 4 participants). Some participants received PT in more than one practice setting, which sometimes were simultaneous with each other, and sometimes not. Some participants also received therapy in multiple geographical locations, which included three countries other than the US (Italy, Argentina, and Taiwan), as well as 13 states in the US.

Participants who received therapy in more than one country were asked to contrast

experiences in those countries. Therapy activities varied across the settings, with walking,

muscle stretching, and developmental motor activities being the most common, and in multiple

settings. Participants reported using the following devices in their therapy: communication

board, plaster cast/night splints for sleeping; prosthesis for upper extremity; shoe insert:

walker, crutches, and braces; and wheelchairs. Seven of the 11 participants reported having

had surgeries, with physical therapy after their surgery.

In the remainder of this chapter, I present themes that emerged from the analysis of the

interviews. I illustrate the themes with quotations from the transcripts in the participant's own

words. The Table of Themes, Subthemes and Categories on the following pages summarizes the

narrative that follows.

TABLE I
THEMES, SUBTHEMES AND CATEGORIES

THEME	SUBTHEME	CATEGORY
A. EXPERIENCES OF THERAPY	1. POSITIVE THERAPY EXPERIENCES	Activities that were play-based, intrinsically fun, sensory, individualized, with meaningful goals. Children felt successful. Social/group aspects of physical therapy.
	2. NEGATIVE THERAPY EXPERIENCES	Lack of choice about going to PT. Rationale for interventions not adequately explained. Equipment uncomfortable or not useful. Activities were painful, where pain not acknowledged or child ineffectively distracted. Children felt unsuccessful. Socially separated from peers.
B. PHYSICAL THERAPY IN THE FAMILY CONTEXT	1. FAMILY ROLES AND DYNAMICS	
	2. CONTINUUM OF SUPPORT FOR CHILDREN'S PT	Involvement. Resources. Time. Values. Investment.
	3. DECISIONS REGARDING STOPPING VS. CONTINUING THERAPY	
C. VALUES CONVEYED THROUGH THERAPY	1. FIXING, REHABING, "MAKING ME/IT BE NORMAL"	
	2. SYMBOLIC VALUE OF WALKING	Universal PT goal. Social emphasis.
	3. "TRUST ME"	
	4. "TRY HARDER"	

TABLE I (continued)
THEMES, SUBTHEMES AND CATEGORIES

THEME	SUBTHEME	CATEGORY
D. THE QUALITY OF THERAPY RELATIONSHIPS	1. POSITIVE THERAPY RELATIONSHIPS	Mutual respect. Empowering. Felt cared about holistically.
	2. NEGATIVE THERAPY RELATIONSHIPS	Medicalized Power and Objectification in Depersonalized Relationships. Power Over Bodies and Medical Gaze. Power over Communication, Information, and Language.
	3. TENSION: COMPLIANCE/DESIRE/ RESILIENCE VS. NON-COMPLIANCE/ RESISTANCE	Assumed over-competence vs. real limitations. Child and PT's frustrations fed each other's and became cyclical.
	4. LONGING FOR CONNECTION AND SUPPORT WITH DISABLED PEOPLE, PEERS	
	5. BLURRING AND DIFFERENTIATING PROFESSIONAL DISCIPLINE IDENTITIES	
E. IMPACT OF THERAPY	1. BROADER IMPACT ON CHILDHOOD	PTs' influence on: body and image, self-confidence, and identity. Children's response to "that's what they do".
	2. LASTING INFLUENCES OF THERAPY	On Adulthood. On (PT and) Development of Disability Identity as barriers or facilitators From Disability Studies Scholars' Perspectives to reclaim power over own bodies, reframe disability, join community

TABLE I (continued)
THEMES, SUBTHEMES AND CATEGORIES

THEME	SUBTHEME	CATEGORY
F. PARTICIPANT RECOMMENDATIONS	1. RESPECTING PERSONHOOD	"Treat the person as a human being." "Treat children like people." "Treat children like children." Avoiding objectification. Acknowledging children as sexual beings
	2. BODIES AND EMBODIMENT	Approaching children's bodies positively. Approaching children as whole people instead of parts to be fixed. Considering disability onset and effect on relationship to their own body and identity.
	3. THE CHIILD AND THERAPY RELATIONSHIPS	Acknowledging and sharing power through choices and communication. Validating children's pain and struggle during PT vs. ignoring or assuming non-compliance.
	4. EXPANDED ROLES FOR THERAPY	Being aware of, and promoting/not impeding disability identity development. Connecting disabled children with disability community/culture: mentors and peers. Becoming disability allies and involved in disability community and culture. Addressing bullying at school around physical activity in gym and recess.
	5. EDUCATIONAL PROGRAMS	Incorporating Disability Studies perspectives into curricula, specific courses, learning experiences. Reflecting on attitudes of ableism, communication and language re: embodiment and disability identity.
	6. PHYSICAL THERAPISTS WORKING WITH ADULTS: WHAT THEY CAN LEARN	Affirming expertise of lifelong physically disabled adults regarding their own bodies. Considering impact of childhood PT memories on adult patients.

A.　　**Experiences of Therapy**

Participants often classified their therapy experiences as enjoyable or positive or negative. These classifications were based upon several factors, including characteristics of the activities and routines themselves; interactions with others; the feeling of self-efficacy or lack of it, and attitudes or behaviors of the therapist.

Some participants had experiences that were primarily positive, some that were primarily negative, and some spoke about them both in contrast to each other. The contrasting experiences will be divided into the respective aspect in order to illustrate each side.

1.　　**Positive therapy experiences**

A participant who did not receive any therapy outside of sessions (at home) with the therapist and spent a good deal of time in her wheelchair, described PT as a "fun outing" that she always looked forward to, and where she always received what she described as "a good workout." Experiences were enjoyable with meaningful activities, and were intrinsically fun. For example, one participant's therapist incorporated swing dancing into his routine and interspersed shooting basketball with stretches, which was motivation and realistic goals for him to complete. Another learned French while the PT was stretching her legs in the whirlpool:

> *So I learned how to count as I recall, and just words and phrases I guess . . . . that was a lot of fun sort of fun. So she stretched me, and I had something else to focus on, so that was a good experience.*

> *asked me to play this game by stringing the shoestring into the different holes. I think they wanted to check how well I used my hands . . . . And I loved it because I love arts and crafts . . . . I had no idea they were observing me, as I really enjoy working with my hands.*

Participants described characteristics of what therapists did to make PT a positive experience:

> *I can recall periods of time when PT was exciting and fun and not a mere thing I needed to do because I have a disability . . . . Those were the times when physiotherapists were encouraging, focusing [on] the things I did well, celebrating with me every new milestone or goal I reached, they tried [to] change activities and exercises a little bit each time so therapy never seemed like a routine of things I needed to do.*

The change in activities, new, achievable goals and activities were personalized to their interests, which was positive for a few participants to keep their interest and not have their therapy become "routine".

Some positive experiences were related to a kind of self-efficacy that participants felt during therapy: ". . . maybe because I was feeling successful in therapy because I was learning French from her."

Some positive memories were associated with specific activities:

> *When I was a child, I would walk to the hospital cafeteria for orange juice as part of my physical therapy sessions. I loved orange juice so this also seemed like a big accomplishment to me.*

The preceding quotation was from a participant who had only walked during her therapy session.

For one participant who contracted an illness at an early age, the totality of the treatment experience and being together with her mother constituted a sensory experience that was remarkable:

> *I also enjoyed the sensuality of PT–being touched, being in the pool with my mother and the therapist . . . I remember so clearly hearing the sound of the water lapping as they were doing PT . . . . the smell of chlorine, the echoing of the sloshing water. . . . It was a way a lot of physical therapy was done in those days. We would all suit up and get in a warm pool.*

For her, it was also the shared experience in her treatment of all three people.

In school, interactions with others during therapy sessions were an important part of PT, and several participants enjoyed group activities. For one participant who described herself as a shy kid, and "uncomfortable with anything that was one-to-one," physical activities that were done in the group setting, like making a "'train' of people" were enjoyable. Another participant, as a student, enjoyed being together with other disabled kids for PT while the rest of her peers were in PE. For her, it was linked to her disability identity, because this was her sole time in her school or community to be with other children with disabilities.

2.   **Negative Therapy Experiences**

Participants who described negative experiences, often contrasted directly with those that were positive. Rather than anticipating PT as an outing, a child who received physical therapy in a residential school, dreaded it because it felt like torment. As children, PT was mandatory:

> *I would have PT five days a week, and it just drove me crazy that I could not get out of it.*
>
> *The negative, was that I had to do it on a regular basis . . . . It was not something that I got to, I didn't have any choice in the matter. I had to do it.*

The lack of choice while in therapy was something echoed by several other participants as well.

A participant who contrasted her positive and negative experiences, said that rather than the same sessions being described as fun and exciting, PT felt more like punishment:

> *PT felt like a very heavy duty, when routine took over and PT seemed like the price I was due to pay because I had a disability*
>
> Sometimes PT experiences were negative because treatment activities made no sense
>
> or were impractical to the child-participant:

> *[A]s a child I didn't quite understand why I needed to wear this piece of plastic thing in my shoes, or having this really difficult thing placed behind my heels. And also why do I have to get a piece of shoe foam when they don't even fit my regular shoes? The only size shoes that I could wear if I wanted to put the mat in my shoes would be a men's shoe size like 8 or 10, which is like gigantic, and it's like, it wouldn't work for my feet!*

Several participants used equipment or "assistive devices" or "assistive technology," which included: walkers, crutches and braces, and prostheses. Some children who used prostheses were able to abandon them, unlike other treatment activities that they did not understand:

> *a prosthetic arm was created for me and I was given therapy to help me use it. They had me pick up objects, try and tie my shoes (which I still couldn't do), etc. I feel like it was mostly a large waste of time and money . . . Unfortunately I stopped using my prosthetic arm not long after I got it, I just didn't find it useful.*

> *The shoes, like the shoes were hard, and it was not comfortable. And besides for it not to being comfortable, it was also kind of ugly and I don't think I wore them for long – maybe a few weeks or – or a few days or something.*

Participants distinguished between liking and deeming therapy experiences as negative when doing activities at which they were unsuccessful, didn't understand, or didn't "buy into."

> *So I probably didn't keep up with it the way I should have, or what they wanted me to or whatever, and so I always felt sort of like a failure but at the same time I just couldn't do it – it was painful.*

Another participant's frustration with activities caused him to change from being a quiet, well-behaved student to "something of a behavior problem" at school:

> *I'm not sure what made those activities so frustrating. I guess there's something naturally frustrating about fine motor activities when you don't feel competent doing them . . . . that's what my experience with PT was! Sheer repetition and failure.*

As might be expected, several other participants described therapy sessions that were painful as negative experiences. One participant's physical therapy was painful both at home and when she had therapy elsewhere:

> *My mother was trained to administer 1 hour of therapy each day to me for several weeks. The exercises were painful. They seemed to last forever . . . . During the [therapist] sessions, I was just trying to hold it together. There was nothing joyful about the sessions. No amount of primary colors or games could make me forget that I was in a therapeutic setting with pain.*

Some participants had pain from positioning devices that either lasted well beyond the actual physical therapy sessions, or extended into other parts of the child's life.

> *The earliest memory I have about therapy is not a good one. I remember this cardboard "V" shaped contraption, it was big enough that I, as a 3 year old, could sit on it. My legs would be strapped down, one leg on each of the lines, so my legs made a "V". I just remember it stretching my legs so well it hurt. I remember crying because how painful this was, and the fact that I was strapped down didn't help because I couldn't move to get comfortable.*

> *I also remember having to wear like these huge splints at night and braces, and so it was kind of like an ongoing process of them trying to keep my knees straight or get them to bend or, you know, those things and they were sort of messing with my whole life-… (Laughing) And I had to sleep with them on all night. And it was **just** miserable you know?! How can you sleep with that thing on, right?*

Whereas some participants had therapists who worked to address the child's needs or potential pain, other participants, in addition to the pain, experienced therapists discounting their discomfort.

> *It just hurt . . . . When it hurt, they did not take what I was saying seriously.*

> *They were telling me that it wouldn't hurt, and it hurt like hell . . . And then you know, they would want me to do the therapy but it hurt so much, that it was like, yeah just be truthful!*

For some students who were pulled out of inclusive classes, thereby separated from their peers for therapy, there were further negative social implications with classmates:

> *Being the only one pulled out of class for SpEdPE made me really conspicuous, especially on top of being a kid that looked disabled, made kids not want to associate with me.*

For this participant, the effects carried over to recess where:

I would literally spend recess every day either shadowing the playground supervisor (because she was nice to me and the kids weren't) or sitting alone against the brick building.

In summary, positive physical therapy experiences were remembered as intrinsically fun, sensual, meaningful activities for the individual child, had realistic and motivating goals, and activities where they felt successful and often done in a group. Negative experiences, on the other hand, were mandatory, routine activities for which they did not understand the purpose; painful activities in which sometimes the child's pain was discounted; and which resulted in social separation. However, it became clear that some of the positive or negative experiences were determined by the quality of the interactions, which are discussed after the Family Context and Values Conveyed in Therapy in Theme D, Relationships.

B.   **Physical Therapy in the Family Context**

Children don't receive PT in isolation. Because they are children, family involvement in therapy is inherent. When participants discussed their family involvement in PT, they talked about it within their family context. They told me how their families participated in various support roles in therapy, the varying levels of both their own and their family's commitment or investment in their therapy, and some of what the involvement meant to them.

1.   **Family roles in physical therapy**

Families generally assist in therapy for their children with disabilities at home to reinforce therapy from the therapist at other times throughout the day and week. Almost half of the participants received therapy at home with their families, and usually one parent took that primary responsibility. For example, participants' fathers built equipment such as an

adapted tricycle, a pipe frame (parallel bars) for walking at home, and a "swimming hole" for pool therapy. One participant practiced walking around the neighborhood on crutches and braces exclusively with the participant's father for leg strengthening, and learned to climb stairs to enable attendance in upper grade classrooms at school. This participant's father's role was the exception, however, as the other fathers were described as working or having businesses while their son or daughter had therapy.

Some participants' mothers carried out home exercise programs with their children – including doing them on a kitchen table, while others encouraged (at times only gently) participants to do their own home exercise programs. Some mothers were advocates regarding their child's therapy, e.g., to help therapists better understand where their child's limitations and/or needs might lie, or regulating medical intrusion, by giving permission, saying "it's okay to take off your shoes" to her child when being examined by a group of physical therapists and medical professionals. Another participant missed having that, or any kind of family input (other than PT reports sent home) regarding therapy in the residential school where the participant lived 3 hours from family. The lack of parental contact and intervention on the participant's behalf intensified the lack of voice and control the participant had in the therapy that the participant received daily. Parents also transported their children to and from therapy when not at home or in school, and some (usually mothers) participated in their session with them. Fathers often only "dropped them off."

Some siblings accompanied participants while doing their PT, either willingly, like joining them on a walk, or unwillingly "being dragged to therapy" with their disabled brother or sister. One participant remembered how sad he was when he had to do his therapy while his sibling

was able to watch TV. Another sibling provided support to his sister and family by visiting her

at the hospital out of town and videotaping PT sessions for her therapists at home. Several

participants surmised that their siblings must have resented or been jealous of the "attention"

that the participant received from his or her therapy or other medical procedures:

> *She thought it was <u>attention</u> that I was getting (laughing), because, you know I needed all this care, and I had to go to the hospital and when I came home from the hospital, people gave me parties or whatever. But, and you know, mom was trying to help me with my exercises. So I don't know that my sister reacted to that.*

Some participants felt they were unable to go to their family for support or to discuss

their feelings about PT and disability. They did not feel their family understood them as a

disabled child or what they were going through in their therapy, or they belonged to families

where discussion about disability was avoided to various extents in their homes. The lack of

discussion about disability in these families appeared to be a kind of chosen family approach to

disability and identity, which set apart the participants as disabled children. These "family

dynamics" were poignantly described in the following responses:

> *As a kid, I was really torn about all of this. It was really hard being the only disabled kid and I know it was hard on my family to be the only family they knew with a disabled kid. It also didn't help that it didn't seem like anyone really understood what I was going through, especially in relationship to therapeutic modalities. It really made me feel like I was damaged goods that they were trying to repair or the flawed first product, with my brother as the good/non-damaged second product.*

> *We don't talk about our disability in the family. And so, when we do have a conversation it's more like, "Yeah let's not care about what other people think – that's okay – they're boring people and ignore it."*

2. **Continuum of support for children's physical therapy**

Participants noted their family's level of commitment to, and investment in time,

energy, and cost that was made for them as children in their therapy. Participants sometimes

framed these investments in family contexts and values considered important to them, and

reflected aspects of their family demographics that indicated sacrifice and admiration:

> *It was a very long drive getting there, and my mom was a self-employed single parent who was barely making ends meet at the time. I don't how she managed to find the time or money, but she did.*

This participant's memory also seemed to indicate the importance of therapy to this mother.

For participants whose parents were very young, and both had to work, there were their

own significant family financial and time commitments.

One person would have liked to have had more practice at home, but parents did not

have time:

> *Because both of my parents worked full-time, I did not do any exercise outside of sessions. So, while my parents made sure I was at sessions on time, they did not provide additional therapeutic assistance . . . . I remember getting frustrated by the fact that I was not getting the help of my parents outside of PT. But it was not all their fault, I did not push myself to do things that I could do because I thought it was easier to just have my parents do it for me.*

By saying that she had not done her part, she seemed to be excusing/defending her

parents as she knew that they could not do more. At the same time, she was taking some of the

responsibility, as a child, for her family's restricted involvement, but which ultimately had led to

the participant not having reached her personal functional goal, or independence.

Another participant, whose parents were also very young, reported that even when

working opposite shifts "so we didn't need day care," her mother did do some physical activity

"homework" with her at home. Also, this participant had received only minimal motor testing

"to work on hand-eye coordination stuff":

> *but it wasn't much because my family was poor...but would refuse any help from government agencies or funds for anything related to my disabilities which has made a mess of my body as an adult.*

In these situations, where family involvement was limited because of limited family resources, participants felt there were negative consequences for their personal goal or for their body.

Participants also described their own investments in therapy in terms of periods of time. For example, they talked about their "kindergarten year" or "the childhood" that was "lost to surgery and physical therapy." However, as children, these investments in their therapy often could not be their choice.

3.   **Decisions about continuing vs. stopping therapy**

Physically disabled children received therapy for many years. Participants spoke of boundaries that families and children, rather than the therapists, placed on their commitments, or autonomy regarding the intensity and duration of therapy. This included making decisions regarding duration of therapy or other interventions, of follow-through. One participant's family supported their child's self-determination in goals for her own therapy:

> *My mom just made sure that my wound was healed properly, and that things were okay, and so I didn't go back . . . I knew that I was going to protest –*

Her mother continued her support of her daughter, which may have been contrary to PT advice or recommendations for post-operative physical therapy:

> *They wanted to make sure that – the surgery got the result . . . was supposed to make them flat. But that was not my personal goal and my family was okay with it too.*

Both child and parents' responses could also be interpreted as resilience or resistance to medicalized dominance.

Scheduling issues were a reason for one participant to end his therapy, and for another, it was not until college when therapy became a choice about having ability to control one's own resources,

that PT was discontinued. For another participant, therapy and surgery continued for a long time

after an illness and rehabilitation:

> *There would always be one more surgery (even though surgery had never improved anything, just traumatized me). . . . After a while, in my early teenage years, I did stop going to PT, although again it was never spoken of as a decision that we had come to: we ended "not with a bang, but a whimper."*

This implies the family's part in discharge, along with, or in opposition to, the therapist's

discharge, which will be discussed further in a later theme.

In summary, participants' family involvement and investment was on a continuum, which was

in some part based on their other commitments and certainly "costs" in time and money, which were

scarce for several families. The participants whose family involvement had the greatest limitations,

expressed how that loss had affected them. In the next themes, I will explore the importance of the

therapists' messages and values, and how they were conveyed to the child in therapy.

C.   **Values Conveyed Through Therapy**

    1.   **Fixing, rehabbing, making me/it be normal**

        As a child, professionals still have hope in your abilities to walk and be 'normal'. . .

Participants received several messages from therapists and other medical professionals as

children: Making the child be or making [body parts] "normal" and walking was the primary aspect of

that normalization. These messages were the dominant social and professional values, beliefs, and

meaning to children-participants and families, which then children often internalized:

> *Growing up, I thought walking was the only way that I could be a whole person. Walking was expected by my family and my therapists.*

But then because children could not accomplish "normalcy," there must be something wrong with

them:

despite the warmth I felt from the therapists, the message conveyed to me –and I don't think this came merely from my therapists, but certainly from surgeons, and also of course from society at large–was that my body was not OK and needed to be changed. I wish there had more acceptance of myself as a person.

Participants said that they felt they were being told that PTs and health professionals knew best, and they should trust them, but some participants said they did not feel that trust. This participant's quote described the value of "trust me":

You know, I don't remember how much was explained to me, but like I would understand. Sometimes I think I was lied to so much, that I wasn't really told what was going on, and asked to trust therapists and asked to do what they say, and asked to trust what the doctors were going to do.

So, children were given messages directly, or they interpreted several other iterations conveying that their bodies needed "fixing," rehabbing, or normalizing or that "PT represented a stigma that I was disabled, and needed therapy to un-disable me." These messages became a life priority, as one participant considered it a forced choice between being pulled out for therapy versus attending regular academic classes at school, and permeated their life:

And those braces – ugh! . . . and it was sort of this ongoing – therapy it seemed like, I don't know, it wasn't quite like therapy, but it seemed like it to me, to sort of <u>make my knees "normal"</u> [underlining to reflect participant's verbal emphasis] you know type of thing … but at the time it just… they were just <u>ruining</u> my life – that's what I thought.

Participants wrote about how they attempted to conform to the therapists' expectations of fixing them, and making them function more normally, but no matter what they did, they felt it was futile:

I really felt like these people were there to fix me even though my birth defect isn't fixable which led me to be really frustrated.

2.   **<u>Symbolic value of walking</u>**

Walking was the universal, primary therapy and rehabilitation goal. A participant

remembered that it was celebrated when accomplished after rehabilitation for an illness:

*I have a memory of walking along the parallel bars, holding on, and everyone being really
excited because I was walking again–that was when I was three years old*

As adults, and disability scholars, a couple of participants noted that walking as a universal goal

was unquestioned as a part of normalcy, as was the notion of why "normal" was okay, or the

goal.

*And, why make me try to . . . why did I have to walk in a walker and use my legs when I
was not going to ever walk?*

*I remember having a strong urge to walk, but no one stopped to ask why. Or questioned
the things that I wanted to accomplish from walking . . . [getting in and out of my chair.]
But I thought walking was the only option.*

Walking as an unquestioned, normative goal and treatment activity, a child's assumed lack of

options to do anything different, plus a sense from the participant that therapists had failed her

in not working more closely with her to realize her needs for learning or movement, all seem to

speak to the strength in the therapist's normative message of the value of walking.

3.   **<u>"Trust me"</u>**

All of these messages were conveyed via, or along with, another message which

could be translated as "trust me," as participants felt that the normalizing, fixing, and push to

walk messages were generally left unquestioned. In this atmosphere of not questioning, not

challenging the experts, and no one asking about why normalization was the goal, the

participants got the sense that the doctors knew best or the therapists "were doing what would

benefit" them:

a lot of it, you know maybe should have been questioned . . . we did sort of give over your power to the "experts" and you let them do what they think was best.

This participant quotation indicates her relinquishment of power as well as power over her body, which other participants had also experienced.

Along with, or another part of the message of trusting the medical professionals, was an implied value and commitment to continued therapy, or perhaps continued commitment to "fixing" that was conveyed to a participant who was in rehabilitation recovering from an illness:

after a while PT started to seem like a charade–I wasn't getting any better, the exercises weren't making any difference, but it seemed we had to go on pretending–me for my mother's sake, my mother for my sake, both of us for the doctor's sake, the doctor for our sake. Honesty would have gone a long way. . .

4. **"Try harder"**

The extension of the message of "trust me" to this participant and family was another common value heard from therapists not only to continue with therapy, but also as motivation throughout rehabilitation and treatment:

nobody wanted to admit "defeat"–to say that the battle had been lost, that I had made all the improvement I was going to make . . . and we should keep on trying, never give up

Although participants said that some messages of "trust me" from therapists – and from other health or medical professionals – were not accepted, the sometimes spoken, sometimes unspoken message of "try harder" was accepted, and even internalized by some participants:

I needed to strive, to try harder, to keep going, to never give up

As I will discuss in the Relationships Theme, these values were paired with some messages of power that had particular significance.

D.   **Quality of Therapy Relationships**

When participants discussed their therapy, they talked about relationships that were important. They described the qualities of both relationships they liked and did not like, and what made them positive or negative. Some remembered their relationships with specific therapists or staff, their approaches to therapy, the quality of their interactions or how personal they were, and how the relationships made them feel.

There were four large subthemes that emerged within the Relationships Theme: characteristics of positive relationships; negative relationships; tension around compliance; and longing for connections, leading to blurring and differentiating professional identities and disciplines' approach to them as children.

The quality of the personal connection in participants' relationships with their therapists was on a continuum, from close and personal with their personhood affirmed on one end, to a lack of connection and being objectified on the other end. Children's responses to those interactions and the type of relationship they had with their therapist varied too, of course, from feeling respected and empowered to feeling dehumanized.

1.   **Characteristics of positive therapy relationships**

In positive therapy relationships, participants felt there was a mutual respect between both individuals; participants perceived the therapists as down to earth, nice, caring, and interested in them personally as children, as people.

> *I loved when I was treated like a person, not a body or case . . . I almost forgot about the therapy per se but not about the physiotherapists that cared about me, asking me about my family, [my] life outside of therapy, that sort of things. We were two people in a relationship that got to meet each other because in this case I needed PT. But I forged friendships that have life even now that I´m not their "patient".*

This therapy relationship exemplified how her personhood was affirmed by the therapist by taking personal interest in the child that greatly expanded beyond her therapy session – both in depth and duration. The participant continued with a description of how the therapists' connection in this type of relationships affected and empowered her as a disabled child in her everyday life:

> *with therapists [where] I felt that I was being treated like a person, that I wasn´t alone (that both the therapist and I were invested in me being the best I could), I really felt encouraged, empowered, like I could tackle every obstacle, every challenge I was presented with.*

It was also this participant's therapist's mutuality in the relationship and expressed commitment to her development as a person that felt empowering.

In addition, and uniquely, this participant was so keenly sensitive to the distinction in her therapists' approach to her, that her (childhood) perceptions about the therapists' feelings towards her also played an important role in how personal the therapy relationships were.

> *Another factor was how I felt the therapist felt about me, i.e. If I felt S/he thought of me like I was another case to treat or if I felt that person really cared about me.*

Participants also described other individual characteristics of positive relationships. Because many children had physical therapy for many years, they felt the child's age influenced the interactions. With younger children, therapists seemed more encouraging and supportive, similar to interactions kindergarten or preschool teachers or family members have with young children. However, as the children got older, they felt more distanced by therapy relationships that became more businesslike, with minimal interactions necessary only for the work to be done.

For some participants, who saw their therapists regularly and long-term (vs. intermittently and briefly, e.g., for prosthesis fitting or training, or at school), there were opportunities to develop relationships that were different in the intensity or intimacy of the connection, and in the type of interactions that occurred. This participant remembered the relationship he had with his PT of six years and how there was a collaboration in the relationship, where the adult gave the child guidance in not only how to relate to her, but he also basic skills in being with others.

> *My physical therapist I had at home, who came to the house, that was also a very strong connection, and you know, sometimes, like with a parent where you really want me to do things, and I wouldn't want to do it and we'd have to work it out. She would have to use her authority. But it was a very close relationship. A very real one. A valuable one*

However, as is obvious, time alone did not determine a good relationship. His statement reflected how the therapist's engagement presented him with opportunities to work things out together.

Power that the participant experienced in therapeutic relationships related to both empowerment in positive relationships and medicalized relating and objectification in negative relationships. Some participants did not experience power issues, and one participant explained that it was avoided because of knowledge and respect of "where the other one was coming from". That said, he indicated there was also a mutual acceptance of boundaries that the participant had made with the therapist.

Mutuality in another participant's relationship, when working together with his therapist on their relationship as a part of the therapy, was also empowering and close because of the things he felt he learned from his relationship with the physical therapist, not the therapy *per se*.

There were power struggles . . . you have different ideas about things, and you work it out . . . what was empowering about it was that they were resolved. You know, it taught me how to work on those things. It made me more skilled in working with people.

Participants' physical and emotional comfort level during physical therapy affected their relationships. The ones that had the closest relationships described their interactions as positive, were comfortable being and talking with them, or joking with them. However, the comfort level of their therapy relationships, as well as the overall therapy experience, as discussed in the previous theme, was sometimes mediated by pain. Therapy relationships in which pain was present will be discussed in the Negative Relationships section.

2.   **Characteristics of negative therapy relationships**

On the opposite end of the continuum from those deep and solid connections and positive relationships that some participants had with their therapists, other participants described what they did not like about their relationships, and how they remembered the negative side of their relationships. The relationships participants considered negative had to do with medicalized relating, or the depersonalized way therapists approached them in therapy, which included power and objectification. Through objectification, therapists further demonstrated power over children's bodies with a medical gaze. Power was also reflected in the communication, language and information (or lack of it) in the relationships, as it was in the tension between the therapist's expectations and child, and the cycles of frustration that resulted. Each of these will be discussed individually.

a.   **Medicalized power and objectification in depersonalized relationships**

Some participants' descriptions of their therapy relationships reflected an obvious presence of a **power** dynamic. For example, participants described themselves as

"having to be submissive", feeling that they had "to obey their [therapists'] directions and … to fulfill their wishes because they want to know 'what's wrong with me'".

Further, the lack of personal connection that some participants felt with their therapist was perceived as a lack of personhood and objectification as part of the medicalized power. In fact, participants described an entire process of objectification from physical therapists, which was then repeated with/in each session (as seen in Figure 1). One person described the therapists' depersonalized approach in this way:

> I hated being treat[ed] like I was a body or case, like if I didn´t have feelings. So those were the times I shut down. And PT became like a business I needed to do and get over with until the next session.

This participant's response (of "shutting down"), one of the few to actually respond back to the therapist, set up a kind of cycle even widening the connection between them, because of the child's response to the therapists' approach.

b.   **Power over bodies and medical gaze**

Hating "being treated . . . like a body" had a number of ramifications. Physically disabled participants probably discussed the depersonalized relationship between therapists and children's own bodies in the most detail, and that objectification included power over their bodies:

> We sort of have to give our bodies over to medical professionals.

Participants didn't like "people having access and permission to their bodies" in their therapy relationships or people being able to "treat in whatever way outsiders wanted to treat it."

Some participants detailed several aspects of objectification in the depersonalized relating and medicalized power. First, there was identification of deficits, and participants told me how

they did not realize they were different or disabled until physical therapists pointed out those

things to them. For example:

> *PT was really my first experience with being asked to do things that weren't possible for me, or weren't possible for me at the time anyway.*

Once deficits were exposed, one participant was left with feelings that "her childhood body was

bad" and therefore, needed "fixes" from the therapist.

> *I did not like or quite care for the way that people are going to observe me because of the way they're looking at you isn't about appreciating the beauty of my feet! They are coming at it from a different angle.*

This was the participant's reference to what is referred to as the "medical gaze"

(Foucault, 1976), sometimes referred to as the "clinical eye", which is the basis of physical

therapy professional skills in a deficit model. This participant went on to describe the process of

"revealing myself" to physical therapists among other medical professionals, and professionals

"wanting to look at what was wrong" and putting her on display for a "show-and-tell," for

public identification of deficits on which professionals chose to focus.

This criticism then became internalized:

> *maybe there was a period of time during my fifth grade or sixth grade, I actually looked down on the ground while I walk, especially when people try to walk close to me, or towards me, because I would be thinking, "Oh, are they going to tell that my feet are not straight? Are they going to tell that I am different?" So that made me nervous.*

Another person as a child with severe physical differences related how she endured not

only stares from physical therapists, but also expressions of "shock and awe" because they had

never seen anything like she presented.

One person epitomized the objectification of the medical gaze in pediatric therapy and

education, in what amounted to clinically teaching objectification to physical therapy students:

I remember every Wednesday afternoon a group of PT students would come to my school and I would have to sit on this table in my underwear while they discussed what was wrong with me. Yeah, I remember that! . . . And I don't think they ever knew my name . . . It made me seem like I was just a guinea pig.

In addition, this professional skill of the medical gaze was so pervasive that it extended beyond the clinical practice, as professional intrusion into the personal life of one participant when going out on a date with a physical therapist, who was "trying to provide professional experience, professional knowledge to me" about how the participant "walked unevenly" or was "off balance."

In another situation, while a participant, who felt that doctors and therapists "were all the same," was eating in a fast food restaurant in another country, a Caucasian woman who "was very gentle" and approached the participant and the participant's mother, and spoke in their native language, saying, "Hello . . . may I look at your [body part]? . . . The doctor actually explained, like 'I work in the hospital here, and I just saw you'. . . "

And I remember that, wow! Like nobody asked me, you know if I could have permission... Actually it was a good experience, because in the past, I know all the doctors that I had encountered were like "okay, give me your [body part]" and then they grabbed my [body part], and then it was back and forth and they take a look … But this time, an adult coming to a child and asking like may I like look at your [body part] – I thought it was really – was a good feeling . . . as young child at [fast food restaurant], eating a particular muffin- or whatever we were eating, I feel like the doctor like, the American doctor was asking for permission. That meant a lot to me as a child.

The participant had been so accustomed to the medical gaze, and power over her body, that the novelty of having been asked to examine the participant clouded the fact that not only was there inappropriate professional intrusion, but that it also occurred in a public place.

c. **Power over communication, information, and language**

As communication is essential to relationships, there were several ways in which participants felt power was manifest in therapy relationships. Some communication issues may have been related to their child status, which felt like power to some participants. They felt that therapists did not listen to them as children, or did not talk to them about what they were going to do and the reason for doing activities. In other words, they felt information had been withheld from them. Other participants felt they had been lied to, especially about treatment outcomes, or continued therapy, or just treatment in general:

> *I had no power when I was a child . . . I had no say in those 18 years . . . And they rarely told me why.*

This participant's voice was further limited, silenced, and ignored about therapy, when using a language board to spell things out and which staff ignored or refused to read.

Some people discussed being "frustrated" and "annoyed" when not told the truth by the therapists, and several longed for honesty from them:

> *Even back then, the therapist's power seemed empty. They were promising me things they had no certainty of, and no right to promise . . . I always wanted a therapist who said something like, "This stinks, huh?" Like someone just honest.*

This participant's statement also indicates that longing for a personal connection in the communication, as to how the therapy affected her individually.

3. **Tension: Compliance/desire/resilience vs. non-compliance/resistance and cycles of frustration**

Another sub-theme of the therapist's medicalized power was a tension that existed between children and the PT's expectations. The tension occurred between the child trying to do what was asked in therapy, with the therapists' assumption, possibly related to

professional expectations and role, that these children could do things that they actually could not do. The frustration on each person's part is, I believe, interrelated but will be discussed first separately to make the point.

One participant was fearful of what would happen to him when he was in a situation with the physical therapist that the therapist might label as "non-compliance":

> *I never really questioned or meant to challenge them [the therapists] . . . I really wanted to do whatever my PT teachers asked but sometimes I just couldn't and sometimes that was interpreted as me being problematic, misbehaving, or challenging the teacher*.

Sometimes children wanted to comply but might need a unique form of assistance or a change of approach to achieve the therapy goal. Without that support, their efforts might be futile:

> *Therapists failed to address the fact that I could mentally understand directions, but sometimes my body has to physically be shown what to do to gain body memory.*

And although child-participants did try in therapy, even as a child, they could see their own limitations:

> *I realized even then that was bullshit: that there were some things I just couldn't do and all the will and gumption in the world weren't going to change that.*

One person told of a situation where he was trying, but his resources were not effective in meeting the therapist's expectations, and what happened as a result:

> *When we were working on my handwriting it was discouraging seeing the examples of a perfectly written lower-case letter 'a' next to my best attempt when my PT teacher wanted my 'a' to look like the one that was already printed on the paper. One time I just kind of shut down, because it didn't make sense. Why was I being asked to do something that I can't do? I think I put my head down on my arms because that's what my teacher told us to do whenever we had to think really hard or use our imagination to picture something. My PT teacher didn't like that, so she kept asking me to try again but slower. I didn't see how writing slower would help, I was already writing at a snail's pace and the only way to write slower would be not writing at all. Eventually she got the principal, I cried my eyes out, and I got detention.*

At best, there seemed to be an over-assumption of competence here, which may also have been based upon ableist attitudes. Certainly, this further exemplified the power attached to this tension as an example of medicalized power of professionals and people in authority.

Frustration was an emotion and word that participants commonly used in their interviews. Within this tension of desire/compliance on the part of the child vs. non-compliance/resistance assumption from the therapist, as previously mentioned, there were two interconnected or concentric cycles of frustration that seemed to have occurred during some physical therapy sessions. As depicted in Figure 2, the therapist initiated one cycle, and the other began with the child's frustration.

First of all, participants picked up on the fact that in the fragile balance of that kind of medicalized relationship, where the therapists' behavior or actions were one-way, i.e., directed [on]to disabled children, *therapists* became frustrated when they could not fix or get the child to do what the PT wanted/required. Then, there was a change in the relationship, and it grew more distant:

> *The only thing I really didn't like about our relationship was how it seemed to turn into the traditional teacher/student relationship when I was getting frustrated, which is to say I had the impression that I would be in trouble if I couldn't do what they asked.*

That frustration was directed to the child as well. In this example, the child was concerned about her/his performance needing to be on par with the therapists' expectation, and the child consequently became fearful.

Another participant's childhood perception of the therapist's frustration then spread to other parts of her life and became cumulative with other negative events she was experiencing

(e.g., bullying). She discussed both regular and Special Education Physical Education/PT

(SpEdPE/PT) classes:

> *If we were working on depth perception stuff like throwing or catching, I could tell when the teacher/staff person was frustrated with me and it added to my experiences being bullied in regular gym class.*

In this situation, the therapist then also became a bully, as the initiator of the frustration cycle,

with bullying becoming the power.

The second cycle of frustration originated from the children, who desired to do their

best, who tried to cooperate in their therapy, and respect or submit to the therapy activity, and

to work within the relationship that they did have within the power structure:

> *I pretty much did whatever was asked of me and tried to not get visibly frustrated or upset when I was having trouble.*

This participant additionally indicated her further coping strategy in attempting to hide her

emotions in her efforts at "complying."

And, at times, when children were unable to do the activity, or meet the expectations of

the therapist, they became frustrated, as in this response from the person who had gotten

detention for doing what the therapist had asked:

> *I guess there's something naturally frustrating about fine motor activities when you don't feel competent doing them. It's like that frustration you get when you're trying to thread a needle with a thread that just doesn't seem to fit. And no amount of strength will change the fact that you can't get the thread through, and a limit to how much a change in technique will help.*

The child's frustration is then expressed back to the therapist, and the therapist becomes

frustrated or angry because the children couldn't, or perhaps the therapist thought *wouldn't*

comply/conform to expectations.

And so, the tension and the frustration in some relationships on both the child's and the therapist's side further divided the therapy relationship.

4.   **<u>Longing for connection</u>**

There also seemed to be a real longing from the participants for connection and support, and for someone to talk to about their disability and their PT experiences. Physical therapy had awakened issues for the disabled child related to her body—of deficits that needed to be fixed, and loneliness with no one to talk about her body, her disability, or the meaning of being a child and/or a child with disabilities.

On the most positive end of this theme, the relationship with a therapist could be so close and the connection felt so strongly, that one participant was able to talk with the therapist as a counselor and a resource for disability related topics:

> *They were my one source of information about my disability. They weren't afraid of talking to me about my disability and didn't make me feel bad about it. They also were a source of information of other things like dating and sex. And . . . as I got older I used physical therapy as mental therapy. It was my one resource that I felt comfortable discussing my insecurities. I would ask my therapist about relationship advice and things of this nature.*

These therapists realized the participant's need to talk about his disability, and as he matured, the relationship and discussion evolved. It also seems to reflect the intensity of the child's need to connect with an adult.

Participants' longing for connection was also evident in non-professional relationships and to professional allies other than PTs, including disability or disabled peer "communities" as support for their physical therapy.

Coming from isolated backgrounds, several people expressed feelings of isolation from other people with disabilities, and especially children with disabilities. The isolation these

children felt stemmed from being the only kid with a disability in their small town or their

families, or, as one participant said, ". . . as a product of mainstreaming and inclusive

education."

A participant whose family member was also disabled, and disability was not talked

about, longed for that connection:

> *I wish, I truly wish if there were other families and other people– adults with disabilities – especially like my kind of disability, if I could have had some role models who, definitely like, you know take in the fact that we are different so, you know, to say to me, "it's okay to be different."*

Beyond the close relationship one participant had with his physical therapist, allowing

him to discuss personal disability-related topics, he would have liked to extend his connections

with disabled peers both during and outside his therapy sessions. He wanted relationship with

a work-out buddy or disabled peers to go with to sports activities and with whom to have

group relationships.

> *The only thing I wish PT gave me was a sense of community. There were always other children with disabilities there when I was, yet I never had opportunity to connect and build a community.*

The therapists had filled a professional role in discussing disability with him, but had failed to

see his need for a personal connection as a child with other children.

5. **Blurring and differentiating professional discipline Identities in approaches**

When discussing therapy relationships, it was interesting that several

participants "blurred" the identities of professionals in the medical system, while others noted

important distinctions and contrasts between PTs and other medical professionals, sometimes

for different reasons. Some grouped them together in their medicalized relating:

> *It is hard to separate where the messages came from.*

> *I don't necessarily remember people referring to doctor or physical therapist or other practitioners – for me, they were the same.*

This participant experienced everyone treating her body and approaching her professionally in the same way, and also specifically noted that she did not really know the differences between a physical and occupational therapist (whose identities are actually similar when working with children).

Another participant explained the reason for her difficulty in distinguishing between physical therapy staff, and proposed that it was intentional.

> *My memory is a little foggy as to the definitions of the people (who was the SpEd PE [special education physical education] teacher and who was the PT), although I think that was a function of mainstreaming and inclusion stuff in the 80s . . . so much of the interactions I had with anyone related to my disabilities were couched in language that avoided the "d word" (disabled) or the "b word" (blind) or any other diagnostic labels.*

However, this purposeful, institutional, political avoidance resulted in an avoidance of disability identity.

On the other hand, participants also distinguished relationships with PTs from other professionals by contrasting their approaches to therapy and their relating to them as children. For example, one participant considered if she had more fun with anesthesiologists because they were getting her charms for a bracelet:

> *or perhaps because the anesthesiologists were . . . not trying to fundamentally change the shape of my body. Or because they were putting me out of pain rather than bringing me into pain.*

This participant was really saying two things with her comparison. First the anesthesiologist, like some therapists, had taken the time to adapt to an individual child's needs and interests which

in her mind, besides the concrete charms, promoted greater closeness. Second, her other focus

was how pain mediated her relationship.

Other participants preferred PT and/or their staff. For example, PT staff's approach to

one participant was more accepting and individualized than in general education:

> *I liked that they usually seemed willing to help and were patient. As I was also in*
> *standard PE with my classmates, I rarely had that help or patience with the gym teacher.*

Another person contrasted the warm feeling she had from her therapist, to the total

lack of contact that her doctor had with her, which was very frightening to her as a young child.

She described a longing for support then, as a child, and an explanation from her mother here

because "as a kid, I was so afraid of him." Fear is the ultimate response of a child as lowest

status in power structure to an adult and professional with power as the highest in the power

structure.

One participant, in his contrasts of PT and OT, noted the difference in both positive and

negative power issues invoked, and how they felt in the two relationships.

> *They [PTs] were more empowering than not . . . you know thinking about the Ots who*
> *kind of had me doing stupid things, feel myself diminished when working with, the PTs I*
> *always felt empowered. . .*

> *the physical therapists knew that they couldn't make me do stuff – I'm the one that had*
> *to do it . . . so their methods were to treat me pleasantly, to talk me into doing it, to*
> *encourage me to do it, whereas the OT's, my memory of them was like "you'll do it no*
> *matter what, G** dammit."*

To summarize participants' responses relating to the major theme "Quality of Therapy

Relationships" positive relationships occurred when children were approached as human

beings, with respect, and via a personal connection. Negative relationships involved being

treated like medicalized objects, and the therapists were perceived as exerting power over

communication and bodies. The latter included the participants' experience of being stared at.

They longed for intimacy and trust, and for someone to talk to about their therapy and their

body and disability, but that was rare from therapists and family. They also longed for disabled

mentors and peers. Depersonalized relationships involved participants' perceived therapist

objectification and power over their bodies. Frustration cycles between the therapist and child

occurred when children could not conform to the therapist's "fixing" approach, and each

person's frustration fueled the other person's as well.

Finally, one participant summed up not only the types of relationships she had

experienced in therapy, but also the type of connections that determine the quality of

relationships:

> *I didn't like or trust them for the most part except for the one you know the one . . . when I was an inpatient. And I can remember what she looked like. The rest of them are faceless, and nameless, and [laughing] you know… So I don't have much of a memory of the rest of them – not really connecting with them at all, feeling like it was so, you know, it was something set up to cause me pain.*

As a child, without a personal connection or trust, she rationalized that the purpose of physical

therapy was only to hurt her.

Relationships played a large part in participants' therapy experiences. In the next

themes, I will explore the impact of physical therapy on the rest of the childhood, and into

adulthood.

Therapist

"Treated me like a body or a case"

Focused on my deficits

Asked me to do things that I could not do

Looked at me

Discussed what was wrong in front of me

Had access and permission to my body

Did "show and tell" with me (my body)

Shut down

Disabled child

Figure 1. The objectifying process in/during therapy. Each of the therapist's approaches in objectifying the disabled child is done TO the child, with the exception of shutting down, which is the only way that the child has to respond back to the therapist. Positions of Therapist and child indicate the power hierarchy.

Therapist   *Disabled Child*

If can't "fix" -------------- -------------------→ frustration

1a   2b

Frustration   1b   Frustration during PT

[expectations*]   "not complying"   [*not meeting expectations]
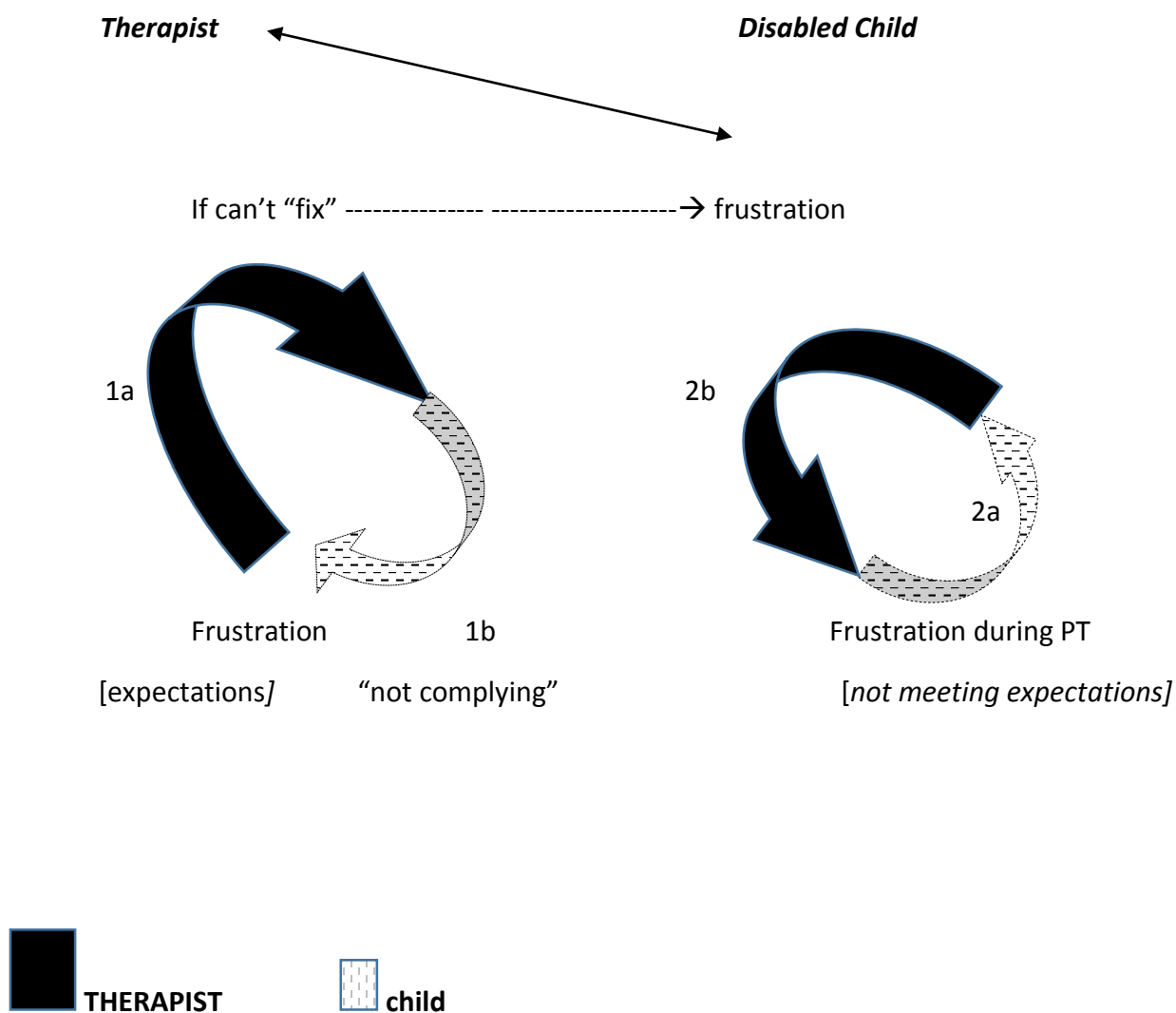
■ **THERAPIST**   ▦ **child**

Figure 2. Negative cycles of frustration. In the first cycle (1), the frustration occurs when the therapist (1a) becomes frustrated at not being able to fix the child (1b), and the frustration is directed towards her (1b). Another cycle (2) originates from the child (2a), who is unable to/can't do the activity being asked of her, becomes frustrated and relays/expresses frustration back to the therapist (2b). The therapist (2b) in turn becomes frustrated, angry, at the child (2a) for being non-compliant, or not meeting therapist expectations.

E. **Impact of Therapy**

From their perspectives as academics in disability studies, participants told me how therapy impacted them emotionally, in their childhood and developmentally as adults, as related to their disability identity. They discussed the long-term effects of therapists' focus on deficits, as well as the values, power, and objectification discussed in previous themes.

1. **Broader impact of therapy on childhood**

For a participant whose therapy relationship was positive, there was also a positive outcome on his self –image:

> *I felt more solid as an individual because I had someone older than me, who understood the nature of my disability that I could ask questions to, knowing they would give me honest, fair answers.*

However, for most other participants, the focus on deficits and effects of the "medical eye" in childhood is what became internalized. For example, a couple of people became more anxious either in one-to-one instructional situations and any part of school specifically disability-related, or when observed doing physical activities. Another participant became "less trusting of professionals." A few participants felt that PT identification of their deficits became internalized so that it affected their self- image and body image. For example, one participant "felt like a walking batch of broken." The inabilities, or imperfections focus of therapy for another participant spread to other aspects of what she was doing:

> *I was too hard on myself. I remember missing a question on a test and crying outside. I think I internalized the medical profession's critiques of my body and that transferred into critiques of my mind.*

This participant noted that her feelings about her experiences were so strong that she had distanced herself from even owning that "the childhood" was hers:

> *I feel the childhood was lost to hospitals and therapists. Like even now, I type "the" childhood, as if I'm assigning it to someone else now.*

The repeated deficit focus, and other aspects of being examined and stared at, combined with the relationship, impacted the child's self-image and body image for this participant:

> *Due to the way people looked, or due to the way that they asked questions about how do I function ‒ I think these questions do play a part in my body image. Because, if I only had, let's say a few times of talking to a physical therapist in my life, but I think of how they played a role in it.*

The therapists' power over children's bodies and objectification, that one person said "happens real easily, really fast," had a lasting impact:

> *We get separated, we get fragmented from who we are because we sort of have to give our bodies over to medical professionals, and that's dangerous . . .*

She went on to describe that fragmentation as "disintegration" and how therapists trigger it:

> *Disintegration, which happens often with, especially children, being rejected by doctors or therapists, or being told that they have "good parts" and the "bad parts" of their body.*

The judgment and labeling of body parts leads into another area of impact that is related to communication and language. Children pick up on what therapists say and do not say, including body language and non-verbal communication, as well as interpret what is and is not being said about their bodies. For example,

> *"Whoa! Well this isn't good! You need to work on this!" Or "your arm is bad" or "your knee is bad."*

While the therapist is really talking about the child's measurements or ability, children interpret what the therapist is saying as a rejection of their body, or of themselves.

Some participants discussed demonstrations of their resilience or resistance to the impact of therapists' medical eye. One participant justified the therapists' observation and explained her strategy for managing the medical eye in this way:

> *it was a . . . like a conflict negotiation in my mind's eye – like "okay---it's actually not that bad". . . maybe I was just like, you know, the idea of I was trying to talk myself into like "yeah, there are things you don't like," and "you know, you sort of know what's going on," but at the same time kind of talk to yourself like "it's okay, you know this is the way that people look at you." And there are, like people in the hospital, they are like medical professionals – that's what they do.*

Another person told how, with self-advocacy, she was able to take back that power over her own body, even as a child:

> *doctors wanted to do more P.T. and bone-lengthening . . . My family let me make the decision. I decided I wanted the doctors to amputate the leg. I wanted a bending knee. It was hugely empowering to make that decision as a child. I simply did not want any more P.T. and I did not want to be a guinea pig for a procedure.*

These examples stood out as some of the only responses of children who resisted the impact of the medical eye dominating them from professionals.

2. **Lasting Influences of therapy**

a. **On adulthood**

Participants' childhood experiences of being handled and objectified changed their behavior as adults to be more diligent and protective of themselves against the type of professional power they had endured as children. For example:

> I really hate to be grabbed, poked and prodded . . . of feeling like my body could be treated in any way outsiders wanted to treat it.

Another example was someone who, as an adult, visibly pretends to try to solve a problem when he in fact knows he cannot do so:

> *Like nowadays, if a professor asks me a question that I don't know the answer to, I spend 2-3 seconds looking like I'm seriously trying to come up with an answer, even if I know I won't come up with any in that time, just to show that I tried to do what was asked.*

In both of these cases, participants' responses were related to their childhood therapists' ableist assumptions and lack of recognition of real limitations.

An unexpected response was how some of those remembered experiences also continue to influence participants in similar ways regarding attending or not attending physical therapy as adults. Again, there was fear related to adult therapists or instructors of other forms of exercise or alternative health activities not acknowledging that participants know their bodies best:

> *I'm often wary of any kind of exercise classes that I will be urged to go beyond the limits I know are safe for me, or be shamed when I insist I can't do something… or not trying hard enough.*

This too directly related back to the earlier theme of tension of compliance/noncompliance, etc., that continues to the present, and adds yet another dimension of continued "oppression" into adulthood by being shamed.

One participant, when released from therapy as a young adult, felt she was further disabled by her therapist proclaiming that the participant had made maximal progress, but then proceeding to turn over her "care" to her parents to do exercises with her to maintain her strength. As a note, this was a family who had not done therapy with the participant as a child. The participant was "distraught" with the implications of this:

> *in my mind this meant that I would not gain independence from my family and I definitely would not be able to walk.*

This was a transfer of control/power to her parents, which emotionally stripped from the participant power over her body and self-determination even into adulthood, perhaps without preparation as a self-advocate regarding own future physical therapy or activity.

In contrast, a participant who had been given a chance to make a decision regarding a personal outcome for physical therapy as a child was willing to try new procedures related to physical therapy as an adult. Another participant whose childhood PT experiences were positive, continues as an adult to balance work and play, and play in work, similar to the integrated therapy and play activities he experienced as a child.

Some participants attributed their professional activities to their childhood PT experiences. For example, one person reported that his appreciation of and competence in physical activity gained from his childhood physical therapy experiences led him to make physical activity an integral part of his future work as a psychotherapist. Another person emphasized that professional students learning to work with disabled children should learn not to take children's power from them, but instead to encourage child self-advocacy.

b. **On physical therapy and development of disability identity**

Beyond the longing for relationships with disabled peers and mentors previously described in the Relationships theme, participants had some things to say about how their physical therapy experiences influenced their disability identity.

One participant who "internalized his idea of what disability is" from discussions with his PT, was able to "pass" as able-bodied, "hiding" his disability. In a sense, he also continued "passing" at home, so as not to be different from his brothers, who were not doing any

exercises. He noted that he did not mind leaving his brothers at home to go out to his PT to

address his disability away from them.

> *I tried to distance myself from this identity. It was part of the reason I wouldn't do my "homework" stretches . . . I think I internalized this idea of my disability needing to be fixed, so I tried to hide it.*

The focus on another participant's inabilities in PT in school, also served to make him

uncomfortable with his disability:

> *I think my experiences had the effect of pushing me away from acknowledging my disability within my social life. With PT being really the only part of my life/education that felt specifically set up to respond to my disability at the time and the fact that my experiences were either neutral or negative probably partially account for me not feeling comfortable "owning" my disability as I do nowadays.. I don't think my experiences with PT had a significant effect on how others viewed me (since PT happened outside of my normal social life, of course), but it certainly played a role in shaping the identity that I presented to others by making me less comfortable presenting myself as someone with a disability.*

Additionally, communication and language of disability used by physical therapists and

professionals, sometimes in attempts at making children with disabilities feel more included,

also had an unintentional effect on disability identity. For example, the disavowal of disability in

this participant's response:

> *much of a medical focus and people saying crummy things like "I don't see you as disabled" or trying to tell me that my disabilities don't impact my worldview (think "person first" language ..."the only disability is a bad attitude", etc.). There's no way I would have claimed my disabilities then, especially with the ways that various professionals interacted with me.*

In another example, realization and acceptance of participants' differences, as "resistance" or

separation from what therapists tried to tell them, changed their perspectives, and their ability

to develop a disability identity:

> *The message to people, like you know, "you are human, and you are people first." But then what does that mean? Like, just you're like everyone else? But then the fact is: like*

> *no, if I'm just like everybody else, why is it that the way that people look at me is different than how they would look at my sister? [who is not disabled]*

Failure to distinguish between differences (regarded as diversity) vs. deficits (needing to be fixed), as well as other values conveyed in PT, distanced participants from a disability identity. Now as adults who have gained that identity, they are able to refute what had been conveyed to them as children in therapy:

> *Now that I have a disability identity, I know that I don't have to walk. I also know that there are other modes of therapies that will help me accomplish my goals, such as yoga.*

c. **From disability studies scholars' perspectives**

A key reason for having participants with backgrounds in DS was to gain the academic perspectives of physical therapy in addition to personal perspectives. With those perspectives, they told me about having a framework to name and categorize the feelings they had about the objectification that they experienced, new perspectives on themselves and their bodies that differed from before their studies, and how difficulties with medical professionals were shared:

> *I now realize that I'm not alone. I'm not the only one who was having tension and conflict with the medical profession as a child.*

Meanwhile, another participant was grateful to DS for PT as a resource available for people with disabilities.

For some participants, DS served to counteract the values that they had received as children, e.g., as an academic, their feelings about their childhood experiences and their objectification were verified. Another gained insight not only about therapy values received but also an important, unique aspect in the relationship:

> *DS has helped me to see that a lot of my PT experiences [placed] a lot of focus on the outer appearance of things, and on making the therapist feel good*

The preceding response indicates that as a child, this participant somehow felt the need (or responsibility) for the therapist's feelings.

Disability studies affected not only disability identity but also a number of corporeal realizations/issues that participants had related to their therapy experiences, which included "reclaiming their bodies." For example, through DS scholarship, participants saw how PT fit in their life:

> *The simple act of identifying as a disabled person has allowed me to come to terms with the medicalized portions of my life like PT because I understand that my body isn't normative, never will be, and that's perfectly fine.*

Disability studies also allowed a participant to "rewrite her story" with a different perspective, and a kind of freedom to move on:

> *I don't have to accept what, you know, how society sees me, or evaluates me. Yeah, and a lot of that came from interactions with doctors and therapists . . . I've reclaimed parts of myself that I let go of as a child . . . I wanted to disappear as a child, and that drive stuck with me until <u>now</u>. So, part of it is reclaimed, and then the things that disability studies has rewritten, I can let go, or are in the process of being let go, let's say.*

Of course, as scholars, disability studies has influenced them professionally. One participant is interested "in starting conversations with medical professionals and therapists to give them 'insiders' perspectives." Some participants specifically commented that my interview process itself had either given them new perspectives or changed their perspective as they were relating specific experiences, as in this example of the participant who told the story (quoted in the section on "Power over Bodies and Medical Gaze") of watching the ground when she walked for fear some observer would question why her feet were different:

So it's just now, talking to you, made me wonder if that had to do with the way that therapists tried to correct my feet.

Other participants expressed "gratefulness," curiosity, and thanked me for making them think about their experiences through our interview, to give them meaning, and for doing what some called "this important research."

F.   **Participant Recommendations for Physical Therapists**

Participants offered recommendations regarding ways they wanted pediatric physical therapists (PPTs) to act, think, or believe/feel differently from the type of childhood therapy experienced by participants. They made recommendations for both the clinical practice of current therapists and for the training of future therapists. Thematically, participants made points about the importance of: personhood; bodies/embodiment; relationships, including power; broader roles for physical therapists than PTs are generally taught to have in disability identity; educational programs and recommendations for therapists working with adults. Discussion of each of these subthemes follows.

1.   **Respecting personhood**

This recommendation is comprised of several other recommendations, not really smaller, but as a complex, that are antidotes to participants' negative experiences where these points were ignored or absent. Although this first set of recommendations regarding respect for personhood may seem obvious and fundamental, participants felt that these first two guidelines needed to be stated explicitly.

a.   **"Treat the person as a human being."**

These ideas are essential to relating with a disabled child are paramount to all else, as this first and the next directly quoted recommendation from two participants exemplify.

b.   "**Treat children like people."**

Beyond respecting the full humanity of their disabled patients, this second quote urges therapists to remember that although children are uniquely different from adults, they require being approached as people with feelings, agency to choose and to speak for what they want and need.

c.   **Treating children like children**

In balance with the recommendation to treat children with disabilities as full human beings was this recommendation to remember that the disabled children with whom therapists work are indeed children who need to be allowed to have a childhood as all children deserve. They are individuals with unique personal lives, interests, goals, and needs outside of therapy who want to be known in those areas as well. Find these out not only to individualize treatment activities, but also to make treatment intrinsically 'fun' and meaningful to the child. Participants further encouraged therapists to play and "joke" with the kids, make "therapy a game," "intersperse activities they enjoy with more difficult ones," and "avoid making therapy routine" (and some said "boring") by varying approaches and activities. Again, although some of these recommendations are basic to pediatric treatment, they were specifically promoted by participants.

d.   **Avoiding objectification**

Participants wanted therapists to know that they actually risk "damaging"

(their word) disabled children with traditional medicalized ways of relating, including through

various ways of objectification. As one participant said:

> *For a child to be treated as a spectacle, as someone who can be looked at, talked about,*
> *examined by anyone who happens along can be profoundly damaging.*

As antidote recommendations, participants urged therapists not to talk in front of children as if

they are not there, not to put children on display or distance them in relation to the therapist

in the name of education. (This includes other professionals, students, and parents, and even

family.) Participants further suggested that therapists talk directly with the child, and to

"remember that the child is always listening" (e.g. when the intent is talking to a parent).

e.   **Acknowledging sexuality**

An often neglected part of respecting the child's full humanity, as

strongly advocated by participants, is the acknowledgement of children as sexual beings for

the present and future. The following direct quote explains the recommendation, and its

importance:

> *there is a sensual element to physical therapy interactions. We are all so (rightfully)*
> *nervous about childhood sexual abuse that saying this may feel transgressive. But if the*
> *disabled child's sexuality isn't being considered, the tendency is to fall back into the*
> *default position that equates disability to asexuality and an instrumental view of the*
> *body; can the therapist see the patient as someone whose body both gives and receives*
> *sensual joy, who in the future will, in all likelihood, have sexual relationships?*

2. **Bodies and embodiment**

    a. **Approaching children's bodies positively**

Participants had a number of recommendations related to their own

bodies, and how they wanted therapists to relate to their bodies.

According to the participants, the way the therapist responds to and handles a child's

body can profoundly affect the child's sense of self.

> *It is very important that physical therapists convey a positive sense of the child's body; that seeing the body itself as a "problem", as something that needs to be fixed, as a broken object, has long-range implications for that child's future body image and sexuality.*

Additionally, participants seemed to be saying that therapists should honor different

bodies, and accept bodies as they are. They warned therapists to be careful and aware of not

only their own verbal but also nonverbal and physical responses to children's bodies, because

children are sensitive. As an example, one participant advised:

> *Don't respond to a child as a unique 'case' with shock and awe, "I never saw someone like you." A child doesn't care—she wants to be like all other kids.*

    b. **"Deal[ing] with us as whole people, instead of parts that need to be fixed"**

The quote was the advice of one participant specifically to prevent the

effects of compartmentalization of "good" and "bad" body parts, and resulting "dis-

integration" of self, identity, and body.

Along with not treating disabled children as "cases," participants asserted that children

don't want to be treated as though they're broken, or so imperfect or needing help, that they

need therapy to be whole. Participants advised that children don't have 'good' or 'bad' bodies or parts of their bodies. They <u>are</u> whole.

Another participant had a similar warning about the effects of therapists who continue in a normalizing and fixing approach with their patients:

> *if they ["medical professionals"] still stay stuck in their thinking in that "we have to fix you" and "we are turning everybody into normal" and "we have to rehab you," it's not going to help us, and it actually creates a lot of damages.*

c. **Considering disability onset**

However, two participants, each with a different type of disability, advised that beyond a positive approach to all children's bodies, there are two different perspectives with specialized adaptations that therapists need to adopt when working with children with physical disabilities. Depending upon whether the child has an acquired or congenital disability, participants suggested there may be a difference in how the child thinks about her or his body, and what the child needs. They felt it is important for therapists to not only realize possible differences in meanings to the child, but also the implications for treatment. For example, one participant pointed out:

> *I would ask therapists to re-consider their assumptions about children who are born with their conditions. These children have an acutely different relationship to their body than a child who has been in an accident. For these children, our bodies are not different, not awesome, not brave. We just are this way and always have been.*

The other participant advised that therapists who work with children with acquired disabilities immediately link the child's body and disability identity. The participant urged therapists to recognize the child's need to learn "not only about a new body, but also how to live with a new identity," and seemed to be saying that rehabilitation needed to include identity work along with physical rehabilitation of the body.

3.   **The child and therapy relationships**

a.   **Acknowledging power of relationship**

Participants related that therapy relationships can be very influential, with a lasting impact on the child's life and instrumental in the child's self-esteem and self-efficacy. On the other hand, they also wanted therapists to realize the importance of acknowledging that there could be an inherent power imbalance between child and professional. Children may feel, as one participant did as a child, that they have "no power, no voice" in what they are doing, power over their own bodies or future**.** The power differential can be played out in the therapist's relationship to the child's body and in therapy relationship itself. Participants made several recommendations for ways of working to "share" the power.

Power means giving the child a voice. Participants advocated therapists "viewing their patients in a 'partnership relationship' rather than a one-down position", working to share the power with mutual respect. In order to make relationships more significant for therapists who do not have ongoing sessions, and whose relationships with children are limited, participants advised that therapists work together with children (and families) to provide devices that the child accepts and uses functionally, and not just something the PT is fabricating, adapting, or pushing to make the child be or look more normal. Also in contrast, participants wanted therapists to be aware of how different or "ugly" a piece of equipment could be that would add to the stigma they felt in using a visible device that added further to their visible disability. One participant even wanted "aesthetics" in the equipment.

In addition to other strategies of ways to approach children's bodies as previously discussed, participants deemed it vital that therapists actually give children power over their

own body, rather than take it from them. Simple, yet important ways they suggested included

respecting physical boundaries and asking permission to see or examine a child's body.

Participants urged therapists toward more child and/or family involvement in therapy,

by giving children choices in their activities, and by "asking them" what they want out of

therapy to find goals that are personally meaningful. Participants also seemed to feel that

encouraging children to learn self-advocacy and sharing with them alternative ways of gaining

their independence or being physically active as disabled adults could be empowering for their

future.

Knowledge and information are also power. Participants recommended that therapists

could reduce power difference by sharing Information and communicating directly with

children about procedures and activities, and particularly the reasons therapists are doing

activities and/or having the child do specific activities. Participants advised: talk with, and

explain to "even a 5 year old" child at an understandable level, "whether you think they

understand it or not." For older children, "use concrete examples to link to lasting impacts of

the therapy activities," that "relate therapy activities to the child's current and future life" to

improve meaningfulness and for motivation.

b.   **Validating the child's pain and struggle**

Pain was an issue with some of the participants, and they recommended

that therapists validate and show "respect for the child's pain." One participant wished that

therapists would have worked harder to help her "to feel good about doing exercises instead of

something I hated." Some participants struggled and sometimes failed. If a child cannot do

home exercises or activities in class or PT, rather than assuming non-compliance, find out why

that is, if there is something at home in the family context that is interfering, or it is too painful, or some other reason. Adjust or modify as possible for success. A participant recommended that therapists find ways of diverting focus away from the pain to something pleasurable. Don't tell children "it won't hurt," when it will. Be honest with children also about outcomes or goals that are uncertain, or difficulty of a treatment. Participants also wanted therapists to "listen to" even young children regarding the difficulty they experienced in therapy.

Several participants wanted therapists to recognize the emotional component and the psychological aspect of physical therapy. They recommended that therapists collaborate with psychology and/or psychotherapy as allies for "mental health support" that some children with physical disabilities may need, as neither the physical therapist nor the parents are "mental health experts."

4. **Expanding roles for physical therapists**

Participants had recommendations in some areas that expanded the roles for PPTs beyond those thought to be typical for patient care and training, which were particularly in the area of disability identity.

d. **Adopting a more affirmative view of "disability"**

This recommendation applies to both children and therapists, and refers to the need to learn an affirmative or disability-positive view: that disability is a difference; that it is okay to be disabled; and that therapists should not reinforce in any way the idea that disability is a tragedy.

However, participants varied as to who they thought should be the people to do that work with disabled children (e.g., pediatric therapists or somebody else)**,** and how the identity

work needs to occur. Especially in light of power issues in therapeutic relationships discussed previously, participants' recommendations for having therapists teaching/doing identity "work" with disabled children seems paradoxical–having someone who is most likely a white, non-disabled female be the person to discuss disability identity with children with disabilities.

Participants wanted therapists to be sounding boards for personal matters, and a source for learning about disability and identity issues. This would mean that therapists must broaden their concept of disability beyond what one participant called "the provider perspective," including what it means to be disabled, disability culture, and that they reflect this attitude in their actions.

Further disability identity recommendations were that, at minimum, therapists should be comfortable enough to discuss disability and disability identity directly with the child. It was deemed important that therapists essentially model this discussion, so that disabled children learn to discuss their disability and disability identity, rather than avoiding the conversation.

b.   **Connecting disabled children with disability community**

Disability culture and having disability mentors are also a part of learning a positive disability identity. Therapists working with disabled children to be aware of disability culture and community, and of adult mentors or activists who are in the community to liaison with them so that therapists, students, and children can learn from them.

> *So it wasn't until . . . I ran into some hip and cool disabled people that I realized hey, it's ok to have a disabled identity. At point I embraced it, because of my political savvy realized that ok, it's a life struggle, and an identity struggle*

Participants also recommended that mentors with a similar disability and "who look like them" can help children "envision life beyond childhood, to know they aren't alone, and to

acknowledge that it's okay to be disabled, and to live your life to your fullest." They urged

therapists to truly become disability allies and become involved in disability culture and with

the community.

Furthermore, participants recommended giving disabled children group opportunities

with their disabled peer "community," for therapy and for play, in school and outside physical

activities. According to participants, groups afford children the time and space to share

activities and their disability experiences, and to decrease loneliness**.** Although it may seem

contrary to inclusion principles, participants had longed for these types of opportunities for

relationships with their disabled peers.

c. **Assuming leadership to address bullying in school physical activities**

A participant recommended that with an increased awareness of bullying

as a form of threat to disabled children's identity in school, and PPTs' expertise in physical

activity and movement, therapists are appropriate people to address this. Physical Education

(PE), Adapted PE, and recess are the major times when children's bodies and movements are

challenged with ableist or "normalizing eye" attitudes from staff or from peers. It was advised

to further address bullying by incorporating strategies to resist bullying behaviors into the

child's school treatment plan and/or student's Individualized Educational Plan (IEP).

5. **Educational Programs**

a. **Incorporating disability studies perspectives**

The importance of the recommendations regarding DS perspectives in

professional training was stated by one participant:

PT is a great thing, but if students are not prepared to work with children with disabilities, it can have a very negative effect.

Practically every participant recommended at least some DS course and class work that should be integrated into the curricula for physical therapists. Some felt that an entire course be devoted to disability studies, and others a class or learning experience at different points in the curriculum. They highly recommended an exposure and introduction to Disability Studies, including what it is, and how it is different from a traditional, medicalized approach (model) to physical therapy. This would include expanding their view of disability not just from a medical model, but to the social model understanding of disability.

Participants urged representation of people with disabilities in the curricula beyond the patient role, who should be people who are living their lives, who are mentors and/or even activists in positions of authority, and who are well-versed in history and the socio-political aspect of disability. Incorporating disability culture and arts into the training was recommended, and one participant felt so strongly about this aspect that she had concrete suggestions regarding specific films that could be watched and readings that depicted culture and other DS topics. Another participant felt that disability should be taught from a cultural competence model. Additional suggestions related to exposure of physical therapy students to the ideas of disability rights and social justice, the disability movement, and the fact that there is a global disability movement. Additionally students should have exposure to the minority model view of disability, studying rights and oppression from the power imbalance, with considerations of intersections with other minority models (e.g., race and gender).

b.   **Reflecting on attitudes**

A participant advised that both practicing and future therapists should "critically examine *their own* perspectives and stereotypes, and work on their Able-ism" (as

normative and dominant social values). For example, a fine line exists between therapists'

assumption of competence in order to challenge and encourage children to do their best, and

continuing to insist that they do something that they physically (or cognitively) cannot.

Recognize the difference, and be aware of potential "negative cycles of frustration between

therapist and child," that can occur during therapy, and the therapists' part in the situation.

Participants advised modifying the activity (or environment) and finding reachable goals for

activities to promote the child's success and self-efficacy.

Additionally, according to participants, therapists should reflect on their language and

communication with disabled children, and the potential impact on the child's body, self-

image, and identity. Work to become more thoughtful, just, and integrate disabilities studies

perspectives in communications. Seeing some specific examples that participants would have

liked to have heard during their therapy may be helpful:

> *If a child says, "Why'd you become a therapist," and your answer is, "I wanted to help people," change your answer… It always made me think, "I must be a child who needs help." I would've preferred anything else. Say you like muscles. Say you like thinking about how the body works. Anything.*

> *"Our bodies move in different ways- Let's see if we can help it move more".*

> *"You are fine the way you are. We are trying to change things, but you are fine the way you are!"*

6.   **Physical therapists working with adults**

Although this study was about children's experiences in physical therapy, several

participants spontaneously discussed experiences that have implications as to what PTs whom

they may see as adults can also learn.

When working with a person with a lifelong disability, participants wanted therapists to respect the expertise of their experience with their own bodies, including the person's real limitations and abilities. Factor their underlying childhood disability and impairment into treatment of the person's current condition. This participant had had an experience where this was not considered:

> *As a person who has had a disability for [x] years, I really know my body: what works and doesn't work. And [the Physical Therapist] didn't listen to me, and she told me these things I should be doing, and I don't think she even factored in that I had [participant's disability]. I think she just gave me the directions that I think she would give anybody. And she was really kind of imperious about it . . . What I have developed over the years, and I think I'm fairly good at it, is using medical personnel as consultants. They have a lot of knowledge, they have a lot of skill, they have a lot of experience, BUT they don't know me, so what I consider to be a partnership, where we work on these things together . . . my sense was that, as I worked with her over the week that I was in the hospital she really didn't listen to me much, she didn't engage with me. You know, I don't know how to describe that relationship that I look for in professionals. We're not peers, but they are experts in advising me on what I need to do. I look to them to recognize my primary role. They're not in charge – I am. Because if I am in charge, I can take their advice, and figure out things we need to do. The PT just didn't listen to me.*

Therapists should acknowledge the physical therapy histories of the adult patient with lifelong physical disabilities, but without ableist assumptions about current knowledge, abilities or needs. For example, do not assume skill for using a new prosthesis or piece of other type of assistive technology just because they have used something similar in the past.

Consider that patients may come, or not come, to PT as adults with feelings and memories of childhood therapy. For example, one participant had received a referral for PT for an evaluation of a condition that seemed to be progressing, but was "putting it off" and skeptical of any value in seeking physical therapy because "after having had PT for 18 years, that . . . didn't really help . . . wondered 'what are they gonna do now that I'm [much older age]?" Therapists should recognize that some of those experiences may not have been

pleasant, and/or may have been related to the therapist's power over them as children. The

power imbalance may still loom for a disabled adult.

> *The only way that I could describe this is that I came to therapy as a young adult with a very negative attitude. And, that sort of stayed with me until recently, and I'm in my... I just turned [age]. So . . . because I didn't like or trust them. That sort of stayed as far as my attitude.*

And certainly, there are also some who may come eagerly from different childhood experiences

that positively impacted them, as this participant said:

> *Since I was born and raised by P.T., it was easy to return as an adult. I actually just met with a neurologist and she was explaining some new techniques in spinal P.T. and I was thinking, Yeah, maybe I'll try that.*

> In this final theme, I have discussed participants' recommendations for today's and for

tomorrow's PPTs or educational programs, as well as what PTs working with adults with lifelong

disabilities could learn.

VII. **DISCUSSION**

A.   **Contributions of this Study**

Very recently scholars have called for exactly what I did in this study. Curran and

Runswick-Cole (2014) advocated for the emergence of a field of study that is not only a synergy

of approaches between DS and childhood studies, but also "more than just a combination of

the two" (p. 1617). The new discipline of "disabled children's childhood studies" reflects the

uniqueness of disabled children's experiences, the distinctiveness of their relationships, the

focus on aspects of embodiment, and identity. Further, on closer examination, they wrote

"disabled children's childhood studies are authored by disabled children" or "by disabled

scholars and activists reflecting on their childhoods" or "as an ally and academic" (Curran &

Runswick-Cole, 2014, p. 1618). Thus, important findings of the current project exemplify this

approach and verify the contribution to this body of literature.

Consistent with one of the study's original aims, these findings bridge the literature

between the disciplines of DS and rehabilitation, particularly physical therapy. This study is

from a DS perspective in that although my participants and I looked at individual experiences,

the focus is not on the individual as the site of impairment. Individual experiences of disability

were explored within a complex social context. This research is a window into the social

dynamics of physical therapy, as well as the direct experience of what it was like for physically

disabled children. Thus, this thesis falls into the genre of work that focuses on the individual

story in order to illuminate the social dynamics of disability.

The current project is "critical physical therapy research." While researchers who are

members of the Critical Physiotherapy Network have addressed issues such as power

(Eisenberg, 2012) and embodiment (Nicholls & Gibson, 2010), relevant to the profession as a whole, this study has applied those concepts to children. It also adds a critique of practice and recommendations for professional education. Within physical therapy, this study also expands the scant literature from U.S. physical therapists (Raman & Levi, 2003; Rousch & Sharby, 2010) who have begun linking DS concepts with general (but not yet pediatric) physical therapy practice and education in the U.S. Also, this research can add to the body of work of the Section on Pediatrics, within the APTA, that has contributed greatly to the treatment of children with disabilities, with its focus on pediatric physical therapy practice, research, and education for therapists and families over the last thirty plus years.

Although the current research used retrospective accounts, and therefore not responses from disabled children directly, this study does answer Gibson et al.'s (2009) and Gibson and Teachman's (2012) call for critical studies in pediatric physical therapy. Whereas a pediatric focus of critical physical therapy research is just beginning, the findings of this study connect with the pediatric researchers who have examined the socially dominant beliefs of children and their parents related to walking therapies (Gibson & Teachman, 2012). The findings of the two studies are in agreement that walking can be the sole, tacit, universal PT treatment emphasis, which preserves dominant values and messages of normality that can interfere with a child's (disability) identity. This study represents a step towards the development of critical PPT practice, and begins to examine how to train physical therapists differently, so students too can have critical perspectives in the treatment of physically disabled children.

Physical therapists have a real opportunity to focus on, and to support a child's strengths, rather than focus on the importance of walking, and the importance of normality.

The physical therapist becomes an important voice to support the child's goals, preferences, and strengths, rather than working to develop a strength because it is socially important, like walking, or looking normal. By accepting where the child is, and collaborating with the child to look at, and develop strengths and preferences; to support exploration of what the child can do and wants to do; the physical therapist can promote the child's self-determination. The physical therapist becomes the consultant, an ally, and collaborator. Collaborating with children and families on goals and activities to meet their needs and preferences, as recommended by participants, are now also considered Best Practices in pediatric physical therapy (Chiarello & Effgen, 2006; Rappaport et al., 2014).

However, being at the nexus of DS research and critical perspectives of PPT, my thesis findings extend beyond these family-centered practices by asking the therapist to be aware of, to question, and examine how social conventions and norms can shape and dominate their therapy goals, practices, and treatment plans. One participant declared "no one ever asked me why I wanted to walk," or what she wanted to do by walking that she couldn't do in her wheelchair. Unaware of any other options, the participant didn't understand why, throughout all of childhood, walking was always her personal goal. In addition, her goal was tied into negative feelings of self-worth, lack of personhood, and thinking that if she only tried hard enough she could walk; until at 20, she realized she wasn't going to walk. This participant's experience exemplified the impact on her life that the normative therapy goals had.

Therapists can also recognize that support and collaboration with the child on his or her goals may, or should, at times differ from those of parents and family members, who are a part of a socially dominant group, rather than the disability community. This is not to say that

walking should not be a consideration, but that there are also others. Furthermore, the therapist who questions and understands his or her own motivations for treatment options is then in a better place to help the family and client question whether they want certain options because that is what is expected or normative, or is it because those options are really going to work for them. Therapists, families, and children can realize that there are many people who have complete, meaningful lives – who don't walk. This is a new kind of advocacy for therapists.

To my knowledge, this is the only systematic analysis of disabled children's experiences of physical therapy across settings and four decades, how it felt to children during and afterwards, and both the short and long-term impact. It may also be the sole piece of literature regarding recommendations for pediatric physical therapy practice and education coming from disabled DS activists and scholars, and by a DS scholar/researcher/physical therapist. The study highlighted how their childhood therapy relationship influenced their feelings about their bodies, their confidence, and their identity into adulthood by analyzing various parts of the experience. Participants reflected on and analyzed their family support uniquely as insiders, the medicalized values conveyed from the therapists, and how therapists depersonalized and objectified children with power over their bodies and with medical gaze. Participants also identified an existing tension between the child and therapist that occurs when the child desires to comply with what the therapist asks but cannot, and that process seems to be interpreted by the PT as non-compliance and resistance. Participants reported feeling the PT's frustration, not only by their own inability to fix the child, but then also from incorrect assumption either of the child's over-competence or non-compliance, and resulting negative cycles of frustration.

This research also extends the limited literature regarding disabled children's

perspectives of their experiences for both physical therapy alone and physical therapy with

physical activity (Bricher & Darbyshire, 2004; Jahnsen et al., 2003; Sandstrom et al., 2009; Taub

& Greer, 2000). Especially like Bricher and Darbyshire (2004) and Gibson and Teachman (2012),

this study examined not only the psychosocial impact of therapy, but also considered first-hand

perceptions of the children's therapy as the source of those feelings. Participants in this study

not only shared, with these other researchers in therapy and physical activity, but further

detailed the disabled children's preferences for activity-based and play-based therapies; their

experiences of pain; and the impact of assistive technology, surgeries, as well as physical

therapy into adulthood.

B.   **Participant Sample Characteristics and Themes**

The participants in this study reported experiences of receiving regular therapy services

that are common among physically disabled children, and reflect the dominant attitudes of

finding, labeling, fixing, and trying to normalize deficits. The research findings deepen and

broaden our knowledge of the life-long emotional impact of these early experiences of therapy

within a medical model framework. Neither the type of therapy setting nor the geographical

location (including country) seemed to influence the participants' experiences: they occurred

everywhere. There were some good experiences and positive relationships in various types of

settings and locations, and the negative aspects also occurred in various locations.

Many of this study's sample of participants' experiences with AT was in a negative light,

being uncomfortable, or ugly, or something which overpowered them as children without

allowing any say regarding their use. Assistive technology or adaptive devices became a

concrete marker of their disability. Still, there was one participant who noted in a positive light

about mobility devices that were used and given assumedly by physical therapy that did allow

the participant the desired accessibility and participation with friends.

Ages of participants, with the exception of the youngest whose experience was more

positive across the board, did not seem to make a significant difference in their experience. The

eldest participant, in member-checking feedback, remarked about "finding it surprising about

how little things had changed." Some participants noted significant differences regarding their

personal body image and identity that related to the type of disability onset (congenital or

acquired), in their specific recommendations for physical therapists when working with disabled

children. However, those disability onset differences that participants cited in the

recommendations remained the only noteworthy differences related to therapy experiences.

That is, otherwise the experiences of physically disabled children that participants discussed

were similar or the same regardless of the disability onset within their first five years of age.

1. **Therapy relationships**

One of the most noteworthy findings coming out of these results is that the

relationship formed between the therapist and the child is really important, and can be

extremely valuable or it can be extremely detrimental. The various aspects of the large Quality

of Relationships theme have the greatest potential for change, because therapists have the

most immediate and greatest degree of control over the way they relate in their therapy. Being

aware of and able to change the way therapists relate with their pediatric patients is in contrast

to a more limited ability to manage political and social structures of the institution and/or

health care/therapy system in which they work.

From this study, we can envision children with two different types of PT experiences. First are children who enjoy therapy and benefit from it, and are not scarred by it. Children have therapists who they feel care about them, and who are interested in them as whole children with outside interests, talents, and activities. The therapist partners with their family, and recognizes the family context from which children come. Therapy activities and sessions are fun, sometimes done with other children. The therapist is encouraging and celebrates accomplishments of mutually chosen goals and achievable activities. Activities are varied with progression, and based upon the recognition of both real limitations and efforts. Modifications are made when needed so that children feel successful within each session. There is mutual respect between the therapist and children. Children trust the therapist, who communicates honestly, and listens.

There are other images of children from the study, for whom therapy is not a good experience. They are of two different types, and both found themselves emotionally caught in the middle between their own and the therapist's feelings during physical therapy sessions. First is the child who has to choose between being recalcitrant or "too far gone" if he or she cannot conform to being fixed. Second is a child who so much needs to have a supportive relationship–a need for closeness, intimacy, and sharing—that the child tries to have that kind of relationship with the PT whom they see regularly. But there is no disability community for the child because the PT has not connected them with other disabled children. They are only "cases," and the PTs are overlooking an opportunity, including the fact that the experience the children have in common is being children and being disabled.

2.   **Disability and identity**

This study detailed how therapists, through the power of their medical/clinical gaze and objectification, affected children's self-concepts, confidence and efficacy, bodies and body image, and thus became the way in which PT socially constructed disability and identity. Physical therapists disabled, oppressed, and turned children away from both the development of, and acknowledgement of, their own disability identity. The entire process of that objectification corroborated the literature in the way that therapists contributed to the loss of power, rights, and identity even as a child, a human being, and a sexual being (Marks, 1999; Olkin, 1997). Physical therapy literature and policies place PPTs as mandated reporters of sexual abuse, but sexuality in disabled children has been an area of little consideration in physical therapy, and could be an area for future research in therapeutic relationships. Also related, the two sides of the experience of touch/being touched were pointed out: that of sensuality of therapy as one participant said, and the pain that others experienced.

The various aspects of physically disabled children's identity development, and the role that physical therapists play in it, are other important findings of this study, which add to another area with little research. Previous literature has documented how other professionals in children's everyday environments (e.g., home and school) negatively influence disabled children's self and body image and self-efficacy, in addition to disablism from general society (Connors & Stalker, 2007; Davis & Watson, 2001; Holt, 2004). The findings of this study confirm that, with the deficit focus in therapy, PPTs are unfortunately also among those professionals. Parents are as well. However, being among the people in disabled children's everyday, "close"

environments, and knowing the potential for harm, can also be seen as opportunities for PPTs to model and educate others, including parents, according to participants' recommendations.

Participants in this research saw supporting a positive disability identity as an expanded role for physical therapists, which means that therapists need to have a comprehensive, complex, and expanded understanding of disability. It means that when therapists work with disabled children, they can't just see a child's body as damaged or lacking. Instead, therapists should see someone who is part of a community that extends beyond their family, beyond their school, across the country, and around the world. There are other children and adults with disabilities, and many positive and interesting aspects to disability. If therapists could understand disability in that way, a lot of the harm that the participants reported from their youth might never have happened.

Therapists shouldn't impede the development of disability identity by medicalizing and wanting to fix and rid kids of disability, but rather PTs should look at the possibility to support children's positive disability identity. Therapists could be alert to the opportunity for children being with other children with disabilities, with whom to identify and to form community, and should respect that need. That community may or not involve therapy in groups, but could provide occasions for group conversations with disabled peers, and connect children and families with other people who live successfully with the same disability.

Children and families look to and are hoping that PTs will help them understand disability. Disability is not just a physical difference, but is evidence that bodies come in many forms; it is a potential part of an identity, or a new identity; a feature around which people have formed a very strong community worldwide; as well as an entire culture. So, physical

therapists could reflect back to disabled children and their families, not just a narrow piece of what disability is, but a broad piece that opens up possibility. This also provides a response to critical physiotherapists Gibson and Teachman (2012) and their comment regarding physical therapists' role in disability identity: "An important task is to determine how best to assist children in maintaining a positive disability identity while pursuing achievable therapeutic goals" (p. 481).

Finally, this study relates to another research study that focused on yet another aspect of identity. Physically disabled children reported feeling successful in their identity <u>as children</u> in being able to <u>participate</u> with their nondisabled peers in a typical childhood activity itself (Taub & Greer, 2000). Participants in the current study also strongly reminded PPTs to treat children with disabilities as children, and the meaning of feeling successful, in participation, and in physical activity. Addressing the barriers that disabled children and their families may have to participation, and to physical activity for successful participation, physical activity, with potential community, are other ways PPTs can support positive disability identity.

3. **Family context**

The Family Context was a more minor theme, but merits a brief discussion because of PPT's work with children, as well as with their family. An additional dynamic with families found in the study was resistance and/or what may be considered resilience to the dominant "power" of therapists, and the expected carryover of therapists' roles by the family and the child. Therapists' messages and values also impacted families. Families' action around disability, found in this study, pointed out conflicts that participants were contending with during therapy and between their home environment and therapy settings. This has

implications for therapists working with families, as well as disabled children, to attempt to find

together a consistent message regarding the acceptance of disability and different bodies, and

positive disability identity.

C.   **Recommendations**

I have taken into consideration the participants' recommendations made for PPT

practice and educational programs, along with other findings of the study, and my experience

as a PT, to make the following recommendations for practice and for training. In addition, I

have some thoughts regarding future research that are based upon reflections from doing this

study, and upon questions that remain. A summary of my reflections and study limitations

follow. Finally, I excerpted some notable feedback from participants as member checking.

1.   **Researcher/Therapist's recommendations for practice and training**

- The therapist can convey the participants' recommendations about

personhood and embodiment in the way that they relate with children from session to session.

Model those positive attitudes and language to families and other professionals working with

children.

- Consider all parts of disabled children's identity in therapy with them. Help

children to build positive disability identities with their families, by talking with families and

providing resources.

- Take time to bond and talk with children about what matters to them – their life,

who they are, and what they are doing.

- Be ever mindful of how power affects therapy with children and their families. Participants' recommendations can provide detailed guidance regarding acknowledgement of power in relationships.

- Work for the child's success in therapy. Be aware of attempts and recognize without shame when children do something in other than the "therapeutic" way. Practice with incremental challenges.

- Accept and work from where the child is. Focus on, and support the child's strengths, abilities, and interests.

- Challenge children with new interesting achievable activities, but let the child repeat and celebrate each accomplishment.

- Partner with families. Appreciate the whole family context. Consider expectations of the child and/or family for follow-through of therapy activities at home.

- Teach families by modeling what to expect of a PT working with their child and warning signs of their child's rights or power being ignored or subdued in therapy.

- Play and joke and have fun with kids. Provide treatment activity options that go beyond dominant therapy approaches, e.g., for mobility. In thinking forward, consider how treatment today may influence the child in the future.

- Participants' recommendations should be very helpful to future therapists and to people who develop educational programs for PTs.

- Practice being a reflective practitioner, not only regarding the participants' recommendations about personal attitudes and language, but also on the relationship with the child, the patient, and the value the relationship may play in the child's life.

- Reflect also on how much therapeutic goals are simply dictated by convention. Learn to disentangle from normative goals first for oneself. Therapists are then in a better place to help the family and the child to disentangle what they want, and where their need comes from; from thinking that normal is the best, and from what society expects of them.

2. **Recommendations for future research**

Expansion of the research could include different participants for comparisons of results with this study. Non-scholar, physically disabled adult participants with different socioeconomic statuses (and less current "privilege" than activists and scholars) may bring different perspectives and recommendations. Differences from the participants in this study that we might expect may relate to the language, concepts and framework used to describe their experiences of the Disability Studies' perspective. Additionally, while some DS scholars differentiated between their "passing" and the development of a disability identity, others may not have the terminology, or the awareness of either. This may be the case, just as during the interviews, some participants had indicated, that they gained those insights for themselves with their DS scholarship. Younger physically disabled adults would bring their experiences in newer techniques and technologies that focus on participation in various therapy activities.

Asking participants for specific recommendations related to improving the family role in physical therapy would be beneficial, and a different perspective from the way parents are usually included in research as an adjunct to what children report. This might be particularly significant, as some participant responses indicated discrepancies in disability identity and acceptance issues between home and therapy.

Because participants with different onsets of their disability did note differences in their childhood experiences, and hence in their recommendations, when researching with other physically disabled adults, it is recommended that disability onset be a consistent consideration as a potential influence in their developmental experiences of disability.

Pediatric physical therapy educators could also join with physically disabled DS scholars to study ways of implementing findings from this study for professional training and continuing education curricula. This could be done within the national PT organization, the American Physical Therapy Association (APTA), or at levels at the Section on Pediatrics (SoP) (devoted to physical therapists working with children and adolescents and adults with developmental disabilities, and newly renamed Academy of Pediatric Physical Therapy), and/or the Education Section (for clinical and academic educators). Committees from the APTA or SoP could reach out to DS organizations, university programs, or disability advocacy groups at a national, state, or local level to partner for input into the curriculum process. For example, the Clinical and Academic Educators Special Interest Group of the SoP is currently planning an Education Summit to update unique competencies for Entry-Level PT Education that were developed previously (Rapport et al., 2014). Pediatric PT educators and clinicians could also work to determine how to integrate disability studies into literature, e.g., Fact Sheets or "best practices", as well as for continuing education curricula.

The SoP has made more advances than the parent organization, APTA, in acknowledging the personal and environmental contexts of the ICF, to include a more holistic approach to various areas of pediatric practice, which also include adolescents and adults with developmental disabilities. For example, the SoP has a fact sheet looking at cultural

competence in health disparities and children with "special needs" that does include

disabilities as an area of cultural competency. In contrast, the APTA *Blueprint for Teaching*

Cultural Competency in Physical Therapy Education (APTA, 2014) does <u>not</u> list disability under

either the eight primary or the six secondary "diversity dimensions" list related to

discrimination in the US.

Additionally, this study could inform LEND programs (Leadership Education in

Neurodevelopmental and Related Disabilities) within the Association of University Centers on

Disability (AUCD). LEND programs are interdisciplinary professional education training

programs where study findings could be integrated as part of their core curricula for working

with children.

D.   **Strengths and Limitations of the Study**

While the strength of qualitative research is that it affords greater depth in exploring

phenomena, the in-depth focus on fewer participants limits ability to generalize findings,

although PT is a very common experience for children with physical disabilities. However, in this

qualitative research study, I used qualitative methods that were sound and was true to the

research question, so this is not considered a limitation to my study. The reliance on email

interviews or telephone interviews as accommodation, represented strength and limitation:

while email has the advantage of regional representation, neither afford the opportunity for,

nor advantage of face-to-face observations. Additionally, because of my purposeful selection of

Disability Studies scholars, some disability self-advocates or activists, or others without the

privilege of being scholars who also have a great deal to contribute, might have been excluded.

Although telephone interviews were offered as an accommodation for access, the primary

email interview method, the mode of data collection may have excluded other participants with more significant disabilities.

Although there was a good representation across age groups from the mid-20's to 60's, the study did not include younger people who may have had experiences with some approaches related to more current social model PPT practices and to the ICF, e.g., with focus on participation. Finally, a physical therapist researcher with a different expertise, e.g., an in-patient hospital experience, might have changed the interview process with different types of questions and follow-up. This might have obtained additional information, particularly regarding working with children who have pain and post-surgical treatment, and which could also be an area of future research.

Skype interviews may have offered a more intimate connection and rapport between researcher and participant, and in fact was suggested by two participants. Skype would have also facilitated the process with a participant using a communication board and an assistant to re-voice the responses, to see when the participant had completed a response, and prevent interruptions or premature questioning. However, it is also recognized that other potential participants with less privilege, as discussed before may also not have access to Skype.

E.   **Reflections**

Consistent with qualitative research methodology and being a reflective physical therapist, I journaled my reflections throughout this project. My reflections related to data collection where I wrote about my responses to the interview process itself, and to the methods, and to feelings about what participants were telling me.

I had some emotional responses regarding participant experiences during and after some interviews. I identified with some PT experiences that resonated with my history of having done some of the things that participants discussed as a professional or as a student. To hear participants' experiences made me feel sad and apologetic for the unintentional "errors" of our profession. I was humbled by what they shared. I also reflected on my feelings of ableism, and as a "dominant professional," related to their experiences; e.g., if someone had not received follow-through with their therapy at home, I wondered if there would have been different outcomes with that follow-through. In addition, as a person with a disability, although my disability is not one that gave me the same experiences of therapy, I found myself identifying with some participants' feelings, common to people with disabilities, regardless of the type.

I felt the tension between my long-ingrained medicalized training and attitudes on the one hand, and disability studies on the other, and was challenged at times in attempts to continue to balance the two perspectives. In addition, or perhaps better, simultaneously, my evolution towards being a critical researcher in physical therapy was challenging. Being able to reflect on these now, I could see my personal growth in each of these areas as a researcher, and as a therapist in trying to apply what I heard with each encounter with parents and with the children with disabilities with whom I work.

F.   **Member-Checking**

The following are some notable excerpts from the member-checking process of participant feedback regarding my findings:

I think this is good! This is great stuff (P3).

My feedback is just- Wow it's wonderful to read the responses, many of which resonate with my experience (P4).

Your findings as a whole seem to me not only very interesting, but illustrative of the situations that as a person with disabilities I experienced in my childhood/adolescence (P7).

Two participants especially related to the Impact of Therapy, one saying how powerful it was, "since it left a lasting impression on how I react to PT today, and on my journey of disability identity and needing to fight against all the messages I received from medical treatments in childhood." Another participant pointed out that "mostly all problems between the physical therapist and his 'patients' are born from the non-recognition of our personhood." Further, they reiterated original interview responses regarding recommendations for PTs being exposed to disability culture through "many videos, books, poetry, films (to) help provide disability perspectives . . . this is what is usually missing from, and can be most powerfully transformative for able-bodied privileged therapists."

G.   **Conclusion**

To see and hear participants' experiences that were oppressive, damaging was jolting even after years in disability studies. It was disheartening to read some of the recommendations that seemed so fundamental. Reading about theories, and hearing criticisms of PT has been an area of tension throughout this process, but the lived experience from this study has been a great instructor. Coming from "experts" in how we relate to children, originating from a history of having been treated so differently, the participants' recommendations are much more powerful. It is hoped that this research will have some of the same jolt, nudging other therapists to realize the unintended consequences or harms of past and current practices that we have been trained for to do, and to further question these

practices as critical physical therapists. As others in the field have said, our profession's history

is important to know and understand.

APPENDICES

APPENDIX A

INTERVIEW GUIDE

You volunteered for this study because you are an adult, who as a child you received physical therapy, rehabilitation, and/or physical activity services*.*

1) I want to ask you the following questions to set the stage for your childhood experiences with physical therapy, rehabilitation, and/or physical activity*.*

   a) *Please tell me how old you were when you received the above physical therapy, rehabilitation, or physical activity?*

   b) *Can you tell me what kinds of activities you did in therapy during a typical session?*

   c) *Please tell me about some of both the best experiences and the worst "therapy" experiences that particularly stand out in your memory, and what you believe made them that way.*

   Probe: You mentioned you had surgery as a child, can you tell me more about that and how it affected you as a child?

   Probe: Can you can you tell me more about….

2) Now I want to ask you about the therapy staff with whom you interacted in those sessions, and what your relationship was like with them.

   a) How did you feel about the physical therapist or therapy staff, and your relationship with them during or after those sessions? What did you like and what did you not like about your relationship with your therapists?

   Probe: How, if at all, did that affect your feelings about yourself?

   b) I've heard that sometimes children with disabilities experience power issues between them and therapists or "therapy" staff. Would you please comment on this in your own experience?

3) Next, I'd like to ask you about *your family involvement with your therapy.*

   a) *Describe your family during the time you received therapy (e.g., who raised you? If not raised by parents, describe your primary "parent figure(s)"? Tell me about any siblings, their gender (M or F) and age relationship to you)*

   b) *What kind of involvement, if any, did they have with your physical therapy, physical activity, and/or rehabilitation?*

APPENDIX A (continued)

INTERVIEW GUIDE

c) How, if at all, did your "therapy" experience(s) as a child affect your feelings about your relationship with your family? Or your family's relationship to you?

d) How, if at all, do you feel your childhood experiences in therapy, rehabilitation, or physical activity affected you as an adult?

4) In the following questions I'd like to explore your views about your childhood "therapy" experiences now that you are an adult. How, if at all, has your thinking changed about your childhood "therapy" experiences?

   a) How, if at all, has it changed since studying disability studies?

   b) How, if at all, has your thinking changed about *disability* since becoming a Disability Studies scholar?

   c)   How, if at all, has your personal Identity changed since growing up?

5) Finally, I would like to ask your advice or guidance:

   a) If you could go back in time and speak as an advocate for your child-self, what would you tell those therapists?

   b) What would you like to tell *current* pediatric therapists regarding working with children [in general, for children with physical impairments, or other health conditions] based on your childhood experiences, as adults, and disability studies scholars? [E.g., recommendations or other things to do or not do, how to relate, family involvement etc.]

   c) What are any additional recommendations, related to your experiences, that you feel should be included in educational training programs for *future physical therapists or pediatric therapists in general*?

   d) Is there anything else that you would like to add about this topic?

That is all of the questions that I have for you right now. I may be back in touch with you in the near future if further clarification is needed. I really appreciate your participation in this study! Thank you so much

APPENDIX B

UIC IRB APPROVAL NOTICE AND AMENDMENT

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice

Initial Review (Response To Modifications)

August 19, 2014

Faye Weinstein, PT., M.M.Mc
Disability and Human Development
4320 N. Harding Avenue
Chicago, IL 60618
Phone: (773) 478-5549

RE: **Protocol # 2014-0500**

    "Disability Experiences of Childhood Therapy: Recollections and Recommendations for   Pediatric Therapy"

Dear Ms. Weinstein:

Your Initial Review application (Response To Modifications) was reviewed and approved by the Expedited review process on August 7, 2014. You may now begin your research.

Please note the following information about your approved research protocol:

> **Please remember to add additional research assistants via Appendix P, accompanied by an Amendment form, prior to their involvement in this research.**

> **Please note that the Recruitment Flyer, version 2, 6/27/2014, has not been approved and released as no clean copy of the document was submitted and there was no investigator response to the request for a clean copy. Kindly remember to submit a clean copy of this document via amendment.**

Protocol Approval Period: August 7, 2014 – August 7, 2015
Approved Subject Enrollment #:   12

APPENDIX B (continued)

UIC IRB APPROVAL NOTICE AND AMENDMENT

<u>**Additional Determinations for Research Involving Minors:**</u> These determinations have not been made for this study since it has not been approved for enrollment of minors.

<u>**Performance Site:**</u>   UIC

<u>**Sponsor:**</u>   None

<u>**Research Protocol:**</u>

   4320 Disability Experiences of Childhood Therapy: Recollections and
      Recommendations   for Pediatric Therapy; Version 2; 07/01/2014

<u>**Recruitment Materials:**</u>

 a) Telephone Script/Screener Response to Recruitment Ads, Flyers; Version 2; 06/17/2014
 b) Email and Listserv Announcement; Version 2; 07/01/2014
 c) Research Information Sheet (cover sheet); Version 2; 07/01/2014
 d) Online screener (no footer)

<u>**Informed Consents:**</u>

 a) Research Information Sheet; Version 2; 07/01/2014
 b) A waiver for signature on the consent document and an alteration of consent have been granted for all of this email/telephone-based research under 45 CFR 46.117©(2) and 45 CFR 46.116(d) (minimal risk; subjects will be provided with an information sheet containing all of the essential elements of consent prior to participating in data collection)

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

6) Collection of data from voice, video, digital, or image recordings made for research purposes.,
(7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

<u>**Please note the Review History of this submission:**</u>

Receipt Date	Submission Type	Review Process	Review Date	Review Action
05/22/2014	Initial Review	Expedited	05/28/2014	Modifications Required
07/29/2014	Response To Modifications	Expedited	08/07/2014	Approved

Please remember to:

→ Use your <u>**research protocol number**</u> (2014-0500) on any documents or correspondence with

APPENDIX B (continued)

UIC IRB APPROVAL NOTICE AND AMENDMENT

the IRB concerning your research protocol.
→ Review and comply with all requirements on the enclosure,

"**UIC Investigator Responsibilities, Protection of Human Research Subjects**"
(http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.
Please before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-2014. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Sandra Costello
Assistant Director, IRB # 2
Office for the Protection of Research

Subjects

Enclosures:
   1. **UIC Investigator Responsibilities, Protection of Human Research Subjects**
   2. **Informed Consent Document:**
       a) Research Information Sheet; Version 2; 07/01/2014
   3. **Recruiting Materials:**
       a) Telephone Script/Screener Response to Recruitment Ads, Flyers; Version 2; 06/17/2014
       b) Email and Listserv Announcement; Version 2; 07/01/2014
       c) Research Information Sheet (cover sheet); Version 2; 07/01/2014
       d) Online screener (no footer)

cc: Tamar Heller, Disability and Human Development, M/C 626
       Carol J. Gill (faculty advisor), Disability and Human Development, M/C 626

APPENDIX B (continued)

UIC IRB APPROVAL NOTICE AND AMENDMENT

UNIVERSITY OF ILLINOIS
AT CHICAGO

Office for the Protection of Research Subjects (OPRS)
Office of the Vice Chancellor for Research (MC 672)
203 Administrative Office Building
1737 West Polk Street
Chicago, Illinois 60612-7227

Approval Notice
Amendment to Research Protocol and/or Consent Document – Expedited Review
UIC Amendment # 1

September 2, 2014

Faye Weinstein, PT., M.M.Mc
Disability and Human Development
4320 N. Harding Avenue
Chicago, IL 60618
Phone: (773) 478-5549

RE: **Protocol # 2014-0500**
            "Disability Experiences of Childhood Therapy: Recollections and Recommendations
for Pediatric Therapy"

Dear Ms. Weinstein:

Members of Institutional Review Board (IRB) #2 have reviewed this amendment to your
research under expedited procedures for minor changes to previously approved research allowed
by Federal regulations [45 CFR 46.110(b)(2)]. The amendment to your research was determined
to be acceptable and may now be implemented.

Please note the following information about your approved amendment:

Amendment Approval Date: September 2, 2014
Amendment:
    Summary: UIC Amendment #1, dated and received August 26 is an investigator-initiated
    amendment submitting **(clean copy)** Recruitment Flyer, v. 2, 6/27/2014 for review and
    approval.
Approved Subject Enrollment #:   12
Performance Site: UIC
Sponsor: None
Recruiting Material:

APPENDIX B (continued)

UIC IRB APPROVAL NOTICE AND AMENDMENT

a) Recruitment Flyer- Disability Therapy Experiences Version 2, 06/27/2014

Please note the Review History of this submission:

Receipt Date	Submission Type	Review Process	Review Date	Review Action
08/26/2014	Amendment	Expedited	09/02/2014	Approved

Please be sure to:

→ Use your research protocol number (2014-0500) on any documents or correspondence with the IRB concerning your research protocol.

→ Review and comply with all requirements on the enclosure,
 "**UIC Investigator Responsibilities, Protection of Human Research Subjects**"
 (http://tigger.uic.edu/depts/ovcr/research/protocolreview/irb/policies/0924.pdf)

Please note that the UIC IRB #2 has the right to seek additional information, or monitor the conduct of your research and the consent process.

Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.

We wish you the best as you conduct your research. If you have any questions or need further help, please contact the OPRS at (312) 996-1711 or me at (312) 355-2764. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,

Betty Mayberry, B.S.
IRB Coordinator, IRB # 2
Office for the Protection of Research Subjects

Enclosure:

1. **Recruiting Material:**
   a) Recruitment Flyer- Disability Therapy Experiences Version 2, 06/27/2014

APPENDIX B (continued)

UIC IRB APPROVAL NOTICE AND AMENDMENT

cc: Tamar Heller, Disability and Human Development, M/C 626
           Carol J. Gill, Faculty Sponsor, Disability and Human Development, M/C 626

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Papadimitriou, C. (2007). It was hard but you did it"- the co-production of 'work' in a clinical setting among spinal cord injured adults and their physical therapists. *Disability and Rehabilitation*, *30*, 1-10.

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Roush, S. E., & Sharby, N. (2011). Disability reconsidered: The paradox of physical therapy. *Physical Therapy, 91,* 1715-1727.

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FAYE H.WEINSTEIN, P.T., M.M.Sc.
4320 N. Harding Ave.
Chicago, Illinois 60618
773-478-5549
E-mail: *fweins2 @gmail.com*

EDUCATION

Masters of Science in Disability & Human Development, University of Illinois at Chicago, Illinois, Anticipated Graduation: Summer 2016

> *Thesis:* **Childhood Disability Therapy Experiences: Recollections and Recommendations**

Masters of Medical Science in Physical Therapy: Education and Pediatric Concentrations, Emory University, *Graduate Programs in Physical Therapy,* Atlanta, Georgia

> *Thesis:* **Essential Considerations for an Integrated Developmental Aquatic Program and Model for School-Aged Disabled Children***,*

Bachelors of Science and Certificate in Physical Therapy, Northwestern University Medical School, Chicago, Illinois.

PROFESSIONAL CERTIFICATION and LICENSURE

Illinois Physical Therapist # 70-1641

TEACHING & TRAINING/ ACADEMIC EXPERIENCE

Physical Therapy Discipline Training Coordinator	Illinois Leadership Education in Neurodevelopmental and related Disabilities (LEND) Chicago, Illinois	2008- 2010
Lecturer, Part-Time Pre-Physical Therapy Program	Chicago State University Chicago, Illinois	2005- 2008
Clinical Associate Clinical Instructor Consulting & clinical PT services	University of Illinois at Chicago Department of Physical Therapy •University of Illinois Hospital •Illinois Children's Rehabilitation Center & School •United Cerebral Palsy EI (Early Intervention) Program •El Valor EI Program	1991-1996
Consultant, Curriculum Development	Chicago State University Department of Physical Therapy School of Allied Health Chicago, Illinois	1987
Assistant Professor	Texas Tech University, Health Sciences Center Department of Physical Therapy	1982-1985

School of Allied Health,
Lubbock, Texas

CLINICAL EDUCATION

APTA: Clinical Instructor Certification, 2002 – Present.
- Midwestern University, School of Allied Health, Program in Physical Therapy, Downers Grove, Illinois, 1997.
- University of Illinois, Medical School, School of Related Health Professions, Physical Therapy Program, Chicago, Illinois, 1991-1996.
- Emory University, Graduate Programs in Physical Therapy, Atlanta, 1978-1979.
- Marquette University, Physical Therapy Program, Milwaukee, Wisconsin and Northwestern University,   Program in Physical Therapy, Chicago, at Elisabeth Ludeman Center, Park Forest Illinois 1975 -1977.

SELECTED CONTINUING EDUCATION WORKSHOPS
Aquatics

Director, Pediatric Aquatic Therapy: Emphasis on Evidence-Based Practice - A Lab Based Course, Rehabilitation Institute of Chicago Academy, Chicago, Illinois, 2008.

Faculty, Aquatic Risk Management, Audio Conferences, Aquatic Physical Therapy Section, APTA, 2004, 2006.

Faculty, Water Safety Plus- Ellis & Associates and Aquatic Physical Therapy Association, APTA, Geneva, IL, 1998.

SELECTED PUBLICATIONS

Bernot, L., Cirullo, J., Morris, D. & Weinstein, F. (Risk management in aquatic programs.) Safety training module for aquatic physical therapists. in: Ellis, JL., Osinski, A., & White, J.E.. **Water Safety + (Plus).** Kingwood, Texas: Jeff Ellis & Associates, 1995.

Weinstein, FHD: Developmental Aquatic Programs for Children Who Are Non-Ambulatory and Living in a Residential Setting. **Aquatic Physical Therapy Report,** 3, (3), 5-8, Aquatic Section, American Physical Therapy Association, Fall 1995.

Dulcy, F.H.: Developmental Aquatic Programs for Children with Autism. *National Aquatics Journal*, Volume 8, Issue 2, Spring 1992, pp. 7-10, 16.

Dulcy, F.H., Guest Editor: *Aquatics: A Revised Approach to Pediatric Management. A Special Issue of Physical & Occupational Therapy in Pediatrics*. Vol. 3, No. 1, Spring 1983.

Dulcy, F.H. (ed.): *Aquatics: A Revised Approach to Pediatric Management.* New York, Haworth Press, 1983. (One of the earliest, and most cited pediatric aquatic therapy publications.)

Dulcy, F.H.: Aquatic Programs for Disabled Children: An Overview and an Analysis of the Problem. *Physical & Occupational Therapy in Pediatrics*. *Vol. 3*, No. 1, Spring 1983, pp. 1-20.

Dulcy, F.H.: A Theoretical Aquatic Service Intervention Model for Disabled Children. *Physical & Occupational Therapy in Pediatrics*. *Vol. 3,* No. 1, Spring 1983, pp. 21-38.

Contributing Author:
   Emery, H. M. & Kucinski, J.: **Management of Juvenile Rheumatoid Arthritis: A Handbook for Physical and Occupational Therapists.** La Rabida Children's Hospital & Research Center, Chicago, Illinois, 1987

American Red Cross: **Methods in Adapted Aquatics:** A Manual for the Instructor, Washington, D. C., 1976.

CLINICAL EXPERIENCE

Private Practice Pediatric & Aquatic PT, owner	**Therapeutic Aquatic Learning** Metro Chicago, Illinois	1987-Present

Consulting, Contractual Services

Director, Aquatic Therapy Program (part time)	Pediatric Therapy Network Chicago, Illinois	2013–Present
Consultant Pediatric P.T (Part-time)	Select Medical and Associates **Chicago Public Schools**:	1994-2008
	Esperanza **Early Intervention (EI)** Program (center & home-based) Chicago, Illinois	1995-2006
	Therapeutic Interactions La Grange, Illinois Pediatric out-pt. facility	1993-1995
	Gilchrest Marchman Easter Seal Center (EI) Chicago, Illinois	1993-1994
	The Pediatric Place, Homewood, Illinois	1991-1992
	Chicago Regional Project, Title I Chicago, Illinois -Private special education schools.	1987-1991
	Park Lawn School Park Lawn, Illinois	1979-1980
	Northwestern Illinois Assoc., Geneva, Illinois	
	Atlanta Area *School for the Deaf* Atlanta, Georgia	1978-1979
	Georgia Regional Hospital & Georgia Retardation Center), Non-Ambulatory Unit Atlanta, Georgia	1977-1978
Director of PT, *Gait Lab PT* *Pediatric Rheumatology* *Grant PT*	La Rabida Children's Hospital & Research Center Chicago, Illinois	1985-1987
Center Director & Physical Therapist	Easter Seal of Metropolitan Chicago Willett Rehabilitation Center Oak Park, Illinois	1980-1982

Weekend Physical Therapist	Children's Memorial Hospital Chicago, Illinois	1979-1980
Director, Physical & Occupational Therapy	Elisabeth Ludeman Developmental Center Park Forest, Illinois	1975-1977
Chief Physical Therapist	Elkhart Rehabilitation Center Elkhart, Indiana	1974-1975
Staff Physical Therapist	Rehabilitation Institute of Chicago Chicago, Illinois	1973-1974
Staff Physical Therapist	Illinois Masonic Hospital Chicago, Illinois	1972-1973

CONSULTATIVE AND ADVISORY POSITIONS
Aquatic Program Consultation

Misericordia: Homes North, Program Consultant (Pool Design), Chicago, Illinois, 1994-1995. Homes South, Pool Curriculum & Aquatics PT services, Chicago, Illinois, 1988 -1991.

Michael Reese Hospital and Medical Center, Aquatic Curriculum Consultant, The Developmental Institute, Day School for children with autism, Chicago, Illinois, 1988 -1991.

Atlanta Easter Seal Society, Aquatic Community Program Consultant, Atlanta, Georgia, 1979.

Program Medical Advisor, Elkhart YM/YWCA, Aquatic Program Committee, Elkhart, Indiana, 1974-1975.

SELECTED SCIENTIFIC AND PROFESSIONAL PRESENTATIONS
Invited presentations

Invited Speaker, The Rehabilitation Institute, Kansas City, "Aquatics as Multidisciplinary Approach to Pediatric Rehabilitation ", Focus on the Future. Ethics, Legislation, and Innovative Programs in Rehabilitation for the 21st Century, 1997.

Guest Speaker, *National Society of Autism of America*, "An Integrated Developmental Aquatic Curriculum", Seattle, Washington, 1989.

Selected Conference Presentations

Speaker, "Pediatric Aquatic Physical Therapy: School-Based Services for Children With Complex Disabilities", Aquatic Physical Therapy Section and Section on Pediatrics, APTA, Combined Sections Meeting (CSM), New Orleans, LA, 2005.

Speaker, "Proactive Elements of a Solid Pediatric Aquatic Physical Therapy Program", Pre- Instructional Course, Aquatic Physical Therapy Section, CSM, APTA, New Orleans, Louisiana, 1994.

Poster Presentation: Developmental Aquatic Programs for Children Who Are Non-ambulatory and Have Severe Disabilities, Aquatic Physical Therapy Section, CSM, APTA, New Orleans, Louisiana, 1994.

Speaker, World Congress of Physical Therapy. Pre-Congress Course, Hydrotherapy Association of Chartered Physiotherapists: "Therapeutic Aquatic Learning: Integrated Developmental Aquatic Programs", Recent Advances in the Theory and Practice of Pool Therapy, *London*, England, 1991.

Speaker, American Association on Mental Deficiencies, National Conference, Physical and Occupational Therapy Subdivision. "Splash to Learn!" Chicago, Illinois, 1976.

Speaker, "Physical Therapy as a Developmental Technique via Aquatics", American Physical Therapy Association, Section on Pediatrics, National Conference, New Orleans, Louisiana, 1976

SELECTED LEADERSHIP
American Physical Therapy Association (APTA)

Aquatic Physical Therapy Section, APTA
Editorial Committee -The Journal of Aquatic Physical Therapy, 2006 - Present
Secretary, 2004-2007. Member, Executive Committee 2004-2007
Task Force on Advanced Competency, 2007-2009
Chairman, Aquatic Physical Therapy Standards of Practice Task Force, 1993-1995

Section on Pediatrics, APTA
Regional Director, North Central Region, 1975-1978 (Charter), 1979-1982
Member, Board of Directors, 1975-1978 (Charter), 1979-1982

Illinois Chapter, APTA
Delegate, Eastern District, Illinois Chapter Delegate Assembly, 1987
Chairman, Committee on Physical Therapists in Educational Environments, 1980-1982
Member, Board of Directors, 1980-1982
Member, Continuing Education Committee, Eastern District, Illinois Chapter, APTA, 1976-1977

Texas Chapter, APTA
Delegate, West Texas District, House of Delegates, National Conference, Las Vegas, 1984
Co-Vice Chairman, Pediatric Interest Group, 1983-1984
Member, Executive Committee & Lubbock Area Representative, West Texas District, 1982-1985

Community Organizations
Member, YMCA of the USA, Office of Special Populations.
Project F.I.T. Publication Committee, 1990 - 1991
Special Consultant, 1989 -1991.

*Chairman, **Elkhart County Special Olympics**, Elkhart, Indiana, 1974-1975*

UNIVERSITY SERVICE

Member, Curriculum Development Committee, Doctoral Physical Therapy Program, University of Illinois at Chicago, Chicago, Illinois, 1993-1996.

Member, PT Accreditation Committee, Department of Physical Therapy, Texas Tech University Health Sciences Center, 1983-1985.

Member, Planning Committee, Physical Therapy Continuing Education, Georgia State University, Atlanta, Georgia, 1978-1979.