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ABSTRACT

This issue of the "Early Childhood Bulletin" features extended excerpts of keynote speeches delivered by two parents of children with disabilities at the Partnerships for Progress meeting held in Washington, DC, in July of 1995. Florence Poyadue and Glenn Gabbard both delivered powerful keynote speeches at the Partnership meeting in 1989 and both returned in 1995 to reflect on the changes they had observed some 6 years later. Both parents, from very different perspectives, exemplify the challenges parents face as partners in the process of improving services for families and children with disabilities. The idea of "leadership from the middle" is discussed in the introduction of the article, and short biographical sketches of both speakers are included. Contact information and brief descriptions of four organizations serving parents of children with disabilities is given, and an annotated bibliography of five recommended books on leadership and change is included. (SG)

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COALITION QUARTERLY
EARLY CHILDHOOD BULLETIN

WINTER
1995

LEADERSHIP FROM THE MIDDLE
PARENTS AS PARTNERS FOR CHANGE

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EARLY CHILDHOOD BULLETIN

News by and for Parents and Parent Members of State Interagency Coordinating Councils

Winter

Prepared by the Federation for Children with Special Needs
Parent Component Staff of NEC*TAS

1995

LEADERSHIP FROM THE MIDDLE PARENTS AS PARTNERS FOR CHANGE

The process of improving services for families and children with disabilities — like all change processes — has moved in steady increments and with sudden waves of progress and ebbs of energy. The issues of the 1990s present all citizens of our nation with an environment of great turmoil and uncertainty. They challenge our work in education and human services and increasingly highlight the importance of communities raising their voices in concerted support for the changes that have most benefited their children and themselves.

This edition of Early Childhood Bulletin features extended excerpts of keynote speeches delivered by two parents who, from very different perspectives, exemplify the challenges of leadership from the middle. Florene Poyadue and Glenn Gabbard were featured keynote speakers at the Partnerships for Progress meeting held in Washington, D.C., in July of 1995. Both had delivered powerful keynote addresses at the Partnerships meeting in 1989 and returned to reflect on the changes that they had observed some six years later.

Introduction

In *Leadership Without Easy Answers*, Ron Heifetz argues that the concept of leadership itself is subject to change and scrutiny in times such as these. Challenging much of the single-hero mythology about leadership that has prevailed, Heifetz defines the singular task of a leader as "mobilizing people to tackle tough problems." (Heifetz, 1994, p. 15.) Leadership then should not be confused with holding a position of authority or influencing people, but instead should be viewed as the task of fostering a complex set of relationships in which individual leaders attempt to help communities of people to face their problems as partners and to make progress toward solving them together.

Leadership can come from those in positions of authority but it can also come from those who do not have officially sanctioned power. It is often from these positions "in the middle" that some of the greatest social changes have been initiated and sustained. In his book, Heifetz describes the social change processes catalyzed by figures such as Gandhi, Margaret Sanger, and Martin Luther King and shows how often the leader becomes the orchestrator of change, the choreographer of learning within an organization or a community. "Armed with a sense of outward commitment to external change and an internal reflectiveness that is guided by a clear vision, leaders from the middle often are unrecognized for their contributions because they are so deeply embedded within the communities to which they belong.

Without official authority, however, leaders in the middle often must deal with a unique set of challenges. First, they have little control over the environment in which they attempt to make change. In essence, these leaders hone their sense of timing and intuition about when to introduce key issues, when to negotiate, and when to press forward toward accomplishing a goal. They also become skilled at flexibly defining the process by which change is introduced, discussed, and decided. Second, leaders without authority must find their own sources of support from within themselves and their communities. With little or no support from the majority and no protection from an official position of power, leaders from the middle often are seen as magnets for conflict and attack. Finally, leaders in the middle focus their attention on mobilizing critical stakeholders in a community rather than working solely with those in traditional positions of power. It is this recognition of the power of communities to implement change that is critical to the change process.

It is clear that parents seeking family-centered services for their children often exert leadership "from the middle." Often, these leaders are asked to create environments where young children with disabilities (or who are at risk) are permitted to enjoy the developmental care and nurturing that is afforded to their peers. These new environments are often within individual families or within programs that believe in the vision of community and dignity to which all citizens are entitled. — Glenn Gabbard

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Florene Stewart Poyadue is a renowned American of African heritage and a parent leader whose son, Dean, has guided her in her advocacy for children with disabilities in California. The founding director of Parents Helping Parents (PHP) in Santa Clara, Ms. Poyadue is responsible for setting up a national network of parent-directed Family Resource Centers that have been instrumental in assisting professionals and parents of children with disabilities in their quest for information and resources to enhance children's care and their quality of life.



Good Morning...

In 1989, we came together to grow our expectations for children with special needs. Back then, I was excited about three main things:

First, my son Dean, who happens to have Down syndrome, was transitioning to a neighborhood middle school at age 13. I was thrilled to see him participating on all of the local sports teams, going to integrated summer camps, *humming* in the children's choir (Dean didn't have a lot of speech), and serving as an altar boy at our church.

Second, I was excited about Public Law 99-457 extending and broadening services for our children, especially, the emphasis on the health care system being involved, not just educational services.

Finally, I was thrilled about the language changes that were happening. We had started this era using the word "mainstreaming." Parents felt like they were hearing, "There is the 'main stream', throw the kid in. If he sinks, he's out; or if he swims, he stays with the regular kids." By 1987, the word "mainstream" had pretty much been replaced by the word "integration." We had come to realize more and more that excluding children or individuals who just happened to have a disability was a violation of their civil rights as Americans and human rights as human beings.

We were just beginning to use the word "inclusion" and some even dared to say "full inclusion." I thought, "Great! We are finally getting there!" For me, "full inclusion" encompasses the whole enchilada. Sometimes, one will hear a group of people (who themselves, by the way, usually have access to every opportunity) ask the question: "What do 'those people' want?" I smile, because I think that they are expecting me to look at the tree of life and pick two or three things and try not to look greedy — while they have automatic access to everything.

"What do 'those people' want?"

What do families want for their children who have a need for special services? The answer is quite simple.

They want the same things most people want. They want full inclusion into all of life's circles and full circles in all of their life. They want family, friends, neighbors, communities, schools, health care, leisure, spiritual involvement, and jobs. And, since I'm old fashioned, I'll say marriage and sex.

Yes, they want the whole enchilada! And, no one needs to empower most families to do this. We can get it done and, to those whose discriminatory policies or attitudes act as barriers to access, we say: "If you take your foot off our necks, you may not have to give us such a huge hand!"

I believe our greatest expectations for our children occur within an arena of a three-ring circus.

The three rings complement and act as catalysts for each other. The first ring spotlights the individual, and his or her accomplishments; the second ring's spotlight shines on the parent movement; and the third ring highlights the broader community which nudges, and sometimes pushes and shoves us in the right direction.

The third ring is the broader community. It includes such things as:

- The movement toward language which is respectful of children. For example, we can now say "children with asthma" instead of "asthmatic children."
- The media is part of this broader community. More television and movies about individuals who have disabilities or who have a need for a special service. By the way, these movies often afford the actors and actresses great expectations for an Academy Award.
- This third ring also includes boards, committees, task forces, and interagency coordinating councils (ICCs) that include parents, consumers, and professionals in equal amounts, working together as equals in a partnership.
- Neighborhood integrated play groups, such as those created by Trudy Grable at the PHP Family Resource Center in Santa Clara, and recently featured in *Exceptional Parent* magazine.
- The laws themselves are included here in this broader ring — the Americans with Disabilities Act, the Individuals with Disabilities Education Act, PL 99-457, and many, many others. All are doing their part to tweak our conscious, soften our hearts, and change and broaden our attitudes. Most importantly, they shape our behaviors and move us to action.

In the second ring is the parent movement. We can readily see that it has grown from three moms sitting on a couch crying on each other's shoulders to a dynamic ring of capable partners eager to collaborate as equals in

a partnership. The parent movement has grown into an institutionalized, dependable, capable, friendly, cost-effective force that is ready, willing, and able. It includes the National Parent Network on Disabilities in Washington, D.C.; Parents Helping Parents in California; the National Center on Parent-Directed Family Resource Centers; and the Technical Assistance to Parent Programs project with its nationwide network of Parent Training and Information Centers. In addition, there is the Family Resource Center Network of California; Family Voices, a grassroots health reform collaborative; and the National Parent to Parent Support and Information System.

And, in that first ring are individuals with disabilities themselves. For example:

- Two young men with Down syndrome who have written a book.
- Individuals with developmental delays on our regional center's Board of Directors and on other boards and councils.
- Individuals with disabilities running their own organizations such as People First.
- Individuals with disabilities holding key, high level positions in local, state and federal government.

It includes person-centered planning for transition to adult life, planning that is done without forcing a wedge between parent and child, even though the "child" is a young adult. ("Regular" kids continue to go to their parents for consultation and input, why shouldn't "special" kids?)

All three of these rings function interdependently, and work collaboratively for the same goals, vision, and great expectations. Working together, each supports and creates a greater synergy.

And now, what is in the future for us?

The future has every opportunity to be all that we desire, as long as we continue to build on the great foundation created by the Gray Panthers, those older parents who have worked hard to bring us to this point and those who are creating models of excellence for us.

These models include Colorado's NICU Consortium; our wonderfully successful Head Start Programs; the mental health wrap around services — that help teach us to blend funding as we integrate individuals; "one-stop shops" (especially parent-directed family resource centers) that make navigating the system sensible; school nurses smoothing the way; personnel preparation now including pre-service as well as in-service, including parents as well as professionals and students.

Our very competent technical assistance systems will help show the way of the future. Some of the best

of these systems include the California Early Intervention Technical Assistance Network; the National Center for Technical Assistance for parent-directed family resource centers; the Institute on Family-Centered Care in Bethesda; the Technical Assistance for Parent Programs (TAPP) project; and, of course, the great NEC/TAS, the "mother" of all technical assistance programs.

What do I see in the future?

I see a future where:

- School starts for all children at age one, in their neighborhoods.
- Every child — not just those with a label — will have their own Individual Education Plan (IEP).
- I see our present "sick care" system really becoming a "health care" system where all ailments, besides accidents, are considered preexisting conditions and all are eligible for care. Eligibility for the system will be determined based on diagnosis plus the need for service and not solely the degree of disability. Services will not depend on the amount of dollars in the pot.
- Supported employment will be widespread.
- Technology will abound and be available to broaden access for all people with disabilities, including children.
- All apartment complexes will be prepared for and open to all to live there.
- Parents will automatically be at the committee and board tables as co-chairs. Families will not have to fight for equal recognition, partnership or respect while at the table while involved in services, policy, problem solving, design or evaluation.
- Affirmative action in education and jobs, unlike now, really will not be needed, as cultural competence and full inclusion will be the mode of the day for individuals who happen to be female, colorful, gay, or disabled.

BUT, until these goals become realities let us not be derailed by smooth talkers, by uninformed newcomers, or nay sayers. Until then, maintain a healthy paranoia and vigilance. Until then, work passionately and collaboratively for what you believe in.

I agree with the person who said, "If we don't model what we teach, we are teaching something else." To those who think it can't be done, please get out of the way of those who are doing it. To those who stand in our way, I say, as they used to say of former president Harry S Truman, for the sake of our kids, "Give 'em hell."

I will, and I challenge all of you to be strong, stand up, be informed, stay involved and speak out until things are as they should be. Until then, give 'em hell.

Thank you.

A Guide to Organizations Serving Parents of Children with Disabilities

In her keynote address, Florene Stewart Poyadue mentioned a number of federal, state, and local programs specifically designed to meet the needs of parents of children with disabilities. Here is a quick guide to these programs.

Parent Training and Information (PTI) Centers.

In 1983, special funding was added to the Education for All Handicapped Children Act (now IDEA, the Individuals with Disabilities Education Act) which established a national network of parent-run projects designed to provide information and resources to parents of children with disabilities. Currently over 70 centers are funded nationally with at least one in each state. PTIs offer workshops, training, and individual problem solving for parents. To contact the PTI closest to you, contact: TAPP, Federation for Children with Special Needs, 95 Berkeley St., Suite 104, Boston, MA 02116; phone: 617-482-2915; fax: 617-695-2939; email: fcsninfo@fcsn.org.

Family Resource Centers are parent-directed, comprehensive "one-stop shopping" agencies that are designed to provide a broad array of services in local communities. Primarily in Arizona, Indiana, New Mexico, Virginia, Louisiana, and throughout California, these centers offer peer support, peer counseling, mentoring programs, parent networking, agency coordination as well as training and conferences related to the needs of children with disabilities and their parents. Some Parent Training and Information (PTI) centers are housed in Family Resource Centers and vice versa. For more information on Family Resource Centers, contact Parents Helping Parents, 3041 Okcott St., Santa Clara, CA 95054-3222; phone: 408-727-5775; fax: 408-727-0182

National Parent Network on Disabilities (NPND) was established in 1988 in Washington, D.C., to act as a public policy advocate for issues affecting parents of children with disabilities, NPND is a membership organization that has gained increases in federal funding for Parent Training and Information Centers and bolstered the rights of families and children in the reauthorization of the Individuals with Disabilities Education Act. It has developed and gained sponsorship for the Family Support Act. For more information, contact: NPND; 1600 Prince St., Suite 115; Alexandria, VA 22314; phone: 703-684-6763.

Family Voices is a national clearinghouse for information and education concerning the health care of children with special health needs. Guided by a commitment to quality health care for all children, Family Voices relies on a network of volunteer coordinators in each state as well as on regional staff across the country. For more information, write: Family Voices, Box 769, Algodones, NM 87001; phone: 505-867-2368; fax: 505-867-6517.

Glenn Gabbard is the father of two children who have received early intervention and special education services. He is currently the director of a national project designed to help parents of children with disabilities become more actively engaged in educational restructuring activities within their communities; he also is the coordinator of a leadership development project serving parent members of Inter-agency Coordinating Councils across the country. Both projects are housed at the Federation for Children with Special Needs in Boston.



In thinking about what I wanted to tell you today...

I went back to listen to the recording of that keynote in 1989 and heard Ann Turnbull from the Beach Center in Kansas talking about the power of taking the "high road" — an uncharted road filled with risks, carved through uncharted waters, but compelled by a family's values for community and equity for all of its members. We talked about the power of the long view: motivated by expectations of change, of excellence, and of the power of collaboration, families could see the power of early intervention and preschools. The power, however, was not in the short-term benefits, but in the view that these systems were, as Ann put it, "launching pads to life."

I am part of a family of four: my wife Ruth-Ann and I share two super children, Megan and Max, both of whom attended early intervention and preschool programs. In 1989, Megan was six years and, just entering kindergarten in her neighborhood school. Max was just three.

Megan is now 12, a young woman entering sixth grade, her first year of middle school. Max is now officially a fourth grader. Our expectations for our children — of each other in our family — are still charted along that "high road" that Ann described years ago. What is different now is that we have traveled down the road a bit farther and learned an enormous amount about friendship, change, and the continuing importance of nurturing possibilities. We have learned of the importance of a shared vision for each member of our family to continue to grow and particularly, a vision that Megan and Max will be valued contributors to the multiple communities of which they are and will be a part.

So much is said about the importance of vision these days.

At a time when the term "family values" has taken on many meanings — many of them shaded by political

manipulation and maneuvering — I am still excited to think about the rich possibilities that Part H offers and the potential for continued development that it still can yield. But this is only true if we continue to adhere to the essence of change that is a natural part of this law. We need to celebrate the beauty of a mandate in which the changing vision of families is the central core. We need to welcome the challenge of a critical strength — policies and programs that celebrate the essential truth of family values and use the diverse strength of these values to continually transform the ways that services and programs are delivered.

Our own family's vision has broadened in many ways. It has been buffered by rejection; nurtured in the company of our friends, neighbors, school leaders; and challenged by a world that is too often clouded by fear and ignorance.

In my own work, I have been looking into how change occurs in organizational systems, particularly in what has come to be fondly known as the "post-industrial" era — our own time — characterized by turbulent change, a high degree of competitiveness, informational overload, organizational decline, uncertainty and dwindling resources. In my research, I've uncovered two important themes. First, change is often driven by a passionate vision for the future that is shared and negotiated over time with many people but which remains unwaveringly true to its underlying values. Second, in times of great strife — and certainly what has happened in the past few months in Washington, D. C., in terms of programs for all disenfranchised people can only be described in terms of chaos and strife — organizations will typically adopt what are called "domain defense strategies," conservative, protective reactions to threat which are intended to create buffers between themselves and the external environment in order to defend the status quo. What researchers of the change process are finding is that all of the turbulence can best be mitigated, however, by domain *offensive* strategies. These are actions that are based in maximizing the strengths of any organization, showcasing what it does best and assertively seeking out new innovations which stretch the boundaries of policy and programs.

The strengths of Part H — of family-centered services — lie in the vision of the families that the programs serve. It is these visions that lie in the center of the actions that we must take in order to assure that legislators understand the significance of one program to one child in one community.

To understand this, I share a portion of a letter that I wrote to my daughter, Megan:

"Megan, parents of children with disabilities — probably parents of children without disabilities — are always told 'you're going to have to let go sometime.' What we've learned to remember though is that parents

should never let go of their vision for their children, simply because it has so much to do with their hopes for change for themselves and for the world. As you grow older, my vision for you and for myself has changed too. When you were a baby, what I wanted most for you was acceptance and the strength of character to help others understand your own powers and gifts. Now, as I see the lovely, strong, and sensitive young woman you have become, I look forward to building a vision to make differences for others — with and without disabilities — with you as a colleague and friend....Poets like yourself Megan, are in the vision business. They help all of us to think and think again about things that are often frightening and confusing. One famous poet, Adrienne Rich, writes about her 'dream of a common language.' The dream of understanding is one which your Mom and I both shared when we met each other and when you and Max were born ... and now which we share with you as you grow up and show us the world that you have discovered within yourself."

In Megan's birth announcement, we quoted a favorite poem by the Chilean writer, Pablo Neruda. This poem — entitled "El Hijo" — compares the birth of a child with the sudden presence of a rare bird, nestled high in the branches of a remote tree.

The children and families that we serve are our inspiration for continued change and our connection to the values that we have our ourselves and for all of our families. As my own family continues to reach toward those high branches together — the branches of change, of community, of possibility — we are comforted to know that you are there with us striving to stretch toward this same vision and listening to the poetry in the lives of our children and ourselves.

from *El Hijo* Pablo Neruda

<i>Como una gran tormenta</i>	<i>Like a great storm</i>
<i>sacudimos nosotros</i>	<i>we shook</i>
<i>el arbol de la vida</i>	<i>the tree of life</i>
<i>hasta las mas ocultas</i>	<i>down to the hiddenmost</i>
<i>fibras de las raices</i>	<i>fibers of the roots</i>
<i>y apareces ahora</i>	<i>and you appear now</i>
<i>cantando en el follaje,</i>	<i>singing in the foliage</i>
<i>en las mas alta rama</i>	<i>in the highest branch</i>
<i>que contigo alcanzamos</i>	<i>that with you we reach</i>

The management section of bookstores across the country seems to expand on a daily basis with new books on leadership and change. Here are a few recommendations from parents of children with disabilities which have helped them in their roles as change agents and advocates on behalf of their children:

Covey, Stephen. (1990). *The 7 Habits of Highly Effective People*. New York: Simon and Schuster. Covey's very readable and highly popular book is filled with examples of the power of personal control and commitment that are directed toward the interpersonal dimensions of change and leadership. Many parents have found special power in Covey's work because he grounds much of his learning in his own experiences as a member of a family, both as father and husband. In describing his journey toward using these 7 principles, Covey concludes his book: "By centering our lives on correct principles and creating a balanced focus between doing and increasing our ability to do, we become empowered in the task of creating effective, useful, and peaceful lives ... for ourselves, and for our posterity."

Kouzes, James and Barry Posner (1991). *The Leadership Challenge*. San Francisco: Jossey-Bass. Recently released in a new edition, this book identifies some important tools for leaders to use as they pursue change and excellence. The book's subtitle, "How to get extraordinary things done in organizations," underlines the authors' efforts to describe behaviors and strategies that may help individuals to foster and enhance the change process through simplicity and consistency.

Wheatley, Margaret (1992). *Leadership and the New Science*. San Francisco: Berrett-Koehler. One of the more abstract and theoretical books in this list, Wheatley's text compares organizational change to quantum physics, chaos theory, and self-organizing systems. Using these areas of study, Wheatley explores how order can inform the seeming chaos of modern day life.

Heifetz, Ronald (1994). *Leadership Without Easy Answers*. Cambridge, MA: Harvard University Press. Currently the Director of the Leadership Project at the JFK School of Government at Harvard University, Heifetz approaches the topic of leadership as an "adaptive" ability: individuals learn to move change by factoring in the various features which confront them, some of which lie far out of their individual control. The book is an excellent response to those that feel they are helpless in the face of the complexities of modern life.

Senge, Peter (1990). *The Fifth Discipline*. New York: Doubleday. This book is a classic in the management literature related to the need for radically different ways to perceive the power of organizations and the postures which individuals must take within them to accomplish both group and individual goals. Though somewhat more difficult to apply directly to the lives of parents of children with disabilities, the book sets out important principles which have influenced the change toward more consumer-oriented systems. Senge describes the learning organization, "an organization that is continually expanding its capacity to create its future."

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