

A PLACE IN THE SUN PARENT COLLECTIVE OF WASHINGTON, DC:

EXPLORING ECONOMIC ALTERNATIVES

FOR PARENTS OF CHILDREN WITH SPECIAL EDUCATIONAL NEEDS

NATIONAL CED PROJECT FINAL REPORT

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I. INTRODUCTION

A Place in the Sun Parent Collective of Washington, DC is an unincorporated, self-funded association of nine African-American women who are parents of children with special educational needs. The Collective developed out of a focus group formed by the CED Student in January 1998. The focus group served as a means to study and document the social and economic status of such parents and to analyze how these two areas impact upon the type and level of special education services each parent was able to secure for their child.

The original thesis of the project suggests that parents of children with special needs within the Washington, DC area formulate a subculture unto themselves. The existence of this subculture is primarily driven by the isolation and stigmatization associated with having a child with a disabling condition. Their language, lifestyle, and economic realities are dictated and influenced by their struggle to seek resources and services for their children.

The antithetical counter to the existence of this subculture presents itself in the form of a historically ineffectual and financially corrupt service delivery system operated by the District of Columbia (DC) Public School System Division of Special Education.

There exists an ever-widening gap between the proposed one half billion dollar annual budget of the school district, of which \$90,000,000 is allotted to the Division of Special

Education (See Appendix A), and the appropriate allocation and spending of such monies to the benefit of students with special needs.

Through the formation of the Collective, an informal social support network was established. Within urban communities, local networks and associations such as the Collective have served to promote and develop positive systems of coping with common problems. “In the midst of urbanization, (such) networks have been shown as highly creative, flexible and inventive means of meeting day-to-day needs in an inadequate and troublesome physical and socio-economic environment”(Martineau, 1977, p. 97).

The Collective has now synthesized their existence and the unmet needs of their children by actively organizing itself into a more formal, economically focused business entity in order to generate greater educational, social, and economic opportunities for themselves and their children.

By so doing, the Collective has sparked the development of a grass roots, parent operated, family centered information network within Washington, DC. Their mission of bringing parents of children with special needs out of isolation and into a zone of empowerment will be realized by:

- Successfully forming a non-profit corporate entity
- Utilizing the non-profit corporation as a vehicle to become recipients of federal and local grant monies(in excess of \$400,000/year) which have traditionally been given to entities who have failed to effectively service their community

- Conducting workshops and seminars for other parents of children with special needs on topics pertinent to accessing and exploiting federally mandated resources and services which can increase their child's ability to function within the economic and social context of the community at large and reduce out-of-pocket expenses
- Generating additional personal income, through the creation of business ventures related to special education issues, which are sorely needed by parents of children with special needs in order to support the costs of activities and services which are not covered by traditional social service and educational agencies

The development of A Place in the Sun Parent Collective of Washington, DC has provided an unusual and insightful opportunity for the CED Student to act as both subject and object of this project, as the student is also a parent of a child with special needs.

Over the last thirteen months of the Collective's existence a progressive transformation has occurred among the members. The release and mobilization of the individual capacities of the membership has been as phenomenal as their search for community redefinition and empowerment.

II. DEFINITION OF THE PROBLEM

Prior to the enactment of the Education for All Handicapped Children Act of 1975 (Public Law 94-142), the special education needs of children with disabilities in the United States were not being met. Over 1,000,000 of the children with disabilities during this time were excluded entirely from the public school system and did not go through the educational process with their peers.

Over the last twenty years, this law and its subsequent amendments at the federal level, have served as the guiding force behind the provision of free and appropriate education within the least restrictive environment for all children with disabilities within the United States.

In 1990, Public Law 94-142 was amended and renamed the Individuals with Disabilities Education Act (IDEA). The most recent legislation, the Individuals with Disabilities Education Act Amendments of 1997 (Public Law 105-17), places significant emphasis upon improving student performance and ensuring that children with disabilities receive a quality public education.

In the city of Washington, DC, there are approximately 70,000 students enrolled within the public school system, grades Kindergarten through twelfth grade, during this 1998-1999 academic year. Approximately 10% of the general public school population identified with a disabling condition are receiving or are slated to receive special educational and related services.

In the attachment of a memorandum dated February 18, 1998, from Judith Heumann, Assistant Secretary of Education, United States Department of Education to the Secretary of Education Richard Riley, the extreme nature of the problem of inadequate compliance with federal regulations is crystallized. As of January 5, 1998, the reported number of students not having received such services was 4,595 (See Appendix B). This means that almost 60% of the total special education population within the public school system have not received a either a timely initial evaluation; three year re-evaluation; or specific related services provided for in their Individualized Education Programs (IEP), all processes which are mandated by federal law.

There are thirteen disability categories defined within Public Law 94-142 and its subsequent amendments (See Appendix C). Even a cursory survey of these thirteen conditions indicates the severity of the disabilities that cause the children affected by them life long challenges. These life long challenges are not only faced by the children but also by their families, and more specifically, the parents; legal guardians; or surrogate parents of these children.

Conditions of this nature place a great deal of economic pressure and social responsibility upon parents. It becomes imperative that parents become quite knowledgeable about their child's disabling condition. In addition, parents need to be able to effectively access the appropriate resources required to assist in their child's growth and development.

Prior to the 1975 enactment of Public Law 94-142, families were often forced to find services outside the public school system, often at great distance from their residence and at their own expense.

Unfortunately, this is still the case in 1999, primarily because most parents of children with special needs do not have ready access to resource and support information.

Government legislation has more than adequately addressed the financial and legal entitlements of children with disabilities for educational and related services. However, the social realities of stigmatization and isolation related to parenting a child with special needs continue to stifle access to the substantial amount of services that do exist.

III. HEIRARCHY OF OBJECTIVES/PROJECT GOALS

A Place in the Sun Parent Collective of Washington, DC seeks to remedy the problem areas of resource identification and support options by establishing a grass roots, community based, parent operated information clearinghouse. The clearinghouse will provide accurate, accessible information to parents of children with special needs on the rights, privileges, and opportunities that exist locally and nationally, and are afforded to their children and themselves under IDEA.

The Super Goal, as defined within the project's Logical Framework (See Appendix D), is to improve parent participation in the delivery of educational and related services to children with special needs within the Washington DC Public School System. This overall goal will be facilitated through actively working within the community to increase parental understanding of how to effectively access and use the procedural safeguards and resources for education and related services for their children with special needs as designated by Public Law 105-17 (IDEA).

The main purpose of the project was to document the Collective's activities while it works to structure itself organizationally into a non-profit organization. In addition, to test both the feasibility and practicality of parents of children with special needs providing services to the community – services which hitherto were provided in by business entities outside of the “parental community”.

The non-profit organization will establish a clearinghouse which will study, plan, and create alternative methodologies and training techniques to respond to the critical informational needs of parents of children with special needs within the Washington, DC metropolitan area.

It is expected that within the context of such goals and purposes, the project will successfully yield three (3) major outputs:

- Formation of a focus group which will make progressive movement into an unincorporated association/parent collective
- Formation of a non-profit entity from the parent collective entity
- Development of a service delivery analysis of the DCPS Special Education Division; Parental Skills/Needs Assessment tool; and an evaluation schema for parental empowerment

IV. PROJECT ACTIVITIES AND OUTCOMES

“On the one hand you must enter the cultural scene you hope to understand. You must get inside the language and thinking of your informants. You must make their symbols and meanings your own” (Spradley, 1979, p. 205).

Although I had experienced many of the struggles with the public school system the other parents of the focus group had, it was still very awkward making the initial invitation participate in the focus group. Each parent was contacted first by phone, and then in person. The basic outline of the project was in place by late December 1997. That is when the initial contact began. But I was unsure of what the future would hold for our small group.

I was uncertain about my capabilities to really understand the dilemma each of the women was in. After all, I had faced my biggest issues with my son’s placement and services and had moved on with my life. Could I, the student and researcher, make these other individuals symbols and meanings my own? Did we belong to the same “community”?

The project had three major areas of activities, each directly corresponding to the projected outputs (See Appendix D). All of the initial activities of the project were centered around the formation and functioning of the focus group. It was imperative that

the monthly focus group stayed in existence long enough to establish the necessary social and communal ties to push the group forward qualitatively.

Monthly meetings were held on Saturday afternoons or evenings at varying locations, both public and private, around the city. Makeshift forms were created in order to document attendance at the monthly meetings; contact with the parents of the group and any communications concerning their child or the group's activities outside of the monthly meetings (See Appendices E and F).

Recruitment for the focus group had appeared relatively easy since I had known all except one of the participants prior to establishing the project. However, even though the first meeting was held in January 1998, it wasn't until March 1998 that the real vision and strength of the idea of the Collective started to shine through. The Mission Statement (Appendix G) was drafted, revised, and unanimously endorsed.

As the Collective is self-funded, an attempt was made to solicit grant funds from a woman's health network in New York City which was closing out their operations and put a call forward for proposals for grass roots women organizations.

The Collective responded as we met the basic criteria. We were a female, African-American grass roots organization who was desperately anxious to increase our supply of economic reinforcements for our fledgling cause (See Appendix H). Unfortunately we were not awarded the grant monies.

No Steering Committee was created or officers elected. The collective currently functions and practices decision-making on the basis of general consensus. All members are free to raise any topic or bring up any concerns regarding the status of the Collective; their child's educational issues; or the status of a parent's functioning.

Record keeping was excessive during the first four months. However, a change in the formality of the meetings occurred during this stage of development. This was dictated by the Collective's need to be more attentive to the demands of the membership for increased peer case management sessions and resource information exchanges. In response to this, the CED student published an experimental newsletter for internal circulation only, in an attempt to recap the discussions that took place and to pass on new information. (See Appendix H)

In July 1998, the student undertook a course of Independent Study that focused upon the development of draft legislation for an Individual Development Account (IDA) pilot program. This legislation is entitled "The District of Columbia families and Children with Special Needs Individual Development Account Act."

Although still in draft form, the legislation calls for the establishment of pilot IDA projects with four key objectives:

1. To provide individuals and families of children with special needs, especially those of limited means, an opportunity to accumulate assets;
2. To facilitate and mobilize savings;
3. To promote education, training, transition services, and/or independent living skills and
4. To stabilize families and to build communities

The legislation allowed for matching funds contributions, up to \$500 per year, on a 1:1 basis. Participants would include Temporary Assistance to Needy Families (TANF) participants, who would not be penalized for attempting to acquire assets over \$1,000 in value, as they presently are. Funds could be withdrawn from accounts only for uses specified within the legislation. Additional work is required on the draft before preliminary presentation is made to the District of Columbia City Council.

(See Appendix J)

In November 1998 an interesting development took place. Discussions around the issue of engaging in the formation of a non-profit entity, in order to solicit funds to sponsor quarterly workshops across the city for other parents of children with special needs ensued.

The very idea that the Collective membership had internalized enough vision and had finally acknowledged the adequacy of their life/professional skills to handle such an endeavor has proven to be timely.

It was also during this time that the CED student and her son were featured in the Metro Section of the November 30th issue of the Washington Post. The feature was included in an article about the current status of the Division of Special Education's Administrative Hearing workload. It was reported in the same article that 2,500 parents had requested administrative relief for their children's' special education issues and lack of services.

(See Appendix K)

By December 1998, the CED student and another parent from the Collective proffered public testimony at a Special Education Sub Committee Hearing at the District of Columbia City Council. The video recording of the hearing was replayed several times on the District Government cable station. It has proved to be an excellent public relations exercise for the Collective.

The December testimony also proved politically advantageous. Five members of the Collective now sit on the Special Education Task Force as advisors to City Council member Kevin Chavous. The Collective also presented a draft of a service delivery evaluation schema for special education to the Task Force at their last meeting.

(See Appendix M)

With the completion of the Business Plan in late December 1998, the Collective moved to accept the plan and to begin drafting Articles of Incorporation and by-laws for the new non-profit entity proposed, Abilities Count, Inc. (See Appendix N) In addition, a Collective member has successfully identified an office incubator space for the business. This, with a local bookseller, Sisterspace and Books.

V. ANALYSIS/CONCLUSIONS/RECOMMENDATIONS

The formation of A Place in the Sun Parent Collective of Washington, DC was viewed initially as an experiment by the CED student. The project has yielded any number of practical, economic and socially empowering applications. Exploring the whole process of utilizing community economic development as a strategy for moving an isolated community of parents of children with special needs into a zone of empowerment and local control of resources has been one of the most fulfilling experiences of my life. And, I truly believe that through this process, I have found my “life’s” work.

The project has taken a lot of individual and collective energy and stamina. Trying to remain connected for thirteen months, on a weekly basis, with the Collective membership was exhausting. The student had to work through her own child’s special needs issues while attempting to assist others and simultaneously participating in the founding of an organization.

The most obvious lesson learned by this student is that community ownership and collective intent must remain legitimate objectives of any community economic development project. In addition, responsibility and reciprocity play a major role within the dynamic of any group relationship. The work of the collective must be distributed according to interest; capabilities or the capacity to learn; and in strict accordance to the financial and human resources available. In other words, always striking a fine balance between skill and need.

There is one issue upon which the student insisted that the Collective make no compromise upon. The major cause of our “success” thus far has been the fact that we have taken time to build the necessary relationships within our organizations and to collaborate with others within our community at large.

Abilities Count, Inc. is scheduled for incorporation no later than March 31, 1999. The Collective has already been offered its first sub contract for a series of grass roots community workshops from the local parent training and information center, which is funded by the U. S. Department of Education. Office of Special Education and Rehabilitative Services. This contract will serve as prime experimental ground for the Collective to get our Collective feet wet in the big world of CED.

If we’ve done anything at all as a Collective, it is to give credence to the 1970s hit song written by Stevie Wonder song which states....” There’s a place in the sun and there’s room for everyone...”.