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## **Participatory Action Research Involving Families from Underserved Communities and Researchers: Respecting Cultural and Linguistic Diversity**

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Participatory Action Research (PAR)—a method of conducting research that involves researchers and the constituencies of the research as equal partners in all phases of the research—requires an understanding and respect for the unique perspectives and resources that each PAR team member brings to the effort. PAR can be particularly challenging when it involves a research institution from the mainstream academic culture and culturally and linguistically diverse families and students with disabilities from underserved communities. In this paper, we (a) provide an overview of participatory action research; (b) provide a contextual analysis of cultural and linguistic issues that must be addressed in research endeavors, we describe the nature of the research partnership; (d) highlight partnership challenges; and (e) highlight partnership promises.

### **Overview of Participatory Action Research**

PAR refers to a process whereby the researchers and constituents together identify the problem to be investigated and collaborate throughout the entire data gathering, dissemination, and utilization process (Bruyere, 1993; McTaggart, 1991; Whyte, 1991). The PAR collaboration of researchers and constituents has two anticipated outcomes: (a) identifying and solving high-priority problems, and (b) ensuring that solutions are not only useful but also used by constituents. A major catalyst for PAR within the disability community is the National Institute of Disability and Rehabilitation Research, which sponsored a conference on PAR in 1989 (Turnbull & Turnbull, 1989), issued a paper several years later (Fenton, Batavia, & Roody, 1993), and sponsored a state-of-the-art conference investigating PAR procedures in 1995. NIDRR encourages researchers and constituents to "...share and utilize his or her unique skills, background, and experiences so that the common objectives of enhancing the quality of life and functioning abilities of individuals with disabilities are achieved" (Fenton, Batavia, & Roody, 1993, p. 11).

Research related to enhancing the quality of life for children and youth with disabilities can be useful to a variety of constituents—general and special educators (teachers, administrators, related services personnel), policy makers, families of students with and without disabilities, and certainly the students themselves. The majority of PAR literature within the field of special education has focused on teachers as the constituents of research (Carnine, 1997; Fuchs & Fuchs, 1990; Kauffman, Schiller, Birman, & Coutinho, 1993; Malouf & Schiller, 1994). The literature on the research-practice gap between researchers and families has received only minimal attention in the professional literature (Parent to Parent Consortium Team, 1994; Santelli, Singer, DiVenere, Ginsburg, & Powers, 1997; Turnbull, Friesen, & Ramirez, 1995; Turnbull & Turnbull, 1993).

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### **Contextual Analysis of Cultural and Linguistic Issues to be Addressed in Research**

I could not speak English when I arrived in the United States ten years ago, even though I had taken some English classes at the Jesuit seminary in my teens. One of my greatest problems was that the things I talk about did not happen in English; they happened in a language that has a very different mindset about reality. There is usually a significant violence done to anything being translated from one culture to another. Modern American English, which seems to me better suited for quick fixes and the thrill of a consumer culture, seems to falter when asked to communicate another person's world view. I found myself trying to ferry meanings from one language to another, and from one reality to another—a process that denaturalizes and confuses them. (Som, 1994, p. 2)

Malidoma Som's words give insight into the intimate relationship between culture and languages, and describe the difficulties inherent in researching human experiences across cultures, languages, and other modes of expression. The idea of an event happening in one language, that cannot be captured in the words of another language suggests the multidimensional context of language and the dangers of what can be lost in translation. Some firmly believe that the failure to respect the cultural context of language is an act of violence. This violence presents the greatest challenge to the kind of communication that is essential to realizing liberty and justice for all in a multicultural society.

There are adults and children all across America who are victims of this cultural and linguistic violence. Their traditions have been slashed, their cultures dislocated, their languages broken, and their histories have been bludgeoned beyond recognition. They have been left in this condition to fend for themselves traditionally underserved communities—communities that as defined by the Report of the Committee on Labor and Human Resources are home to families of "diverse racial, cultural, and linguistic backgrounds who are isolated by geographic, social, language, cultural or racial factors" (Senate Bill 717, 1997, p. 39). These underserved urban and rural communities have been historically deprived of services because the people in them are different. Here they have been isolated behind barriers of racism, cultural discrimination, socioeconomic and geographical bias. It is a world with sparse resources—one in which many children with disabilities live and one which rarely benefits from the scientific advances that come out of research.

The schools in these communities are largely racially segregated, isolated institutions that present a microcosm of the communities that surround them. In his book *Savage Inequalities: Children in America's Schools*, Kozol (1991) described his experiences visiting children in their schools and homes in neighborhoods from Illinois to Washington, D.C., and from New York to San Antonio.

My deepest impression...was...that these urban school were, by and large, extraordinarily unhappy places. With few exceptions, they reminded me of "garrisons" or "outposts" in a foreign nation. Housing projects, bleak and tall, surrounded by perimeter walls lined with barbed wire, often stood adjacent to the schools I visited. Police sometimes patrolled the halls. The windows of the schools were often covered with steel grates....Looking around some of these inner-city

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schools...I often wondered why we would agree to let our children go to school in places where no politician, school board president, or business CEO would dream of working. (Kozol, 1991, pp. 4-5)

These are the settings where learning is taking place for thousands and thousands of children in America's schools every day. Their faces are hidden behind the statistics that depict their academic and social deficits but fail to depict the long history of racism, discrimination, and apathy that has led to these conditions. How much of children's reality has been lost in the translation by researchers who have discounted the ways these factors affect learning? Research that offers this kind of information out of context can lead to erroneous and dangerous misconceptions and generalizations about people who are culturally and linguistically diverse.

Ask most people in traditionally underserved communities about their experiences with research and you are likely to encounter a blank stare. Some may conclude that research has largely been conducted by and for the direct benefit of the majority culture. Some may remember Charles Drew, the African-American scientist who developed a method for preserving blood plasma and later, after being injured in a car accident, died when he was refused plasma. More will recall the infamous Tuskegee incident in which African American men were left to weaken and die of treatable syphilis. Others will mention their experiences with IQ tests and other evaluations that are based on the experiences of the majority culture, English-speaking population. However, for most people in traditionally underserved communities, the world of research is a distant planet from which they receive occasional televised reports of medical breakthroughs, educational advances and brilliant new discoveries that are exciting in the first few moments before they realize that the benefits of research will most likely never reach their families.

Yet, parents of culturally diverse learners in underserved communities need research partners to help answer many questions. Sweet Alice Harris and the Parents of Watts want to know how to work more effectively with children who have acquired disabilities as a result of violence. Santiago Garcia and Marilyn Ruiz want to learn how to ensure continuity of special education services for children of migrant farm workers whose families must move often to follow work. Theresa Cooper and the parents of Loving Your Disabled Child in south-central Los Angeles and Nichelle Ames of Creating Opportunities for Parent Empowerment, need strategies for inclusion of children with disabilities in the mainstream that do not jeopardize their safety and progress.

In rural Pennsylvania, Gail Walker and parents involved with the Mentor Parent Program need to find ways to ensure that qualified teachers and related services are accessible to children who need them. Yvone Link, through her Parent Power program in Tacoma, is searching for ways for Korean and other Asian families to assist their children in the sometimes difficult transition from school to work, while Lourdes Putz and Carmen Rodriguez investigate ways to get school officials to respond to the special education issues of the Spanish-speaking families served by United We Stand of New York.

D. J. Markey and Brenda Quant of Pyramid Parent Training in New Orleans want to learn more about the effects of living and learning environments on behavior, and Carol Ironrope-Herrera wants to codify her use of Lakota-Sioux traditions in teaching parents how to work with their infants and toddlers with special needs. Mr. Chu and the Vietnamese Parents with Disabled Children Association, Inc., are interested in citizenship issues surrounding their children and adult family members with disabilities, and Rose Ferguson and Agnes Johnson of Special Kids, Inc., want to learn more about adult mental health issues and their relationship to children's disabilities in homeless families. Carol Kennedy's Island Parents

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Educational Support and Training Center on Martha's Vineyard and Rehema Glenn's parent program in the Virgin Islands are finding ways to defeat the isolation that can result from geographical location, while Edith Sharp is hoping that their answers may apply to communities in inner-city Detroit that go unserved because of the sheer density of culturally and linguistically diverse people and the crime and violence that have come to be associated with such communities.

What are the implications of educational research for families of children with individual differences who are also from diverse cultures? How does research expand to include strategies that result in practices that translate meaningfully into their day-to-day lives? How do we move past the pain and mistrust that characterize the relationships between the research community and those who have been historically underserved due to cultural and linguistic differences? If Malidoma Some is correct, these may be impossible tasks because there is simply no way to capture what will be lost in the translation. Yet, we must find a way to accomplish this kind of communication in the America we are building. The ultimate goal of the PAR researcher working in a sophisticated university setting and the single mother raising her child with a disability in a public housing development is the same—to find the truth, about what interventions can really improve the quality of life.

### **The Nature of the Research Partnership**

In describing the nature of our PAR partnership, we first highlight the mission and resources of the Grassroots Consortium on Disabilities, followed by a description of the Beach Center on Families and Disability's mission and resources. We then briefly describe our collaborative partnership.

#### ***The Grassroots Consortium: Mission and Resources***

*Mission.* Parents in underserved communities have never given up the struggle to get quality special education services for their children. For as long as there has been a parent movement, there have been parent leaders in these communities who have hunted for, gathered, and carried information and training in special education and disability legislation into the farthest regions of urban and rural settings. With scant community resources and virtually no outside funding, they designed and established small, community-based parent organizations in the places where they live. These community parent centers have been gathering places where parents share information and lend support to each other in culturally and linguistically meaningful ways.

In 1993, fifteen of these community-based organizations came together to form the Grassroots Consortium on Disabilities. Created in the spirit of respect for each other's work, The Grassroots Consortium on Disabilities is a national, multicultural organization consisting of these 15 different community-based parent centers that, individually and collectively, focus primarily on supporting and fostering the empowerment of traditionally underserved families of children with disabilities. Its mission is to support community-based parent-run organizations that foster empowerment for families of children and young adults with disabilities in traditionally underserved communities.

*Resources.* Each of the member programs has had a great deal of experience, both in longevity/duration of operation and intensity of effort in working on behalf of these families. While each of the 15 model programs is unique in its supportive responses to families, program activities that are common to all

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include outreach, informing parents about the educational and legal rights of their children with disabilities, helping families to meet their basic needs through ongoing, often one-to-one technical assistance delivered by parents who reside in the home communities, and parent leadership in community development. The Consortium also publishes *Tapestry*, the journal of the organization—an, information and dissemination resource that reports on issues having impact on families of children and youth with disabilities in diverse communities, narratives of the real-life experiences of those families in accessing special education programs and services, and strategies Consortium member organizations use in working with these families. In 1997, the Consortium was awarded a grant from the U.S. Department of Education Office of Special Education and Rehabilitative Services (OSERS) as the first multicultural, multi-state Parent and Training Information Center, to support its work among families of children with disabilities in traditionally underserved communities.

All 15 of the Grassroots Consortium programs have been developed and are administered by parents, on a volunteer basis or a shoe-string budget, in order to provide the greatest possible personalization and responsiveness to underserved families. The 15 programs have, over the past five years alone, served over 150,000 families in traditionally underserved communities. Because the directors of the Grassroots Consortium programs have a shared history with the families served by their programs, they have an easy and comfortable access to these traditionally underserved families. What they do not have, however, is easy access to research-based information about best practices in family support that might make an immediate and beneficial difference in the lives of traditionally underserved families.

#### ***Beach Center on Families and Disability: Mission and Resources***

*Mission.* The Beach Center is a constellation of rehabilitation research and training efforts primarily funded by the NIDRR Rehabilitation Research and Training Center program. Operating since 1988, the Beach Center has a major commitment to conduct research and training that will make significant and sustainable differences in the lives of families who have a member with a disability. Some of the topics of this research include documenting family needs related to positive behavioral support, describing successful friendships of Latino children and youth with disabilities, measuring the efficacy of Parent to Parent support, constructing an instrument to measure the empowerment of families and adolescents with disabilities, and conducting policy research on family support legislation. The Beach Center also carries out a broad range of dissemination and training activities, including the preparation of research-based textbooks and other supplementary books, multimedia training packages for families, comprehensive syntheses and translations of research into practice for the benefit of families and service providers, and a comprehensive website.

*Resources.* The Beach Center's resources are quite similar to the resources of externally funded research institutes at universities around the country. It has access to a number of resources that enhance the efficiency of its work, such as over 30 interdisciplinary staff with advanced training, a broad computer network, an extensive library of family studies and special education books, and a broad national and international network of colleagues. These resources are enhanced by the Beach Center's collaborative relationship with the Department of Special Education and the Schiefelbusch Institute for Life Span Studies—two University of Kansas units that are extensively funded by federal and state grants and have a long history of resource acquisition.

However, as is true for most other university-based research institutes, the Beach Center has significant gaps in some resources—particularly collegial partnerships with families and educators in traditionally

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underserved communities. Beach Center researchers have been increasingly concerned that, in spite of extensive efforts to have a random or representative sample of families in research projects, almost invariably research samples have been drawn from the majority culture. As Beach Center staff reviewed the research literature related to families of children and youth with disabilities, they noted this same trend of having the research sample comprised primarily of white mothers (mostly middle and upper-middle class). Disturbingly, the results of this research on mostly middle and upper-middle class, white mothers is often generalized to families of all cultures and to each and every family member.

Beach Center staff have increasingly recognized that quality family support and educational practices occur within the context of culture, language, and environment. Given that many underserved families, schools, and communities continue to experience disproportionately fewer resources, Beach Center staff have been eager to establish new partnerships. Thus, when the paths of the Beach Center and the Grassroots Consortium first crossed, both organizations recognized that they shared a similar value base—a commitment to enhancing empowerment for individuals with disabilities and their families who live in underserved communities.

### ***Collaborative Partnership***

The collaborative partnership that has been forged and is continuing to develop between the Grassroots Consortium and the Beach Center brings together the unique resources of both partners and enhances the overall capacity of the partnership. With the personal and professional wisdom of members of the Grassroots Consortium on meeting the needs of underserved families affected by disability issues, the research, training, and dissemination activities conducted by the Beach Center will be more relevant and appropriate for culturally and linguistically diverse families. The professional expertise in research methodology and the national visibility of the Beach Center will mean that best practices for meeting the needs of underserved families that are currently being implemented by the Grassroots Consortium will gain enhanced credibility among the research and service delivery communities. Our partnership will enhance the capacity of each of our organizations to fulfill our mission on behalf of all families.

Historically, partnerships between large, well-established research organizations in the dominant culture and smaller, newly developing, community-based efforts on behalf of underserved families have been beset with challenges stemming from cultural differences and priorities (Kritek, 1994). The Grassroots Consortium and the Beach Center are well aware of these potential pitfalls and recognize that we are employing a different sort of collaboration—one built on a foundation of an enhanced understanding, trust, mutual respect, and equal participation in all decision making. We also recognize that, more often than not, families believe that researchers come to an underserved community, conduct research, and leave...all without creating any direct benefits to families. We are committed to reversing that history by developing a different kind of partnership

### ***PAR Partnership Challenges***

As is true for most new collaborative ventures, PAR brings with it new opportunities and new challenges—both for researchers and for parents in underserved communities. In the next section we discuss some of the challenges of PAR for families in underserved communities and for researchers.

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### *PAR Challenges for Families in Underserved Communities*

Development of the PAR partnership is painstakingly cautious with partners having to strike agreements on policy and procedures that do not impose added duress on already beleaguered families. One of the partnership's first challenges has been to frame it to meet both Beach Center's needs and those of the Grassroots Consortium. The process is being collaboratively designed to model values and structures that can make for successful collaborations between established and developing organizations without disempowering the latter. In the Consortium's experience, weaker, developing organizations are often enticed by the money and resources available in large powerful organizations to change their missions and long-term goals, and thus are ultimately destroyed. This is the history of these relationships.

Consortium organizations have shared experiences and developed trusting relationships with families in their communities over time. These are the bonds that allow for ongoing sharing and leadership development within communities. Given the stormy history of research and its portrayal of culturally and linguistically diverse learners in underserved communities, Consortium member organizations must be certain they will not be exposing families to the negative attitudes and biases of some researchers. If researchers introduced to families through the Consortium disrespect families, then the Consortium's credibility may be placed in jeopardy. Thus, certain procedural safeguards must be developed before researchers are introduced to families.

Leaders of Consortium member organizations also worry about the amount of time required to participate in research. Many researchers do not realize how time-consuming everyday tasks are for those who live in urban and rural communities that lack adequate transportation services, child care, health care and emergency services. In such places, just getting to the grocery store or doing the laundry can take up most of a day. Parent leaders often provide their services and support to other parents after they fulfill their responsibilities to their own job and family. Thus, they worry that the time requirements for participation in research will be prohibitive. The challenge will be to construct realistic goals, clearly defined and designed with families, to ensure the progress of research while respecting the time constraints of the participants.

Moreover, for culturally and linguistically diverse families in underserved communities, as with most families in America, whether they are black, brown, white, red or yellow, the ultimate reality is green—money. People must have money to keep their families going. Relationships between researchers and families can become strained when researchers do not consider this very basic financial reality and do not understand the motivations of families. Consortium members always welcome the opportunity to share their experiences and information about their work and are highly motivated to do so with those sincerely interested in reaching underserved communities. They also are motivated to participate in and gain knowledge about research that is meaningful and beneficial to underserved families. However, Consortium programs operate on a shoestring budget, often out of their homes, and after regular job and family responsibilities. These circumstances often pose hardships for them in terms of time and money. Thus, they must receive compensation for their participation in research and as speakers at conferences and other events. Otherwise, researchers are asking community-based organizations to deplete their meager resources that are strictly dedicated to directly serving parents. As the research community continues to plan for the inclusion of families of diverse cultures, it must take into consideration the disparity in fiscal resources that exists between highly sophisticated research entities and developing community-based organizations, and then discuss what supports are necessary.

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Additionally, from the Consortium's perspective, PAR teams will have to plan for research that will immediately and directly benefit families and communities who participate. The partners will have to collaborate on ways to bring best practices already identified in a given area of study to the community. Parent leaders will then at least have the opportunity to modify these practices to suit the needs of culturally and linguistically diverse families. Some examples include the sharing of positive behavioral support techniques, the provision of communication devices, and strategies to address the impact of welfare reform and SSI cutbacks on children with disabilities.

Further, researchers are accustomed to long delays for the final and conclusive results of a study. However, families, who have already been long underserved could benefit from the "best guesses" of PAR teams. Even when findings are incomplete, the partial results may have useful applications for underserved families. Moreover, follow-up support after the completion of the research is essential to ensure that the research does not leave a family or a community less well off than it was before the research was conducted.

Another challenge the partnership faces will be to find ways to ensure that parents gain confidence in their new roles as research leaders, co-researchers and ongoing advisors. Too often researchers use technical terms that intimidate and confuse family participants. The partners will have to find meaningful ways to communicate sometimes complex cultural and linguistic issues, theories, and research methods.

Perhaps the most challenging areas of the partnership will be to come to a common understanding and agreement about values with regard to research. For Consortium member programs, research must lead to social change. If it does not, it is not worth the energy.

#### ***PAR Challenges for Researchers***

One of the biggest and most pervasive challenges for researchers on PAR teams is simply that PAR takes more time. Because PAR values and employs a democratic group process that benefits from the contributions of all PAR team members, group decisions are made only after the whole group has had time to learn from the diverse perspectives of all team members. Members of a PAR team may not always easily reach consensus during a single meeting or conference call, and often multiple meetings conversations need to occur before a common understanding is reached and all PAR team members are comfortable moving ahead. Researchers accustomed to working alone and making unilateral decisions may feel frustrated by and have concerns about how much time it takes to implement PAR.

Because PAR brings together team members working in a variety of organizations in a variety of different contexts, the team as a whole may discover that the pace of individual team members and the capacity of their organizations may also be quite different. The universities that are home to most researchers typically have office staff, fax machines, access to e-mail, multiple university library systems, and high speed copy machines. The result is that researchers have the capacity to accomplish their primary mission (write grants and carry out research) in a time-efficient way. Parents representing parent programs in traditionally underserved communities generally operate out of their homes with no administrative support and perhaps, at most, a fax machine and a computer. This lack of administrative support, coupled with the fact that the primary mission of parent program directors is providing direct support to families, may mean that parent program directors move at a slower pace in accomplishing the research goals of the PAR team. When parent program directors are responding to the needs of families in crisis, they



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may not be immediately available to complete a PAR team activity. Researchers may find the turnaround time needed for accomplishing PAR tasks is longer than they expect and that even granting agency time lines allow.

The time/pace factors in PAR activities are accompanied by a related financial reality. Group decision making, because it usually involves more time spent in multiple meetings and conversations, costs more in terms of staff time and conference call/meeting expenses. Researchers are often conducting their research on limited grant funds and limited time available in the grant cycle. Until public and private funding agencies recognize the value of PAR and provide sufficient funding and time to support PAR activities, researchers may feel torn between wanting to implement PAR and yet having insufficient funds and time to do so.

Another financial reality that may be new and perhaps unsettling for researchers is the need to build a project budget that compensates all PAR team members for their contributions to the collaborative effort. Historically when parents have been involved in research, they have participated only as respondents. Perhaps they were compensated for responding to questionnaires or participating in focus groups, but because they were not involved in other ways, there was no line item for their participation as PAR team project personnel. Generally, grants are submitted by researchers at universities, and the budgets are prepared by the universities. Researchers may have some hesitations about carving the already-limited budget pie into even more pieces.

One of the most serious challenges to PAR is the belief held by many researchers that PAR research is less rigorous than that conducted by researchers alone. Because most parents have not been formally trained in research methodologies, some researchers believe involving them in decisions about research design will lead to a weaker design and one that favors family-friendly methods over scientifically rigorous methods. Researchers who work on PAR teams with parents may find that their professional colleagues give less value to their work and that the work of the PAR team is less likely to be accepted for publication in peer-reviewed journals or presentation at national conferences than work done solely by researchers. Researchers depend on publication in peer-reviewed journals and presentations at national conferences for their own career growth--without these kinds of additions to the vitae, promotions within the university system are considerably more difficult. Until PAR becomes more widely accepted and valued, researchers may be hesitant to risk their own professional careers by participating on PAR teams.

PAR is based on shared responsibilities in all phases of research—determining the research questions, designing the study, analyzing the data, and preparing and disseminating the final products. Some researchers may find it difficult to share authorship of the final reports about the research. Universities often consider the number of solo and lead authorship articles in peer-reviewed journals that a researcher has when they make decisions about tenure and promotions. PAR-generated articles are produced by the PAR team and typically have multiple authors. Until there are changes in university systems, participation on a PAR team may not lead to the kind of career enhancement opportunities that researchers seek. PAR Partnership Promises

While challenges do exist for PAR teams of parents and researchers, the PAR experience brings with it opportunities that typically do not exist in more traditional research. In this section, we discuss some promises for families from underserved communities and for researchers that may evolve from PAR collaborations.

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### *PAR Promises for Families from Underserved Communities*

Some educational researchers accept and celebrate the differences that exist within our ethnically diverse citizenry. They are discovering the need for a larger, more encompassing truth—one that is as diverse as the cultures and communities that make up this country. In response, some parents are realizing the need to move past their fears and participate in the kind of research that makes solutions to problems meaningful to them and of practical use in raising their children. A promise of PAR for families from underserved communities is that partnerships between families and researchers will mean that research will be more relevant for families and will, in fact, make immediate positive differences in their lives. For families, PAR presents a long-awaited opportunity to partner with researchers to find realistic solutions for improving the quality of their lives. Through the PAR process, families, individual members—their faces, personalities and the conditions they face daily in their communities—will become real in the minds and hearts of researchers. Once that happens, the needs and concerns of these families will take on unprecedented priority in the research community.

Families from underserved communities, through their ongoing interactions with researchers, will be able to dispel myths and misconception, that may be held by researchers. Researchers will, in turn, through their interactions with these families, discover the potential these families have for introducing nontraditional, culturally based approaches to problem solving that may be applied in research across cultures. A new, confident, and enduring leadership will emerge among culturally and linguistically diverse families in underserved communities, supported by research-based information, that will command the attention and respect of people of good will everywhere.

Together, researchers and families will develop a new "cooperative language" that allows them to work together without fear that culture and context of their lives will be lost in narrow translations. Families will then never have to suffer the kind of violence that occurs when their experiences and perspectives are documented and presented without their involvement.

Through the PAR experience and because they will have research-based information, families will gain confidence in their abilities to comprehend and influence special education and other issues surrounding children and adults with disabilities. Armed with research-based information families will experience perhaps for the first time, empowerment to work for systems change—the same kind of empowerment that Paulo Freire says can result when adults learn literacy skills for the first time:

In fact, those who, in learning to read and write, come to a new awareness of selfhood and begin to look critically at the social situation in which they find themselves, often take the initiative in acting to transform the society that has denied them this opportunity of participation (Freire, 1970, p. 9).

Families will also grow to appreciate the power of research as they implement research-based, best practices in their homes and communities. As these research-based, best practices take hold in communities, more and more families, beyond those on the PAR team, will discover a new perspective of the research community through its commitment to partner with culturally and linguistically diverse families to create positive social change.

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Families as research partners will ensure that researchers see the importance of joining with them to solicit the allocation of resources for implementation of established and promising best practices. Thus, the acquisition of resources becomes a goal and expected outcome and promise of PAR. These resources will serve to actually improve the quality of life for children and adults with disabilities in underserved communities.

News of research breakthroughs and advances will inspire lasting hope and joy in the realization that families from underserved communities will finally share in the benefits. The word will be spread across communities, and the resources will follow until no one in America will live outside of the promise.

This partnership will provide a model for collaboration between sophisticated, highly developed research entities and families all across this nation in the interest of improving the quality of life for all children and adults with disabilities everywhere. The promise is that PAR teams composed of researchers and culturally and linguistically diverse families will discover a new relationship that broadens the scope of their commitment to research as a means of social change and contributes to a deeper understanding of the critical role research plays in finding practical solutions for families. For underserved families, PAR rekindles the hope that there are answers through research that will indeed reach their families—answers that will make an immediate, relevant, and meaningful difference in their day to day lives.

### ***PAR Promises for Researchers***

The PAR process by its very nature involves a sharing of perspectives, wisdom, and expertise by all PAR team members. The commitment of the PAR team to decisions by consensus and decisions made out of shared perspectives means that time for this important sharing is built into the PAR experience. Life offers few such opportunities for learning about and valuing the richness of each PAR team member's perspective. Participation on a PAR team with parents from underserved communities is a powerful opportunity for personal growth and for the enhancement of one's own cultural competency. The PAR process for most researchers is unlike any other, and researchers who are open to new experiences often find the PAR process to be stimulating and intellectually challenging.

While those who are not experienced in PAR fear that the PAR process diminishes the scientific rigor of research, successful PAR teams find the opposite to be true. A PAR team of parents and researchers working to determine the efficacy of one-to-one Parent to Parent support discovered that the recruitment strategies suggested by the parents on the PAR team allowed the PAR team to recruit many more parents than the researchers thought possible (Parent to Parent Consortium Team, 1994; Santelli et al, 1997). The larger sample size added greater weight to the results of the statistical analyses—thus increasing the rigor of the findings.

PAR also increases the relevance of the research. While some research topics are chosen out of the researchers' priority intellectual interests, most researchers prefer to engage in research that will be meaningful and useful to others. PAR creates research opportunities that, because the research questions are mutually defined by the PAR team, are guaranteed to be of interest and more relevant to a wider audience.

### **Conclusion**

In summary, the process of PAR involves a shift from a business-as-usual to a business-in-a-new-way mind set. Researchers and parents in underserved communities on PAR teams must come to the PAR experience with a willingness to acknowledge their respective histories but not let past histories pre-

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determine the outcome, and to recognize that a multicultural partnership between researchers and underserved families is a concept that is not embraced by all families or by all researchers. Courage will be required by all partners to withstand the inevitable critique from the groups represented in the partnership and to explore new ways without feeling threatened by the unknown. We conclude with our shared commitment to the position suggested by Martin Luther King Jr.:

Cowardice asks the question, is it safe? Expedience asks the question, is it politic? But conscience asks the question, is it right? And there comes a time when one must take a position that is neither safe, nor politic, nor popular, but he and she must make it because their conscience tells them it is right.

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