# On the Complementarity of Cultural Historical Psychology and Contemporary Disability Studies

Peter Smagorinsky

The University of Georgia (USA)

Michael Cole

University of California-San Diego (USA)

Lúcia Willadino Braga

SARAH Network of Neurorehabilitation Hospitals, Brazil

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In this chapter we juxtapose two perspectives on the study of human "disability." We place this term in quotation marks because the notion that human difference constitutes a disablement of human functioning is, to many, a social construction rather than a biological condition that necessarily reduces one's ability to navigate the physical and social worlds. The perspectives that we feature in this chapter in general contest the illusion that there is a "normate," or idealized human form (Garland-Thomson, 1997) beyond that which is constructed by those in authority.

We begin by describing an approach to cultivating the potential of people with anomalous makeups growing out of the tradition that traces its origins to L.S. Vygotsky (1929, 1934/1987, 1993), a Soviet psychologist whose major work was carried out between 1924 and 1934, when he died at 38 years of age. We refer to this approach through a term coined by Cole (1996), cultural-historical activity theory (CHAT). Next we compare and contrast Vygotsky's approach with recent scholarship in the contemporary fields of disability studies (DS) and critical disability studies (CDS), which have come to prominence in Western and Northern Europe, the United States, and elsewhere in the late 20<sup>th</sup> century (Goodley, 2011). For our purposes here, given that DS and CDS have considerable overlap, we combine them into a single field as DS/CDS.

Our goal in making this comparison is to seek to better understand what different groups of scholars can contribute to providing a more humane and supportive environment for those to whom terms such as "disabled" are widely applied, and to

consider their areas of both complementarity and difference. At the risk of oversimplifying, we find that DS/CDS, as a "critical" perspective focused on unpacking the power apparatus that supports hegemonic structures, has largely emerged from the humanities and is oriented to textuality, including spoken and written constructions of "disability." Although some versions of DS/CDS are concerned with material environments, that focus is more the concern of CHAT and Vygotsky's (1993) defectological writing. CHAT might involve critique, but as a discipline grounded in the social sciences, has a greater interest in the empirical world and how to investigate and understand it through studies of and interventions in the material world.

#### **Vygotsky's Cultural Historical Theory**

Core ideas about atypicality were central to the field of cultural-historical psychology as it took shape in the early decades of the twentieth century. In Vygotsky's first publication in English (1929), the second of a set of three articles presented as a series about "the cultural development of the child," the opening sentences succinctly summarize key elements of the theory he and his colleagues went on to develop:

In the process of development the child not only masters the items of cultural experience but the habits and forms of cultural behavior, the cultural methods of reasoning. We must, therefore, distinguish the main lines in the development of the child's behavior. First, there is the line of natural development of behavior which is closely bound up with the processes of general organic growth and the maturation of the child. Second, there is the line of cultural improvement of the psychological functions, the working out of new methods of reasoning, the mastering of the cultural methods of behavior. (p. 415)

"Cultural methods of behavior" were the focus on Alexander Luria's lead article in the series. This idea rests on the assumption that human ontogeny is the emergent outcome of the interweaving of two "genetic domains" or "scales of time." The first is phylogenesis, the natural and evolutionary history of the human species from its earliest forms preceding homo sapiens, while the second is cultural history, which dates from the appearance of homo sapiens and refers to the manner in which people mediate their collective development as a society.

According to this view, the inclusion of tools and signs as constituents of human action in the course of human cultural history gives rise to an entirely new morphology of behavior: "instead of applying directly its natural function to the solution of a specific task, the child puts between that function and the task a certain auxiliary means . . . by the medium of which the child manages to perform the act" (Luria, 1928, p. 495). In somewhat different terms, in addition to acting directly on the object of their activity, human beings are able to act indirectly, by mediating their actions through tools and signs, including psychological tools such as speech-mediated thinking. Any "cultural form of behavior" involves the coordination or merging of the two streams of history.

Working from these assumptions, Vygotsky (1929) and his colleagues argued that in the course of typical development,

the two lines of psychological development (the natural and the cultural) merge into each other in such a way that it is difficult to distinguish them and follow the course of each of them separately. [However], in the case of sudden retardation of any one of these two lines, they become more or less obviously disconnected as,

for example, in the case of different primitiveness<sup>1</sup>, e.g., a delay in cultural development . . . primarily due to the fact that for some external or internal cause they have not mastered the cultural means of behavior, especially language. (p. 16)

Two key ideas are contained in this paragraph. First, the two "streams of history," the biological and the cultural, merge into each other, making it difficult to follow their development separately. Second, developmental processes can be seen especially clearly when there is a sudden disruption of either stream, since either can upset the ordinary, well integrated, merged processes of development by forcing a change in their relationship. For the purposes of this chapter, we consider anomalies rather than the typical rate of development, which was Vygotsky's concern with this general statement. If some people do not grow according to the sort of schedule detailed in stage theories of psychological development, or typically in relation to cultural mediation from society, what is at work, and what are the consequences of have physical, cognitive, or neurological aspects of makeup that produce a different developmental trajectory?

# **Vygotsky's Approach to the Anomalous Human**

Vygotsky regarded nonconformities from typical developmental pathways as a means to understand processes of development in general. His work in defectology (Vygotsky, 1993) was specifically oriented to providing education for the many young people who were maimed, dismembered, blinded, deafened, cognitively impaired, or otherwise affected in their ability to navigate their worlds by the many explosions and

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<sup>&</sup>lt;sup>1</sup> In this translation of Vygotsky's text, the term "primitive" is a developmental stage "characterized by non-intellectual or thoughtless speech. As babies, we goo and gah and cry and babble. These are examples of the primitive stage of language development. The sounds produced serve no real purpose except to produce the sound. The baby may make sounds without producing speech." It thus does not suggest a more primitive way of being, but rather what he characterized as an embryonic stage of language development.

violent impacts of the lengthy warfare that produced the Soviet Union in 1924, roughly when he began his career in Moscow. These conditions are known in Vygotsky's parlance as "primary disabilities": the specific condition that causes one to be viewed as different and often deficient. This central role of "disability" in Vygotsky's scientific program has gone relatively unnoticed, even as Vygotskian ideas became prominent in many areas of developmental psychology, including special education (Gintis, 1995; Kozulin & Gintis, 2007; Smagorinsky, 2012a, 2012b, 2016).

A number of factors help to explain the relative neglect of Vygotsky's ideas on anomalous children, and by extension those who grow through their teens into adulthood. As recounted by McCagg (1989), Russian academic ideas about anomalous children were heavily influenced by European, especially German ideas, at the time that the first special research and training centers were opened in the decades preceding and following the Russian Revolution of 1917. Authoritative texts of the time used the term "defective" to refer to what would now be called "special needs" children.

Although this period might also correspond to the rise of eugenics in Germany and elsewhere (including, briefly, the Soviet Union; see Graham, 1977), Vygotsky and others in the nascent Soviet Union were oriented to challenging debilitating views of the physically different by arguing that if there is a problem, it is a social problem rather than one of the individual of difference. In opposition to eugenics, in which such people should be put to death lest they infest the population with more imperfect progeny, Vygotsky's goal with the Russian concept of *defectologia*, translated as *defectology*, was to create more humane settings to help cultivate the potential of those widely considered either to be of no social value, or more extremely, detriments to the greater good.

The Latin origins of *defectologia* invoke strong negative connotations of failure, shortcoming, and other terms associated with human deficiency. Consequently, as McCagg (1989) comments, "this term would not survive 3 minutes in a discussion of the handicapped in the Western world today because it carries too much negative connotation toward the disabled" (p. 40). With McCagg's comment now long past and with the since-launched field of DS/CDS advocating for more humane constructions of the physically different, McCagg's "3 minutes" strikes the 21<sup>st</sup> century ear as roughly three too many.

Whatever the causes for the marginalization of Vygotsky's work under the label of defectology, it is based upon a fundamental misunderstanding (Gintis, 2003; Knox & Stevens, 1993). Vygotsky (1993) explicitly contrasts his views with those of the "old defectology," which he characterized as "Viewing a handicapped condition as a purely quantitative developmental limitation. . . . Reaction against this quantitative approach to all theoretical and practical problems is the most important characteristic of modern defectology" (p. 30). He advocated his own approach in succinct terms:

The thesis holds that a child whose development is impeded by a defect is not simply a child less developed than his peers but is a child who has developed differently. . . . A child in each stage of his development, in each of his phases, represents a qualitative uniqueness, i.e., a specific organic and psychological structure; in precisely the same way, a handicapped child represents a qualitatively different, unique type of development. . . . Only with this idea of qualitative uniqueness (rather than the overworked quantitative variations of separate elements) in the phenomena and processes under examination, does defectology acquire for the first time, a methodological basis. (p. 154)

Vygotsky (1993) was adamant about the misguided view, predominant in both his day and ours, that those who take the position that "children develop 'along biological tracks' [so that] we may dismiss the laws determining the social development and formation of a normal mind. This mechanistic notion is unfounded methodologically speaking." Rather, he argued, the appropriate approach is to consider "the alliance of social and biological regularities in child development" in a dialectical fashion (p. 124).

As we have noted, Vygotsky (1993) regarded the biological difference—in defectology, blindness, deafness, and cognitive impairment—as a person's *primary disability*. This point of difference served as the sole focus of attention for the diagnosticians of Vygotsky's day, a problem that continues today. As we will detail in the next section, the primary disability is only a problem when people in the environment treat the person as inferior for having these points of difference. When this belief in the inferiority of those who are bodily or cognitively different<sup>2</sup> is appropriated by people of difference themselves, they develop the far more damaging *secondary disability* of feelings of low self-esteem. The "problem" of disability, thus, is to Vygotsky *a social problem* that requires a re-education of the general population so that they provide avenues for wholehearted participation in cultural practices through which people of difference develop feelings of value.

Attempting to repair the defective person, Vygotsky (1993) believed, was misguided. Rather, he sought to assimilate people of difference into mainstream society

<sup>&</sup>lt;sup>2</sup> In general, our references to "difference" are concerned with those differences associated with "disability." At the same time, we should recognize that other, non-"disability" oriented points of difference, may also be treated phobically. People who are extremely short, for instance, might be subject to social ostracism. Even such a benign point of difference as hair color, while not a disablement, is at times constructed as inferior, as indicated by the phrase "red-headed stepchild" to indicate a person of low and outcast status.

by cultivating their potential by means of "roundabout" or alternative means of mediation made available to achieve cultural ends, such as the use of a cane to assist the unsighted. Vygotsky's approach to the anomalous human makeup was thus positive, optimistic, and future-oriented; "no theory," he maintained, "is possible if it proceeds from exclusively negative premises" (p. 31).

The whole-person, integrated, potential-oriented perspective that he took emphasizes the possibilities for culturally-mediated developmental processes to produce capabilities that lead to fully productive lives in social context. To Vygotsky, providing alternative means of mediation such as braille for blind readers would allow for alternative or roundabout ways of developing higher mental processes: those ways of thinking that are characteristic of a society and its goals and practices. This perspective is grounded in the Cultural-Historical perspective on human development that Vygotsky (1934/1987) championed, one that considers one's biological growth to be mediated by the cultural practices, signs, and tools through which a person becomes constructed by others and often through which a person appropriates a strong conception of self, for good or ill.

#### The Effects of Feelings of Inadequacy

Vygotsky argued that feelings of inadequacy have two very different consequences for those who live with physical or cognitive disability. First, he asserted that the feelings of inadequacy could serve to motivate positive new ways of engaging with society. Drawing on the work of Adler (1933), Vygotsky (1993) argued that "Via subjective feelings of inadequacy, a physical handicap dialectically transforms itself into psychological drives toward compensation and overcompensation" (p. 33; emphasis in

original). This approach relies on the principle of compensation, which involves a circumvention of obstacles by means of adaptation that emerge from a generative response to difference, one that "represents a continually evolving adaptive process. If a blind or deaf child achieves the same level of development as a normal child, then the child with a defect achieves this *in another way, by another course, by other means*" (p. 34; emphasis in original). In this sense, a person "with a defect," as expressed through defectology's terms, makes adaptations through indirect, mediated means that allow for participation in societies cultural practices.

Deviation from the evolutionary norm, which Vygotsky referred to as "dysontogenesis," needs to be valued for its potential to motivate a personally-initiated productive adaptive response, to produce a new order through cultural channels: "Cultural development is the main area for compensation of deficiency when further organic development is impossible; in this respect, the path of cultural development is unlimited" (Vygotsky, 1993, p. 169). He thus sees the necessity of mutual adaptations: one by society in providing environments that promote development toward cultural ends via roundabout means, the other by individuals who hope to navigate their surroundings with greater fluency. A feeling of inadequacy can thus have a beneficial effect when learners are treated as productive people adapting to their environments. Within alternative developmental pathways provided by a supportive setting, "the most important and decisive condition of cultural development—precisely the ability to use psychological tools—is preserved in such children" (p. 47). In contrast, the field of psychology in general took the view that people of anomalous makeup should be pitied or

treated with charity, both of which to Vygotsky contributed to the feelings of deficiency that comprise the secondary disability.

A reciprocal process of adaptation must be undertaken by the people surrounding the anomalous child, who accept these alternative mediational means nonjudgmentally and respectfully. Vygotsky (1993) argued that when people of difference are treated as inferior, they become subject to the secondary disability. To Vygotsky, in addition to adaptations undertaken by people of difference, and no doubt of greater importance, those surrounding them have an adaptive responsibility to construct alternative pathways that allow for satisfying navigation of the world such that one's positive sense of self is affirmed. Vygotsky's approach was thus oriented to assets rather than deficits. Among his favorite examples, for instance, was his contemporary Helen Keller and her development of ways of navigating her environment while deaf and blind, through the sensitive care of Anne Sullivan, in ways that helped her cultivate her human potential.

Through the creation of future-oriented, affirmational mediational settings, alternative pathways of development are cultivated for people of anomalous makeup such that their points of difference are not foregrounded in people's construction of their potential. By asserting that problems of human difference are social rather than individual, Vygotsky (1993) shifted the terms of the debate *from re-mediation of the deficit to education of the surrounding community*.

This attention to *settings* was a critical dimension of Vygotsky's (1993) concern for children lacking normative means of engaging with the world, diverting attention from the individual and toward the social consequences of differential treatment. This approach maps neatly onto his broader interest in the necessary integration of all aspects

of human development with one's affective engagement with the world (Vygotsky, 1971, 1994, 1999a, 1999b). "Full social esteem," he insisted, "is the ultimate aim of education inasmuch as all the processes of overcompensation are directed at achieving social status" (1993, p. 57).

What matters in this conception is that, using modes of organizing activity with appropriate mediational means, children have the potential to develop higher mental functions, even in the absence of a given phylogenetically typical capacity of the normate, e.g., seeing or hearing. For example, those who are blind still have access to the possibility of developing higher mental functions that approximate those available to the sighted, if that is what they wish for. Many groups of people whom society views as disabled have asserted their rights to live on their own terms, with adaptations made by society rather than themselves; see, e.g., the International Stuttering Association's (2000) Bill of Rights and Responsibilities, written

to foster attitudes and actions whereby individuals who stutter are provided the opportunity to fulfil their aspirations and to lead successful, productive lives. It recognizes the dual responsibility of listeners and society to create the environment in which people who stutter can develop their aspirations and talents and of people who stutter to advocate better understanding and to become active partners in their own future. (n. p.)

Many other groups have strongly denied efforts to colonize them into viewing their differences as deficits to be cured, suggesting that the notion of being disabled is indeed a social construction and not a medical fact.

For those who do choose to compensate for a "disability" by learning roundabout means, their unconventional ways of integrating themselves into society could conceivably lead to capacities for insights not available to those whose makeup does not require adaptation. In Vygotsky's (1993) conception, those who develop such capabilities are encouraged and embraced as valued productive members of society by fellow citizens whose own willingness to shift their understanding of difference helps to construct and support those alternative means of participation.

# **Examples of Vygotskian-Inspired Work with Anomalous People**

We next illustrate Vygotskian approaches to people of anomalous makeup with examples from the Soviet Union and Brazil.

#### **Education of the Blind and Deaf in the Soviet Union**

From early in his career, Vygotsky exhibited a special interest in the development of blind, deaf, and mute children. This interest was pursued through his acquaintanceship with I. A. Sokolyansky, an early Soviet pioneer in the education of the blind and deaf.

Consistent with Vygotsky's views on anomalous children, Sokolyansky argued that

The deaf-blind child possesses a normal brain and the potential for normal mental development. However, while possessing that potential he can never achieve even the most insignificant degree of mental development relying on his own efforts. Without special instruction such a child remains a complete mental cripple for the whole of his life. (Sokolyansky, quoted in Mescheryakov, 1974, p. 29)

Sokolyansky's ideas came together with those of Vygotsky in the 1950s, well after Vygotsky's death from tuberculosis in 1934, when he and his student, Alexander Mescheryakov, with the support of Vygotsky's surviving colleagues in the Soviet

Academy of Pedagogical Sciences, opened a special school for the deaf and blind in Zagorsk, a small city not far from Moscow in 1955. In 1963 a residential home for deaf and blind children was opened in association with the school.

The cultural-historical psychologists who supported the Zagorsk program argued that the predicament of the blind and deaf was as important to modern science as it was a statement of humanitarian principles, providing an opportunity to set moral benchmarks for the state of a society. Alexander Zaporozhets (1974), a colleague of Mescheryakov, described the special scientific importance of studies of the development of the blind and deaf in these terms:

blind-deafness represents a truly unique phenomenon of nature providing unparalleled opportunities for the study of the conditions necessary for the formation of human personality and the patterns to be found in that formative process. All the processes which occur at breakneck speed in the course of a normal child's development, intricately interwoven one with another and shaped by a whole host of spontaneous influences that are most difficult to assess, are easy to distinguish in the deaf-blind child since they unfold slowly; and what is particularly important, do not arise naturally, but are engendered with the help of special teaching methods that can easily be ascertained. It is this factor which provides unique conditions for experimental research into the dialectics of human mental development. (p. 6)

Mescheryakov notes that the first impulse of many psychologists when they encounter the blind and deaf is to develop their linguistic skills, on the premise that language is the central medium through which their intellectual functions can be

awakened. This idea has been propagated through famous cases, such as that of Helen Keller's well-publicized "breakthrough" when she understood that the experience of water, and the sign being communicated into her hand by her teacher, were connected such that the pattern of movement "re-presented" water and thus opened up the possibility of tactile communication for Keller and other blind and deaf individuals.

Mescheryakov (1974) explicitly rejects this idea. While acknowledging that language acquisition is crucial to the development of blind and deaf children, he argues that "fostering speech skills in such children is not and indeed cannot be tackled as the first objective in nurturing of a human mind" (p. 84). Instead, basing his perspective on the tenets of cultural-historical psychology, he argues that the inclusion of the children in socially organized, culturally mediated, joint activity is the essential precondition for their development:

The essence of interaction with things and people consists in the fact that in both cases this is interaction with a human factor. Expressing this idea in somewhat paradoxical terms we may say that the individual's relationships with other people are realized through things and his relationship to things through his relationship to other people. (p. 86)

These principles began with the very careful creation of predictable, fundamental forms of human activity occurring in routine cultural practices involving feeding and self care. This process was accomplished, in so far as possible, by having the caretakers insert themselves into the child's spontaneous activities in such a way as to guide the movements for incorporating everyday objects into their actions on the world. Language learning began as an intrinsic part of actions. The details of this process are impossible to

summarize in this format, but suffice it to say that its end product is a person who can read and write in dactylic or metered Russian.

Moreover, it can result in a wide range of possibilities for full participation in society. This goal of constructing settings, including the intentional acceptance of people of difference, through which people may participate in cultural practice, is in accord with Vygotsky's goals in accommodating people of anomalous makeup. From this perspective, the role of pedagogy and situated practice affirms forms of civic participation rather than law or state mandates for inclusion, such as the laws that helped to create the field of special education in the U.S., i.e., the Education for All Handicapped Children Act in 1975, which has since been surpassed by the Individuals with Disabilities Education Act (IDEA) of 1990 and the Individuals with Disabilities Educational Improvement Act (IDEIA) of 2004 (see Wright, 2004).

# A Design Experiment in Brazil: The MetaCognitive Dimension

In the late 1990s, through a chance meeting at a memorial conference for Alexander R. Luria, coauthors Braga and Cole decided to collaborate on a project that involved Braga's work with pre-adolescent children who had experienced acquired brain injury (ABI) with Cole's development of The 5th Dimension Program (5thD), a playworld model system that was initially designed for implementation among diverse preadolescents of both sexes, with respect to a range of ages, ethnicities, and social classes (see Cole, 1996). Although we appear to be making a great leap across time and space with our examples, they are connected by Cole's role in bringing Vygotsky to the English-speaking world as co-translator and –editor of Vygotsky (1978) through his post-doctoral studies with Vygotsky's student/collaborator A. R. Luria in Moscow in the

1960s, and his work as editor and translator of Luria (1976, 1977, 1978), whose neurological research is indebted to Vygotsky's work in defectology.

Braga and Cole undertook research to determine if it would be possible to create a form of activity that brought about consequential changes in the ability of pre-adolescent children who had experienced ABI to engage in broader social participation (Braga, Rossi, & Cole, 2010, 2012). The activity they created is called the "MetaCognitive Dimension," (MCD) and illustrates many Vygotskian principles for constructing mediational settings that provide multiple avenues for entering activities, diverse ways of participating, collaboration with both peers and young adults, and a teleological goal of incorporating people of difference into valued social practices through which status differentials are flattened.

A special virtue of the 5thD playworld in this regard is that it was designed to facilitate modifiability depending upon specific populations and local circumstances. The playworld had been organized as a local idioculture (Fine, 1987), that is, a culture-within-a-culture. This idioculture was established in out-of-school, community-based settings such as youth clubs, libraries, churches, and after school programs organized at schools. For this collaboration, the setting was modified to enable participation from children with brain injuries who would typically be excluded from engaging with their normate peers.

Cole's founding 5thD playworlds in California (Cole and the Distributed Literacy Consortium, 2006) involve the participation of college undergraduates who are trained to interact with the preadolescents to promote joint learning using Vygotskian principles. While the students are given the opportunity for practical, hands-on experience using development theories to guide their practice, the preadolescents are given the chance to

learn and develop in interaction with more experienced peers, who are variously known as buddies, amigos, or student, depending upon local norms. Although special needs children have participated in 5thD centers in the U.S., their inclusion was been enabled by modifying the structure of the local activity to the particular child. Consistent with Vygotskian defectological principles, the people in the environment were tasked with making fundamental adaptations in how they constructed the setting to allow for the greatest participation for brain-injured children as full-fledged members of the activities.

The project we describe here took place at the Sarah Hospital in Brazilia, one of many sites within the Sarah Network of Rehabilitation Hospitals, whose mission involves the treatment of people with injuries under the assumption that people are agents in their recovery and not objects on which techniques are applied. Its approach is consistent with Luria's (1929) method of helping to rehabilitate a man who suffered a terrible head wound from a bomb explosion, leaving his memory, vision, capacity for reading and writing, and other prior capabilities damaged or absent. Under a therapeutic regime organized by Luria encompassing many years, he was able to return to his native town where he lived independently on a disability pension.

As a co-researcher in his own recovery, he laboriously authored, over a 25-year period, a journal initially titled "The Story of a Terrible Brain Injury" but later changed it to "I'll Fight On," designed to help others understand his experiences, including the therapeutic procedures Luria invented on the basis cultural-historical psychological principles. The tenet of having those undergoing rehabilitative therapy participate as coresearchers of their process of recovery was adapted for the intervention at Sarah. The Brazilian MetaCognitive Dimension (MCD) was designed to enrich and stimulate the

social, academic, intellectual, and neuropsychological development of preadolescents with ABI. Special focus was placed on the children's ability to monitor their own cognitive processes in order to promote self-regulation and other socio-cognitive functions, and doing so within highly social environments.

Although it used many of the 5thD concepts, they were adapted to meet the special needs and challenges of this population. The program was conducted twice a week for 13 weeks to coordinate with the university student schedules. Because the project took place at the Sarah Neurorehabilitation Center, located by the lake in Brasilia, instead of at the Sarah Hospital in downtown Brasilia, Sarah bussed the children and their parents to the sessions. At the beginning, the parents would arrive at the 5thD room, eager to participate in the child's activities with the undergraduates. This parental reaction is perfectly normal because they had grown accustomed to the difficulties that their child had when interacting with strangers. Strikingly, they soon noticed that the children were quickly developing relationships with the undergraduate students, and saw that they were capable of participating without their help.

Seeing the parents' evident interest in their children's activities, the organizers arranged for the parents to meet together with the children and the undergraduates over snacks at the end of a MCD session so that the parents could get a first-hand account of what their children had been doing from the children and their undergraduate partners. In addition the staff met on a regular basis to explore and document the parent's interpretation of the program.

During their sessions with the children, the students deployed deliberate mediational strategies to foster the preadolescent's neuropsychological development and

metacognition. For example, if the preadolescent asked the student a specific question, the student would not simply answer; instead, the student would reformulate the question and pose it back to the child. At the same time, the students were careful to insure that the interactions, whether around a computer game or throwing a ball through a hoop, were done together and were fun both for themselves and the children, regardless of how much assistance the child seemed to require. With a goal of participation rather than expertise, the emphasis was on finding ways to develop competencies through affirmational engagement, and not to be repaired as an object of diagnosis.

A broad range of changes were seen in the children's behavior at the end of 13 weeks. Changes in the children's behavior were evident in the reports of the parents:

- "My daughter was stagnated but has grown so much now. She's more
  independent and was even able to travel by herself during her recent vacation.
   She is self-confident enough to make new friends."
- "My son has changed a lot—and so have I. Before, he was really dependent on me, and now I let him go some places by himself. Now I have more confidence in what he is able to do."
- "[My son] was playing basketball with some normal kids. His team was losing so he called one of his teammates over. He said to him, 'Take my place, you can play better than I can. His teacher praised him for resolving the situation without feeling diminished. I owe this change in attitude to the program."

Parents also acknowledged the importance of the undergraduates, especially with regards to the intergenerational nature of the undergraduates' relationship with their

children: "The fact that there are college kids around helped my son become more centered and focused. . . . They're closer in age to the children." Finally, the parents' accounts underscore the importance of sharing experiences with other families: "When we hear another mother talking about what she is going through, we see that it's not just our kid who has problems; it's all of them. So you stop treating your kid like he's different, because you see that he's like many other children."

These observations by the parents converged with the data from standard psychological tests. Tests to assess learning strategies and the metacognitive abilities and tests to evaluate the children's self concepts both showed significant increases when compared with a control group of comparably affected children who received the normal Sarah regime of family visits and consultations with the hospital rehabilitation team.

# **Disabilities and Critical Disability Studies**

Taken together, the research programs carried out in Russia and Brazil demonstrate how the organization of activity "rehabilitation" may move beyond its roots in the notion of repairing defects to enable radically transformed modes of social participation. The challenge then moves into the arena of the broader society, and the willingness of people to make those new modes of social participation general in society. In this sense, there is much potential for complementarity and co-alignment between such approaches and those that fall under the rubric of the academic movement referred to as Critical Disability Studies. This is not to say that the two are parallel or mirror images of one another.

Critical Disability Studies reflects the conjoining of two movements which began from initially different intellectual roots and areas of social engagement: Critical Social

Theory, on the one hand, and on the other the study of populations conventionally referred to as "disabled," Disability Studies (DS). Although the earliest Disability Studies scholarship is often linked to emergence of disability rights activism, such as the work of blind legal scholar Jacobus tenBroek (1966), it is possible to observe critical (and not merely pathology-based) thinking about categories of difference in much earlier texts.

Virtually any contemporary academic enterprise that contains the word *critical* in its title is concerned with the role of power in human relationships and the role of political power in knowledge creation (Meekosha & Shuttleworth, 2009). Understandably then, this central critical orientating concern is a key feature distinguishing those who self-identify as critical disability theorists (Goodley, 2011).

Disability Studies (DS) has its own prior history both in academia and society at large. Disability Studies in the United States came into being as part of the broad push toward social equality represented by Disability Rights activism, which grew out of the Civil Rights, Women's and Sexual Liberation movements characteristic of the progressive political activism in the 1960s and 1970s (Simon, 2013). During the decades when these general social movements were diffusing into the academic arena, myriad legal decisions, large-scale public events such as the Special Olympics, and Hollywood films like *Rain Man* (Levinson, 1988) made attitudes toward atypical people and how society deals with their lives a topic of broad social and academic discourse (though often failing and more often than not reproducing insidious or banal stereotypes in the process; see Longmore, 2016).

Academic interest in the concept of disability, the study of handicap, and means of rehabilitation had been long established in the medical arena, as our brief history of

Russian and Soviet research makes clear. However, when the study of disability came into prominence among academics, it was precisely a revolt against the "medical model" that characterized difference as deficit became embodied as the core definition of the field.

This point is made clear by the American Society for Disability Studies (first initiated in 1986) when it provided a widely-cited definition of the field that immediately distinguishes it from its historical antecedents in medicine.

[Disability Studies] examines the policies and practices of all societies to understand the social, rather than the physical or psychological determinants of the experience of disability. Disability Studies has been developed to disentangle impairments from the myths, ideology and stigma that influence social interaction and social policy. The scholarship challenges the idea that the economic and social statuses and the assigned roles of people with disabilities are the inevitable outcomes of their condition. (quoted in Church, 2015, n.p.)

This focus on disability as a *social formation*, or as a social/environmental experience of discrimination rather than one embodied in individual pathology, became a hallmark of both DS and CDS in a way that clearly marks the point at which they make direct contact with CHAT. Agreement on disability as a social formation is the point where complementarity among schools of thought becomes possible, and also a point of potential conflict.

In the sections to follow, we examine key commonalities and differences between the two intellectual programs. We begin by focusing on commonalities, and then turn to examine ways in which diversity appears within the fabric of a common set of commitments.

#### A Focus on Commonalities

First there is a common interest in what Vygotsky referred to as the "secondary" source of disability: the social constraints placed on the individual that interfere with the process of attaining full personhood as a member of society. Virtually everyone in both fields would agree with Vygotsky's declaration that "the social aspect formerly diagnosed as secondary and derivative, in fact, turns out to be primary and major" (Vygotsky, 1993, p. 112).

This fundamental stance finds broad acceptance in the DS/CDS literature. To Biklen (2000), critical approaches are concerned with acknowledging "disability as a social construct . . . occurring within shifting political, economic and social contexts, often highly marginalizing and discriminatory in nature" (p. 337). Davis (2010) has observed that "The problem is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person" (p. 9). This common focus on the utopian goal of inclusionary social participation, and the barriers to this goal produced by "myths, ideology, and stigma" puts both groups at odds with "ableist" views of difference that justify status quo inequalities.

An important second commonality is the fact that both CHAT and DS/CDS have important roots in Marxism, albeit Marxism as interpreted from markedly different historical and geopolitical locations. Vygotsky lived during the turbulent period following the Revolution in a society governed by an official ideology of Marxism/Leninism, and ultimately Stalin's repressive imposition of his own take on their

ideas. Their emphasis on understanding anomalous children in the context of cultivating an egalitarian society predicated on equity achieved through collective human activity could be easily interpreted and justified.

When the Frankfurt School initiated a critique of social theory in the 1930's, the Soviet implementation of Marxist ideas was producing political show trials and CHAT psychologists were under heavy threat. Under duress now from Fascism, Frankfurt School theorists were highly critical of capitalism but they found the Marxism of their day insufficient on many grounds. It had failed to explain, let alone predict the dynamics of capitalism, and its road to communism was manifested in totalitarian states. Central to the development of critical studies across academic disciplines was the effort of those within the Frankfurt School to seek more adequate explanations for the processes by which society engages in systematic oppression of its least powerful citizens: those subjugated due to traits associated with race, gender, socioeconomic class, and other factors that lead those considered normal to contribute to their oppression.

This primary concern leads critical theorists, regardless of specific focus, to consider the manner in which social structures of control and exclusion are constructed and maintained. These oppressive structures provide advantages to those at the top of the *status quo* social hierarchy such that whole classes of people—categorized by race, social class, gender, and in this case, bodily difference or "disability"—are constructed as victims of oppression and must be emancipated. The terms *oppression*, *control*, and *emancipation* appear central to any *critical* theory. Meekosha and Shuttleworth (2009), for instance, include many of them in a single sentence when writing about DS/CDS: "The defining feature of *autonomy* that interweaves throughout critical theory's history is

its meaning as *emancipation* from *hegemonic* and *hierarchical ideologies* that structure personal consciousness, representations, social relations and practices in everyday life" (p. 53; emphasis added).

A third commonality is the interdisciplinarity of both the CHAT and C/DS research programs. This possibility was not always the case with CHAT. Institutionally, Vygotsky was a psychologist, but he was also a polymath: a psychologist, a classroom teacher, medical researcher, the head of an Institute of Defektology, theorist of art and literature, husband and father. But while he and his colleagues could and did draw upon Marx for a socio-cultural-historical theory of development, he could not engage professionally in a critical study of his own society without risking his life; political reality did not permit it (Zinchenko, 2007). Sociology, anthropology, linguistics, art, literature: the entire study and practice of human cultural life, although it produced a few important figures, was truncated by its top down, highly regulated role in providing as an ideological tool of Soviet power. From the time when cultural historical psychology began to spread beyond Russia, it was envisioned as necessarily interdisciplinary, ranging across the human sciences. (For a current assessment, see http://www.iscar.info/.)

As the early members of the Frankfurt School gathered adherents seeking a full-fledged critique of social theory, they did so at a time when Hitler had risen to power and communists were outlaws in capitalist societies. In seeking to maintain what they saw as useful and important in Marx, they included in their search a broad range of academic expertise that encompassed both the social sciences (political science, sociology, communication, anthropology), the humanities, and the arts. It was a thoroughly interdisciplinary undertaking.

Finally, a clear area of common commitment is the need for a methodology in which theory is constantly tested in the fire of practice and modified in light of the changes wrote by such encounters. This commitment is clear in the examples we provided on the basis of Russian and Brazilian work with two disparate forms of physical anomaly. It plays an equally prominent role in the writing of CDS advocates. For example, Meekosha and Shuttleworth (2009) list as one of the necessary components for CDS the principle that "Critical social theory links theory with praxis in the struggle for an autonomous and participatory society" (p. 52). This declaration could easily have been made by any adherent of a CHAT perspective and bears a clear common affinity with Marx's exhortation for scholars to make the struggle to change society an integral and necessary part of their work.

Vygotsky's early formulation remains an appropriate expression of CHAT's view of the theory/practice relationships: "most complex contradictions of psychology's methodology are brought to the field of practice and can only be resolved there. Here the dispute stops being sterile, it comes to an end. . . . That is why practice transforms the whole of scientific methodology" (Vygotsky, 1926/1982; quoted in van der Veer & Valsiner, 1991, p. 150). This agreement on an appropriate theory/practice methodology appears to be a key area of complementarity between CHAT and DS/CDS.

#### **Focusing on Differences**

Each of the core common foundations serves not only as a common reference point for considering the complementarity of CHAT and DS/CDS, but as a vantage point from which to re-assess the sources of differences in theory and practice that hinder greater mutual understanding.

**Social formation.** While both approaches agree on the need to see disability as a social formation, a next level of specification reveals several differences.

- 1. From a CHAT perspective, a singular focus on the social nature of disability ignores the fact that different forms of disability require different forms of "re-mediation" to attain inclusion in the broader social world. The developmental challenges of control associated with perinatal stroke, for instance, cannot be meet without taking into consideration the entire bio-cultural-social system.
- 2. From a DS/CDS perspective, CHAT is woefully inadequate in its ability to analyze the social forces operating to structure everyday life experience, even with its axiomatic attention to the social contexts of human development. This limitation relegates CHAT to the margins of attention for DS/CDS: physiological and psychological contributions to the study of disability were, more or less officially, declared off limits. DS/CDS seeks to deal with the products of social formations as social facts.
- 3. From a DS/CDS perspective, both a CHAT and a DS/CDS perspective stop short of interrogating the notion of inclusion that is putative goal of each approach. They remain caught in a modernist project that has already lost its ability to inspire the hopes of late capitalist neo-liberalism.

Marxism as a common source of ideas. Seismic geopolitical changes have occurred since the 1920's in Russia, the years of German Fascism, the Cold War and McCarthyism, 9/11 and post 9/11. Each shift has greatly modified the ways in which Marx's ideas were appropriated in countries across the world. We do not presume to provide a detailed survey of the matter, which would take us radically off course. Rather, it seems safe to say that in so far as Marx's ideas prove useful in seeking to understand

the phenomena of human life forms as studied in different areas of human life (as they do currently in CHAT), they will maintain their current authority. Marx's (1975) utopian ideal of human interaction, inscribed in the formula he adapted from Louis Blanc and Étienne-Gabriel Morelly, "From each according to his ability, to each according to his needs!" provides the moral benchmark by which a society judges itself: its ability to provide for those who need the most provision.

Interdisciplinarity. The simple fact that CHAT and DS/CDS share the characteristic of interdisciplinarity says little about the commonalities and differences that characterize them. CHAT draws upon psychology and education as its core disciplines. The enrichment it seeks is likely to come from evolutionary biology, anthropology, sociology, and linguistics. DS/CDS, having discarded academic psychology and biology as irrelevant to their interests, draws upon experts in the presumed social mechanisms that constitute disabilities. They, too, draw upon the social sciences but particularly in recent years, the humanities have come to play a major role in developing new theoretical concerns that go far beyond the forms of critical social theory envisioned by the Frankfurt school.

Relating theory to practice. Despite theoretical agreement on the necessity of adopting a theory and practice methodology in the study of disability, this crucial element in all three of the research programs we have discussed remains a topic of ongoing discussion and critique. The theory/practice relationship in the two CHAT examples we provided appears straightforward. Within a circumscribed field of influence, in one case, a special school for deaf-blind children, in another case a special educational program for children with severe brain trauma, the researchers have considerable ability to organize

the forms of interaction in order to realize the social changes necessary to bring about the desired forms of inclusive participation. In each case, the major challenge, assuming the success of the program, is to have it appropriated into routine social structures so that it becomes a norm and not something to remember on ritual occasions.

In the DS/CDS arena, several decades of research have demonstrated, using widely accepted norms of social science research, the enormous, inequitable, distribution of social resources to those most in need of it. The "intersectionality of race, gender, and class" is depressingly evident in figures showing the desperate conditions that routinely emerge from a combination of poverty, racial, and gender exclusion in modern society (The Stanford Center on Poverty and Inequality, 2014).

As McDermott and Varenne (1995) note, the model of theory-practice relationship in CDS appears to be consistent with much postmodern and poststructural thought; many in the larger DS community argue that disability is constructed discursively (e.g., Dudley-Marling & Dippo, D (1995). Goodley (2013) is among those who are concerned that DS/CDS's discursive approach has at times placed them "on the veranda" and above the fray (see Ogden, 2007-2008) rather than in the midst of the people whose lives are affected by the discussions and writing of CDS scholars. Goodley argues that "while theoretical avenues have been widened, the field has lost touch with the real material problems of disabled people's lives [and a] preoccupation with theory over politics. . . . [DS/CDS] are in danger of becoming a new uncritical orthodoxy—one distanced from empirical evidence and often only internally critiqued" (p. 641).

### The Case for Complementarity

Despite important ongoing debates within the CHAT and DS/CDS communities, we hope that our summary of their similarities and differences facilitate conversation between adherents of differing perspectives to see the value of promoting their complementarity. At a simple level, it is obvious that the CHAT perspective, with few exceptions (e.g. Smagorinsky, 2016), has focused its attention on designing theory-based activity systems that constitute existence proofs for the possibility of achieving inclusive participation. It is equally elementary to recognize that each CHAT case, while successful on its own terms as a demonstration proof, has not developed a theory or a practice designed to bring about widespread social inclusion as a basic social value or realized social policy in any country.

While it is proper to note the limits to a theory of practice that remains encapsulated in an academic discourse, it is significant that the discursive approach, too, can produce unexpected results. It should not go unnoticed that when the press sought to interview students at the University of Missouri who were forcing out a university president in support of Black Lives Matter, one of the student organizers shouted at the reporters trying to cover student conversations: "We are going to control this narrative." This example demonstrates the institutionalization of discursive practices that scholars such as Bell (2012) have found perpetuate inequity and the advantages it accords those whose privilege is so well established that it becomes invisible.

Indeed, the Black Lives Matter movement illustrates a dynamic interplay between discursive acts—through engagement with formal academic texts and through the use of social media to both represent a perspective and call others to action—and demonstrations designed to enact social, material, and administrative change in the

conditions surrounding the postsecondary schooling experiences of African American Students and, fundamental to the movement, changes in policing methods that have produced shocking levels of violent actions toward many innocent, unarmed citizens. As these examples show, the project of CHAT and DS/CDS often align with other human rights movements focused on race, ethnicity, class, and citizenship and their intersection with larger critiques of normativity and typicality (see, e.g., Erevelles, 2000).

This coordination of discursive and material actions has often been lacking in scholarly efforts to articulate an inclusive perspective on human difference. We see the possibilities outlined in this chapter for the benefits of continuing to critique oppressive and inequitable social structures while also providing material alternatives that allow for compassionate approaches realized in new social norms and material structures. This project is potentially valuable in moving toward, if never quite reaching, the utopian vision of developing a society in which difference is constructed as potentially dynamic and valuable rather than a form of deficit, as has been the case in social practice for as long as humans have gathered in societies in which the "other" has been considered a social ill.

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