

Creating an idioculture to promote the development of children with cerebral palsy

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Abstract

This study presents the preliminary results of the adaptation of an educational system called the Fifth Dimension (5D), in which social interaction is a means for generalizing information and a basis for the development of skills beyond the constituent tasks. Originally created by Michael Cole – Laboratory for Comparative Human Cognition at the University of California at San Diego (UCSD) – this system was, for the first time, applied to a rehabilitation setting with children with brain injury, at the SARAH Network of Neurorehabilitation Hospitals, in Brazil. Undergraduate college students majoring in psychology and education participate in the program and interact with children who have cerebral palsy, engaging in playful/educational activities of collaborative learning. While interacting with the child, the student is encouraged to put formal theoretical concepts and personal experience into practice. In this article, we describe the changes made to the original program to adapt it to the rehabilitation setting as well as the artefacts that mediate the activity, necessary for the interaction and expression of the child with cerebral palsy. Also discussed and presented are the effects of the activity on the child's development - based on the parents' reports - and the impact on the learning process of the undergraduate students. The program opens alternative pathways for a reflection on, and education of, the child with brain injury, based on the development of individual potential, context and interests.

Keywords: Social interaction – Collaborative learning – Cognitive development – Cerebral palsy – Rehabilitation.

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There is a major problem in the broad range of efforts to design interventions for promoting cognitive and social development in children with various kinds of disabilities such as mild mental retardation to ADHD, cerebral palsy, and traumatic brain injury. The predicament is that intervention procedures specifically targeted at the presumed deficits, while producing changes in the target behavior, fail to

generalize beyond the specific conditions of training (Brown; Campione; Murphy, 1977; Tharp; Gallimore, 1985; Ylvisaker; Turkstra; Coehlo, 2005).

These sorts of findings have led to the conclusion, in the words of Tharp and Gallimore (1985), that in order for remedial training procedures to be useful, “tasks must be learned in the contexts of eventual application”. Or, as Ylvisaker (2003) phrases the issue, one should engage in context-sensitive rehabilitation or remedial instruction based upon forms of activity that are of particular interest and concern to the affected individuals.

The aim of this paper is to report on one promising approach to designing rehabilitation activities that can be engaged in simultaneously by several people, and which produce cognitive and social effects that generalize beyond any specific tasks that constitute elements of the activity setting.

Briefly stated, our strategy is to create a socially organized idioculture saturated with a wide variety of cognitive tasks in which the norms of social interaction serve as media for the generalization of the information and modes of behavior appropriate to the constituent tasks. The specific, component tasks in this specially organized system of activities are often in the form of games, in which undergraduate students with little or no specific training in remedial/rehabilitative techniques engage with children in a complex playworld. This playworld simulates, in many respects, a microculture with rules, obligations, divisions of labor, tool use, friendship formation, and multiple forms of communication among all variety of participants – the children, undergraduate students, and staff. Participation in such a playworld, our evidence indicates, produces cognitive and social changes that generalize broadly to cognitive tasks and social behaviors that are not an explicit part of the playworld within which they are encountered. That is, the playworld serves as a medium for the generalization to a large ensemble of cognitive tasks and social behaviors that are not explicitly the object of training.

A description of the original playworld

The model for the playworld that we have adapted for use with children in this research is called the Fifth Dimension. The Fifth Dimension was originally designed as an activity system for children from marginalized social groups in the United

States who were performing poorly in school. Its goal was to serve both as a medium for diagnosing specific learning deficits that individual children might display and as an environment rich in opportunities for cognitive and social re-mediational potential (Cole; the Distributed Literacy Consortium, 2006).

An essential feature of the Fifth Dimension is its adaptability to specific local conditions. Nonetheless, there are similarities across implementations which make it useful to provide a provisional description for purposes of understanding how and why the specific adaptations described in the current research came about.

The following is a normative description based upon several years of research in the United States in a variety of socio-ecological circumstances

This is an educational activity system that offers school-aged children a specially designed environment in which to explore a variety of off-the-shelf computer games and game-like educational activities during the after school hours. The computer games are a part of a make-believe play world that includes non-computer games like origami, chess and boggle and various other artifacts. "Task cards" or "adventure guides" written by project staff members for each game are designed to help participants (both children and undergraduate students) orient to the game, to form goals, and to chart progress toward becoming an expert. The task cards provide a variety of requirements to externalize, reflect upon and criticize information; to write to someone; to look up information in an encyclopedia; and to teach someone else what one has learned, in addition to the intellectual tasks written into the software or game activity itself.

As a means of distributing the children's and undergraduates' use of the various games, the Fifth Dimension contains a maze consisting of some 20 rooms, ordinarily in the form of a wooden or cardboard box placed on a table top or pictured on a wall chart. Each room provides access to two or more games, and the children may choose which games to play as they enter each room, depending upon what games they have played before and what is available at the moment.

There is an electronic entity (a wizard/wizardess) who is said to live in the Internet. The entity writes to (and sometimes chats with) the children and undergraduates via the Internet. The children and undergraduates often write back. In the mythology of

the wizard/ess, he/she acts as the participants' patron, provider of games, mediator of disputes, and the source of computer glitches and other misfortunes.

Because it is located in a community institution, the activities require the presence of a local "site coordinator" who greets the participants as they arrive and supervises the flow of activity in the room. The site coordinator is trained to recognize and support the pedagogical ideals and curricular practices that mark as "different" – a different way for kids to use computers, a different way of playing with other children, and a different way for adults to interact with children.

The presence of university and college students is a major draw for the children. The participating college students are enrolled in a course focused on fieldwork in a community setting. At UC San Diego, an institution that emphasizes research, the university course associated with student participation is an intensive, six unit class that stresses deep understanding of basic developmental principles, the use of new information technologies for organizing learning, and writing field notes and research papers. The undergraduates write papers about the development of individual children, the educative value of different games, differences in the ways that boys and girls participate in the playworld, variations in language use and site culture, and other topics that bring regular course work and field observations together.

In short, considered in its community context, the Fifth Dimension is organized to create an institutionalized version of the form of interaction that Vygotsky (1978) referred to as a zone of proximal development. From time to time there is creative confusion about who the more capable peers might be (for example, when novice undergraduates encounter children highly skilled in playing educational computer games about which they know nothing). But the general culture of collaborative learning that is created serves the development of all. Extensive studies of the influence of participation in the Fifth Dimension have shown that it is an effective educational innovation across a broad range of children varying in ethnicity and social class.

Adapting the fifth dimension model to children with special needs

As Fifth Dimensions are generally located in community institutions that are by their nature inclusionary, it was common to have special needs children participating along

with other children. The nature of these special needs varied widely: some children were on medication designed to ameliorate symptoms of hyperactivity or ADHD. Some children were mentally retarded. At least one child suffered severe Asperger's syndrome. Over many such cases, spread over several years and numerous instantiations of the Fifth Dimension, informal evidence accrued that such children benefited from Fifth Dimension participation no less than their peers who were not identified as having special needs beyond the need for academic enrichment.

In 2002, the current authors met and became acquainted with each other's work at a memorial conference for Alexander Luria and his work on rehabilitation of people who had suffered some form of traumatic brain injury. Lucia Willadino Braga, a Brazilian neuroscientist whose clinical and research focuses are on the rehabilitation of children with cerebral palsy and traumatic brain injury, became interested in the way Michael Cole was using ideas inspired by Luria (1973) and Vygotsky (1978) to organize educational enrichment for children. Cole, who had been a post-doctoral student of Luria's, began to think about the potential of using the Fifth Dimension as a medium for rehabilitation of special needs children, based upon the fragmentary evidence of such efficacy from the prior experience that he and his colleagues had using the program with a variety of children. From this mutual interest, the current project was born. The central question we sought to address was whether the basic Fifth Dimension model could be adapted for use in a rehabilitation hospital where, heretofore, remediation was carried out only by trained professionals and where the idea of creating an entire rehabilitation regime on a large group basis using principles of cultural-historical psychology had not been attempted.

We entered the project fully aware that even for the populations for which it had been designed, the Fifth Dimension varied widely in the details of its idiocultural implementations, so that we would, in effect, be creating a truly new idioculture under unprecedented conditions. It had long been demonstrated that the model could be used effectively in a wide variety of cultural milieus outside of the United States, having been adopted successfully in Russia, Finland, Mexico, and Brazil on prior occasions. (See www.uclinks.org for further information of such generalizations of the activity system across national cultural boundary lines).

The fifth dimension at the Sarah network of neurorehabilitation hospitals in Brasilia, Brazil

The SARAH Network of Neurorehabilitation Hospitals consists of nine fully operational hospital facilities, of which two are International Centers for Neurosciences and Neurorehabilitation, dedicated primarily to the treatment of neurological problems in children and adults. SARAH patients come from the four corners of Brazil, with widely varying socio-economic and educational backgrounds. Because of the large pediatric patient population with cerebral palsy and traumatic brain injury, who come for consultations and stay for ongoing therapy in the various subspecialties dedicated to childhood brain injury and its attendant manifestations, the physical facilities at SARAH have been designed with this patient population in mind, with open child-friendly gymnasiums, playrooms, pools and rehabilitation halls. The Network also counts on an extensive infrastructure for surgical, rehabilitation, imaging, and research activities, such as fMRI scanners and movement laboratories. (For further information see www.sarah.br).

The Fifth Dimension project at SARAH takes place at the International Center for Neurosciences in Brasilia. The project began in March 2006 with 11 children with cerebral palsy (CP), most with a diagnosis of spastic diplegia. Strategically, the neuropsychological disorders in this group of children were very heterogeneous. This was due in part to one of the project's main objectives of fostering different levels of cooperation among the children and providing opportunities for experience-sharing and support among the families; and also, because of the difficulties of obtaining a homogenous sample of brain injured children, given that clinical etiological criteria are commonly applied, despite recovery being an individual process that depends on social, familial and educational factors. These goals reflect the basic theoretical principles of the SARAH Rehabilitation Method (Braga; Campos da Paz, 2008; Braga; Campos da Paz; Ylvisaker, 2005).

The college undergraduates for the Fifth Dimension at the SARAH Network are selected from various universities in Brasília. Students apply and are selected based on their knowledge of child development, education and learning, as well as their own personal experiences and formal education. Elements of the Fifth Dimension at SARAH mirror the Network's multidisciplinary team approach to rehabilitation, in which professionals from different areas participate in the rehabilitation of each patient. Because in cerebral palsy many developmental areas may be affected, such

as motor function, cognition, and language, better outcomes are obtained from having integrated teams comprised of professionals from different specialties. Thus, over time, students from various majors have been accepted into the program, such as speech therapy and education, in addition to those studying psychology. This plurality permits enriched understanding of the social interactions of brain injured children and helps integrate knowledge from various fields at an early stage of the students' academic careers. They are, on average, 20 years old, and in their freshman or sophomore years of college.

In this study, we present three fundamental aspects of this initial experience with children with brain injury: 1) the changes made to the original model to more adequately adapt it to the developmental needs of the child with cerebral palsy, which involved studying the ways that CP children's families participate in the program; 2) an analysis of the families' impressions and reports after their child had participated in the program; and 3) an analysis of how interacting with the children impacted the undergraduate's development.

The group of 11 children with cerebral palsy that launched the first Fifth Dimension project at SARA in May 2006, were between the ages of 8 and 12 years. Most of them had little access to video or computer games, and limited knowledge of email, web search engines and text editing. Several had contact with some of these tools in school, and five children had computers at home but rarely used them. Only two children from this group had a videogame at home.

As far as neurodevelopment is concerned, all of these children had varying muscle tonus and motor disorders (mixed tetraplegia, spastic triplegia, spastic diplegia and spastic hemiplegia). Levels of motor independence ranged from unassisted gait to assisted wheelchair use and from relatively normal upper body and fine motor control of the hands and fingers to more or less severe difficulties with these functions. In general, the group's linguistic abilities were above the expected average for their age bracket. On the other hand, in performance tasks, the group demonstrated significant difficulties with skills related to perceptive discrimination, anticipating and planning a given activity, and organizing a whole from disparate parts. These performance difficulties were not directly related to movement disorders. In addition to these challenges, some children had attention deficits and visual impairment, e.g., strabismus, problems with acuity and hemianopsia. The families' socio-economic

levels varied greatly. Also, while some of the parents had high school diplomas, college degrees or Doctorates, others had not finished grade school. The children's program of activities run parallel to the Brazilian school calendar; on average, each child participates in 57 hours of activity per semester, spread over two afternoon periods per week.

Adapting Mediational Means to the Child with Cerebral Palsy in a Neurorehabilitation Program

Computers

New software, with a special voice mail feature, was developed. Geared towards children with motor or cognitive writing deficits, these changes facilitate their communication with the Wizard, which can be written and sent by e-mail or voice mail. The font size was made larger to accommodate possible vision problems, and new interfaces were created to help those with difficulties using traditional keyboards due to motor disorders.

Individual projects

The performance level, limits and potential of children with brain injury vary widely, and are associated with biological, cultural and epistemic factors (Braga; Campos da Paz; 2008). Some children with brain injury are unable to attain particular levels of performance in a given task, e.g., a child with cognitive dysfunction may not be able to progress to the advanced phases of a video game whose level of difficulty gradually increases with each new phase. In this sense, adjustments needed to be made and strategies reworked, such as the degree of difficulty in the labyrinth and the development of individual programs based on the child's potential, which was associated with the roles that each took on within the microculture of the project.

Family participation

Since the SARAH Network's entire pediatric rehabilitation process is founded on a context-sensitive, family-based approach, the family's role in this playworld model needed to be taken into account (Braga; Campos da Paz, 2008). Unlike prior Fifth Dimension projects, the children treated at SARAH do not live nearby, have problems

getting around, and depend on their families to bring them to the rehabilitation center; thus, children always come in the company of their parents. This initially raised the issue of what role the parents should play during Fifth Dimension time.

At the beginning, the parents would arrive at the Fifth Dimension room, located in a rehabilitation area expressly designed for this purpose, eager to participate in the child's activities with the undergraduates. This parental reaction is perfectly normal because they had grown accustomed to mediating their child's interactions with his/her peers; the parents wished simply to help their son or daughter make the most of the experience. They soon noticed, however, that the children were quickly developing relationships with the undergraduate students, and saw that they were capable of participating without their help. Some of the children even began asking their parents to wait outside.

To accommodate this new situation, the research team created an exclusive place in the project for the parents: a support group open for debates and discussions between the family and the team. These groups are psychoeducational in nature allowing the participants to learn from each other's experience. During these sessions, led by staff psychologists who also participate in the Fifth Dimension, the families talk about their lives at home, their feelings and thoughts about the project, changes they are noticing in their children, suggestions they may have for the program. Other issues are also addressed in the group, such as development, rehabilitation, learning, and ways of coping.

The course for undergraduates

The course is organized into three modules each semester. The group has a heterogeneous level of experience and participation in the Fifth Dimension. The new students (Module I) are given basic responsibilities, such as activities with the children, field notes, debates, discussions, system changes, and so forth. The responsibilities of the more experienced students are expanded (Modules II and III) to include tasks such as writing the Wizard's replies to the children's e-mails, coordinating discussions, and overseeing plans. Every semester, each group has an average of 11 to 16 students.

All of the students note down the day's activities in a structured report (Field Journal). A website was created to help the rehabilitation team and the students share

thoughts and experiences and to allow them to send in their field journals and comments. Each field journal is read and commented on by the whole team, fostering a direct pathway to guiding each student's learning process. The students currently have the chance to comment on their peers' field notes, and answer comments online. The site also helps organize the bibliography and relevant links, as well as the debates, discussions, reports about what the children are doing, and an e-mail for internal communication.

One of the central issues that we sought to address pertains to the information given to the undergraduates. Information about each child's individual problems, specific neurological exam data, diagnostic imaging results and development are not addressed directly; the undergraduates use principles of cultural-historical psychology to interact with the children with CP but are not given specific prior information. Reading topics are selected for further study as the need arises, based on the students' increasingly complex interactions with the children. They also discuss and share theoretical-practical information with the rehabilitation team and with their peers about the child's cognitive, behavioral or etiological development.

Preliminary results

Parents

At the end of the first year of activities with the parents, (based on discussion groups, shared experiences, conversations with the undergraduates, and observation of the child in the program), the team, consultants and family met to openly discuss the parents' opinions and feelings about the project.

After witnessing their child's increased independence, improved interactions and self-esteem, a number of parents said that they saw how much their child was really progressing. They talked about changes, about how much their child was evolving. One mother said: "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." Another mother stressed: "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." One mother talked about an important situation involving self-esteem: "[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 aspect: "The fact that there were college kids around helped my son become more centered and focused...they were closer in age to the children".

Finally, the parents' accounts underscored the importance of sharing experiences with other families: "When we heard another mother talking about what she was going through, we saw that it's not just our kid who had 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."

Undergraduates

Each undergraduate answered an open-ended questionnaire about their participation in the project, at six and 12 months after starting the course at the SARAH Network.

The results showed that length of time in the project and the quality of the interactions were important factors in how they established connections between their exchanges with children at the Fifth Dimension and theories of child development. The undergraduates' main observations were grouped into three categories: 1.) sharing common interests with the children; 2.) various dimensions of interaction within the setting; and 3.) how they learned things they did not expect to, the theoretical-practical associations that they were able to make, and information from the other students' transcribed accounts:

1. Throughout the process of experiencing and sharing common interests with the children, the undergraduates began to grasp the project's educational goals: "Since we undergraduates are much younger, we had a lot more in common with the children, in terms of what's going on in the world, pop culture, games, ways of thinking."
2. They perceived the various dimensions of interaction within the setting: "One of the things that made the Fifth Dimension very important was its setting – the hospital, the treatment - where a child oftentimes does not have a voice. Here, children could say what they liked and didn't like; they could be themselves without having to squeeze into a pre-established mold – they

could learn about who they are as individuals. They take this new knowledge to school, to their families, to their interactions with friends. So children also felt happier, because they felt freer.”

3. They understood the child’s involvement in motivational, challenging activities; and, in this context, learned to establish associations between theories of development and social interaction and also learned things they do not expect to: “I’d never met anyone with cerebral palsy before, so we got here thinking ‘I wonder what we’re going to come up against...’ Then we started the program and we met these amazing kids! We gave these marvelous children a little of ourselves and they gave us so much more back to us. So I think that the project was really good for both us students and the children, because we grew right alongside them and were able to watch them grow too. I have learned on a personal level...changes that I saw happening to me, things I will take with me into the future.”

Discussion

In this article we have summarized our attempts to adapt the system of educational activity called the Fifth Dimension, first designed for use with North American children who were experiencing school difficulties, to the setting of a rehabilitation hospital in Brazil. Overall qualitative results indicated positive changes in the development of children with cerebral palsy after they began participating in the Brazilian version of the activity. These gains were reported by the children's parents, as well as the undergraduate students who worked and played with the children as a central part of the activity. Consequently, we can conclude that the Fifth Dimension approach to remediating the intellectual and social development of children is applicable across a wide range of populations.

In addition to this general conclusion, we aimed at raising several questions about how to interpret these preliminary results, and their potential significance as part of a regime of rehabilitation for children with various forms of early brain damage.

The first question pertained to how to contextualize the project within a rehabilitation setting. What is it about the way the Fifth Dimension activities are organized that appears to produce such generalized positive results in many domains of development after so few hours of rehabilitation therapy?

If we adopt what is called the social-ecological concept of "context", represented by a group of concentric circles in which the focal activities are at or near the center, then context constitutes and is constituted by different levels ranging outward from the center (Cole; the Distributed Literacy Consortium, 2006). Consequently, an

ecologically integrated rehabilitation activity, in which the subject's different life settings are either directly or indirectly implicit, may impact more significantly on the development of the child with brain injury than mechanical, repetitive activities, as has historically been done.

Since the 1980s the SARA Network has been working on developing a program based on the family's and the child's context (Braga; Campos da Paz, 2008). The family's participation in the Fifth Dimension was processually co-constructed by the families, the child, the rehabilitation team and the undergraduates. The family's participation allowed us to systematically integrate the different generational roles in the individual development of the child with cerebral palsy. Including the family in the program adapted for children with cerebral palsy can serve as a model for Fifth Dimension projects conducted in other countries.

The adjustments that needed to be made to the Fifth Dimension to adapt it to the development of the child with cerebral palsy included adding artefacts to mediate communication and expression, within a setting whose rules, routines and ways of interacting were created specifically for the child with brain injury. The creation of individual projects permitted each child to develop his/her social role within this microculture, based on individual abilities and potential. This concept can be adopted as a basic principle of an educational model, not only for rehabilitation but also school, for children with learning difficulties secondary to neurological disorders.

One last observation, for which we still have more questions than answers, is how to explain these results, given that, to a large extent, they involved interactions between the children and undergraduates who themselves had little prior training. We should note that an analogous question arises concerning positive results obtained in North American and European implementations (Cole; The Distributed Literacy Consortium, 2006). Perhaps the best path to the answer lies in affective learning: The activity allows the undergraduate to interact with the child with brain injury and, through this process, the students deconstruct preconceived notions of human development, are able to learn from each other, and develop as individuals through a process of personal growth and increased maturity. This educational process complements academic learning and represents different means of learning about the same phenomenon.

The children, in turn, are engaged in activities tailored to their needs and potential. They are also afforded the chance to interact with peers with similar challenges, as well as students and professionals, who guide them through tasks that strengthen their skills and impact their development in ways that transfer to their daily lives. This mutually enriching environment for both students and children may significantly contribute to the results obtained with the 5th Dimension.

These preliminary results show that collaborative learning, based on social interaction, is an important tool for the development of the child with brain injury, and can be conducted in a pleasant, fun, challenging manner. Children will attain significant goals when they are intellectually and emotionally engaged in the task at hand. The personal and educational benefits of collaboration depend on the degree to which the individual is involved in the collective activity, as children may be less inclined to cooperate if the activities and tasks are not meaningful to them.

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